

## Quality of life among caregivers of patients with epilepsy and alcohol dependence

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### Abstract

Epilepsy is an unpredictable, often chronic and debilitating disorder that impacts not only those bearing with it but also those who care for them. Equally individual with alcohol dependence no longer remains a source of problem limited not only to the alcohol dependence person; rather it usually becomes a continuous source of stress and suffering to all those people who are closely associated with the alcohol dependence. The present study consisted of 120 samples, among which 60 participants from the caregiver of patients with epilepsy and 60 participants from the caregiver of patients with alcohol dependence. WHO Quality of life -BRIEF was used to collect the data. Statistical analysis was performed by using the SPSS programme 16.0 version. The result suggested that the caregiver of patients with alcohol dependence have poor quality of life than caregiver of patients with epilepsy.

**Keywords:** Quality of life, Caregivers, Epilepsy, Alcohol dependence

### 1. Introduction

The concept of Quality of life has assumed special significance in the medical field in the wake of a progressive move towards re-humanizing hi- tech medicines. It is no longer important merely to add years to the patients' life. Even more important than that, is to add quality in those years of life. While emphasizing more on the recovery of physical symptoms, in the process, physicians have neglected other aspects of the patients' life, for e.g. emotional well-being and subjective reporting about his/her life (Raj kumar *et al.*, 1992) [7]. The lack of emphasis on subjective reporting of quality of life is particularly striking in psychiatry, a field of medicine that has traditionally placed the subjective experience of patients as its main concern (Okin & Pearsall, 1993) [6]. It is well established that epilepsy impacts the quality of life (QOL) of patients. Loss of control and independence, low self-esteem, fear, depression, stigmatization, lifestyle, social and employment restrictions, and financial strains are ways in which this impact occurs. The same factors also indirectly affect care providers for those patients (O'Dell, 2007) [1]. The WHOQOL-group definition of Quality of life was referred to as someone's perception of his or her position in life within a social and cultural context (Kuyken, 1995) [4]. More specifically, it was assumed that QoL is a generic value judgment reflecting "an individual's evaluation of the level of his or her functioning within a number of life domains, and the value or importance assigned to these domains" (Leventhal, 1997) [5]. Expectations, aspirations, behavioral repertoires, coping strategies, former and actual personal and symbolic experiences will result "in a unique combination of weightings for a set of life domains" (Oliver, 1995) and will produce a generic value judgment of life. A more elaborate definition of Quality of life was recently presented by the so-called World Health Organization Quality of Life group (WHOQOL-group). According to this group, QoL can be defined as the:

"individuals' perception of their position in life in the context of the culture and the value system in which they live and in relation to their goals, expectations, standards, and concerns" (Kuyken, 1995) [4]. The patient's perspective on Quality of life is at the core of this definition and encompasses the personal assessment of the patient of his physical health status (e.g., daily physical functioning) and his psychological and social status (e.g., mood, companionship, and recreational activities) (Devinsky, 1993) [2]. In our opinion, this definition or conceptualization rightly excludes the use of so-called "objective social indicators" (e.g., employment, socioeconomic status, recreational facilities) or "objective" health-related indicators of Quality of life (e.g., comorbidity, health care use), which can be considered as "necessary conditions for satisfaction and happiness" (Rogerson, 1995) [8]. They are assumed to be conducive to Quality of life on the individual level. As such, they are very important resources and should of course be included in studies of Quality of life. Consequently, Quality of life is "subjective" or, more adequately phrased, "subject-bound."

The present study was to examine the difference in the perception of quality of life among caregivers of patients with epilepsy and alcohol dependence.

### 2. Methodology

The present study consisted of 120 samples, among which 60 caregivers of patients with epilepsy and 60 caregivers of patients with alcohol dependence. Purposive sampling techniques were used and data collected from outpatient and inpatient department of Ranchi institute of Neuro Psychiatry and Allied Sciences (RINPAS), Ranchi. Patients were selected as per ICD -10 DCR criteria. Tools: Socio- demographic data, GHQ-12, Severity of Alcohol Dependence Questionnaire, and WHO Quality of life scale were used.

### 3. Results

**Table 1:** Socio demographic variables of caregivers of patients with epilepsy and alcohol dependence

Variable		Caregivers of patients with		X <sup>2</sup> / t	Df	p
		Epilepsy n=60(%)	Alcohol Dependence n=60(%)			
Gender of caregivers	Female	39 (65.0%)	40 (66.7%)	.037	1	1.000
	Male	21 (35.0%)	20 (33.3%)			
Marital status of caregivers	Married	59 (98.3%)	55 (91.7%)	2.807	1	.207
	Unmarried	1 (1.7%)	5 (8.3%)			
Relation of caregivers	Spouse	29 (48.3%)	36 (60.0%)	7.761	3	.050
	Parent	22 (36.7%)	9 (15.0%)			
	Sibling	7 (11.7%)	11 (18.3%)			
	Children	2 (3.3%)	4 (6.7%)			
Income of caregivers	Lower	50 (83.3%)	47 (78.3%)	.484	1	.643
	Middle	10 (16.7%)	13 (21.7%)			
Type of Family	Nuclear	52 (86.7%)	51 (85.0%)	.069	1	1.000
	Joint	8 (13.3%)	9 (15.0%)			
Education of caregivers	Primary	17 (28.3%)	20 (33.3%)	.396	3	.960
	Secondary	31 (51.7%)	28 (46.7%)			
	Graduation and above	12 (20.0%)	12 (20.0%)			
Occupation of caregivers	House wife	28 (46.7%)	25 (41.7%)	.913	4	.928
	Private	19 (31.7%)	21 (35.0%)			
	Govt. Service	4 (6.7%)	3 (5.0%)			
	Farmer	6 (10.0%)	6 (10.0%)			
	Unemployed	3 (5.0%)	5 (8.3%)			
Religion	Hindu	42 (70.0%)	46 (76.7%)	.682	1	.536
	Non Hindu	18 (30.0%)	14 (23.3%)			
Age of caregivers (In Years)		40.13±11.06	37.58±10.51	1.294	118	.198

Table (1) shows comparison of the income of family, type of family, education of caregivers, occupation of caregivers, religion and age of caregivers of persons with epilepsy and alcohol dependent. This table shows that most of the caregivers of epilepsy and alcohol dependence patients were from female gender, married, spouse in relation, lower socioeconomic status, nuclear family, secondary, house wives, and Hindu.

- In terms of gender, in caregivers of patients with epilepsy 65.0 % were female and 35.0 were male caregivers whereas in caregivers of patients with alcohol dependence patients 66.7% were female and 33.3 were male caregivers.
- In terms of marital status, in caregivers of patients with epilepsy 98.3 % were married and 1.7 were unmarried caregivers whereas in caregivers of patients with alcohol dependence patients 91.7% were married and 8.3 were unmarried caregivers.
- In terms of Relation of caregivers, in caregivers of patients with epilepsy 48.3 % were spouse, 36.3 % were parent, 11.7 were sibling and 3.3 were children whereas in caregivers of patients with alcohol dependence patients 60.0% were spouse, 15.0 % were parent, 18.3 were sibling and 6.7 were children.
- In terms of Income of caregivers, in caregivers of patients with epilepsy 83.3 % were from lower income, and 16.7 % were from middle income whereas in caregivers of patients with alcohol dependence patients 78.3% were from lower and 21.7 were from middle income.

- In terms of Type of family, in caregivers of patients with epilepsy 86.7 % were from nuclear family and 13.3 % were from joint family whereas in caregivers of patients with alcohol dependence patients 85.0% were from nuclear and 15.0 were from joint family.
- In terms of Education of caregivers, in caregivers of patients with epilepsy 28.3 % were primary education 51.7 % were secondary education and 20.0 % were graduation and above whereas in caregivers of patients with alcohol dependence patients 33.3% were primary education 46.7 % were secondary education and 20.0 % were graduation and above.
- In terms of Occupation of caregivers, in caregivers of patients with epilepsy 46.7% were house wife, 31.7% were private, 6.7 were govt. service, 10.0% were farmer 5.0% unemployed whereas in caregivers of patients with alcohol dependence patients 41.7% were house wife, 35.0% were private, 5.0 were govt. service, 10.0% were farmer 8.3% unemployed.
- In terms of Religion, in caregivers of patients with epilepsy 70.0% were Hindu and 30.0% were Non Hindu whereas in caregivers of patients with alcohol dependence patients 76.7% were Hindu and 23.3% were Non Hindu.

**Age of caregivers:** The mean age of caregivers of epilepsy was 40.13±11.06 years and the mean age alcohol dependent patients were 37.58±10.51years. There were no significant different was found in the socio-demographic variable of caregivers

**Table 2:** Socio demographic and clinical variables of patients of epilepsy and alcohol dependence

Variable		Group N=60		X <sup>2</sup> / t	df	P
		Epilepsy n=60(%)	Alcohol Dependence n=60(%)			
Patient Education	Illiterate	12(20.0)	5(8.3)	9.619	4	.046*
	Primary	14(23.3)	16(26.7)			
	Secondary	24(40.0)	22(36.7)			
	Intermediate	8(13.3)	6(10.0)			
	Graduate	2(3.3)	11(18.3)			
Patient Occupation	Farmer	15(25.0)	13(21.7)	2.905	3	.420
	Private	29(48.3)	24(40.0)			
	Govt. Service	2(3.3)	6(10.0)			
	Unemployed	14(23.3)	17(28.3)			
Age of patient (In Years)		31.28±6.15	36.51±7.55	4.159	118	.000***
Age of onset (In years)		23.91±8.13	26.86±6.66	2.173	118	.032*
Duration of illness (In years)		7.35±4.26	9.51±5.66	2.365	118	.020*

\*Significant  $p < .05$ , \*\*\*Significant  $p < .001$

Table (2) shows comparison of the patient education, patient occupation, and age of patients, age of onset of illness and duration of illness between patients with epilepsy and alcohol dependent. This table indicates that significant differences were found in patient education, age of patients, age of onset of illness and duration of illness ( $p < .05$ ,  $p < .001$ ). There were no significant differences in patient occupation.

- In terms of education of patient, in caregivers of patients with epilepsy 20.0 % were illiterate, 23.3 % were primary education, 40.0 % were secondary education, 13.3 % were intermediate and 3.3 % were graduate whereas in caregivers of patients with alcohol dependence patients 8.3% were illiterate, 26.7 % were primary education, 36.7 % were secondary education, 10.0 % were intermediate and 18.3 % were graduate.
- In terms of Patient occupation, in caregivers of patients with epilepsy 25.0 % were farmer, 48.3 % were private, 3.3 % were govt. service and 23.3 % were unemployed

whereas in caregivers of patients with alcohol dependence patients 21.7 % were farmer, 40.0 % were private, 10.0 % were govt. service and 18.3 % were unemployed

**Age of patients:** The mean age of patients of epilepsy was 31.28±6.15 years and the mean age alcohol dependent patients were 36.51±7.55 years.

**Age of onset:** The mean age of onset of epilepsy was 23.91±8.13 years and the mean age of onset of alcohol dependent patients were 26.86±6.66 years.

**Duration of illness:** The mean age of duration of illness of epilepsy was 7.35±4.26 years and the mean age of duration of illness of alcohol dependent patients were 9.51±5.66 years.

Significant different was found in the socio-demographic variable of patient's i.e. patient education, and age of patients, age of onset of illness and duration of illness between patients with epilepsy and alcohol dependent. However there were no significant different found in patient occupation.

**Table 2:** Comparisons of scores of Quality of Life scale caregivers of patients with epilepsy and alcohol dependence

Quality of Life scale	Group N=60		t Value (df=58)	P
	Epilepsy n=60	Alcohol Dependence n=60		
	Mean ± S. D.	Mean ± S. D.		
Physical health	21.63±1.90	19.85±3.94	3.154	.002**
Psychological health	27.20±2.96	17.08±4.51	14.513	.000***
Social relationships	11.48±1.58	9.21±2.53	5.863	.000***
Environment	18.48±1.53	19.06±5.06	-.854	.395

\*\*Significant  $p < .01$ , \*\*\*Significant  $p < .001$

Table (2) shows comparison between caregivers of patients with epilepsy and caregivers of alcohol dependence on various domains of quality if life scale. It reveals that caregivers of epilepsy patients had scored significantly high on Physical health, Social relationships, and Environment ( $p < .01$ ,  $p < .001$ ), which suggests that caregivers of patients with epilepsy had good physical health, psychological health, and social Relationships compared to caregivers of patients with alcohol dependence. There were no differences between these two groups on environment of WHO quality of life.

#### 4. Discussion

##### 4.1. Discussion of Methodology

This study was conducted at the Ranchi Institute of Neuro-Psychiatry and Allied Sciences, Ranchi. It was a cross sectional study about the quality of life in the caregivers of

individuals with epilepsy as compared to the caregivers of individuals with alcohol dependence. The aim of the study was to assess the quality of life in the caregivers of individuals with epilepsy as compared to the caregivers of individuals with alcohol dependence. The present study was conducted among total respondents of 120 samples, consisting of 60 caregivers of individuals with epilepsy and 60 caregivers of alcohol dependence, those who are willing to participate in the study and inclusion and exclusion criteria have been included in the study. The socio demographic data sheet had been used for collecting socio demographic details of the caregivers of individuals with epilepsy as compared to the caregivers of individuals with alcohol dependence. To assess the alcohol severity of the patient, the alcohol severity index scale was applied. For assessing the quality of life, quality of life scale was used and

## 4.2. Discussion of Results

### Socio-Demographic Variables

In the present study, the sample size was 120, out of which 60 were caregivers of individuals with epilepsy, and 60 were caregivers of alcohol dependence. In the present study majority of caregivers were female gender in both group such as epilepsy [n=39 (65.0%)] and alcohol dependence [n= 40 (66.7 %)], majority of the caregivers were married in both group such as epilepsy [n=59 (98.3%)] and alcohol dependence [n= 55 (91.7 %)], majority of the caregivers were spouse in both group such as epilepsy [n=29 (48.3%)] and alcohol dependence [n= 36 (60.0 %)], majority of the caregivers from lower socioeconomic status in both group such as epilepsy [n=50(83.3%)] and alcohol dependence [n=47(78.3%)], majority of the caregivers were from nuclear family in both group such as epilepsy [n=52(86.7%)] and alcohol dependence [n=51(85.0%)], and majority of caregivers were educated up to secondary in both group such as epilepsy [n=31 (51.7%)] and alcohol dependence [n=28 (46.7%)]. In this study, maximum numbers of caregivers were married women and housewife. Caregivers of epilepsy 33(55.0) were housewife's and Caregivers of alcohol dependence 39(65.0) were housewife's. Most of the caregivers were from Hindu religion in both groups such as epilepsy [n=42(70.0%)] and alcohol dependence [n=46(76.7%)]. The similar kinds of studies were done by Samira (2012). The mean age of caregivers of epilepsy patients was 40.13±11.06 years and mean age of caregivers of alcohol dependence 37.58±10.51 year. The majority of patients were educated up to secondary in the both group such as epilepsy [n=24(40.0%)] and alcohol dependence [n=22 (36.7%)]. The majority of caregivers were doing private job in the both group such as epilepsy [n=29 (48.3%)] and alcohol dependence [n=24 (40.0%)]. The current study findings matches with previous study done by Folorunsho, et al. 2010 [3]. Found that majority of the caregivers are female and close to 40% are mothers. This is similar to a recent report among caregivers of patients with schizophrenia in Nigeria. The cultural belief that men should work, and in most cases they are the bread-winners, may have shifted the responsibility of caring for the sick to the women. Whereas epilepsy patients mean age was 31.28±6.15 years and alcohol dependence patients' mean age was 36.51±7.55 years and mean age of onset of taking alcohol was a 31.86±8.45 year. Result also revealed that the age of onset epilepsy patient's illness was 23.91±8.13 and mean age of onset of alcohol illness was 26.86±6.66 years. Result also revealed that the mean duration of epilepsy patient's illness was 7.35±4.26 and mean duration of taking alcohol was 9.51±5.66 years. The current study findings matches with previous study done by Folorunsho, et al. 2010 [3]. Found that caregivers the mean age was 43.6 ±9.5 years and mean year of education was 9.7 ±6.0. For the patients; the mean age was 28±13.2, mean duration of illness was 9.5 ±8.2 years and mean seizure-free period was 26.4 ±36.5 weeks.

### Quality Of Life in Caregivers of Patients with Epilepsy and Alcohol Dependence

The study shows that there is a significant difference between caregivers of individuals with epilepsy and caregivers of individuals with alcohol dependence of quality of life measuring instrument i.e., WHO Quality of life Scale. It shows caregiver of individuals with epilepsy has good quality

of compared to caregivers of individuals with alcohol dependence in almost all the domains such as Physical health, Psychological health and Social relationships. In particular, similar to our study, a Dutch outpatient study identified a trend of decreased mental component of QOL in caregivers of refractory Epileptic Seizure patients (Van, 2009) [9]. Westphal, 2007 [10] suggests that caregivers of patients with epilepsy showed a decrease in QOL and developed mild to moderate burden regardless of the frequency of seizures and duration of the syndrome and the emotional component was primarily affected. Several variables-gender, age, person responsible for medication, and number of daily hours the caregivers worry about the patients-interfered with QOL and contributed to burden in the caregivers. Another study of 65 patient-caregiver pairs from Hong Kong identified below average scores on the quality of life measure applied and severe levels of depression and anxiety in 14% and 22% of caregivers respectively (Lee, 2002).

## 5. Conclusion

The result suggested that the caregiver of patients with alcohol dependence have poor quality of life than caregiver of patients with epilepsy. The regular follow-up in an out-patient setting along with the caregivers improve the compliance and enables the patients to pursue their work and take up other responsibilities. This enhances the self-esteem and achieves complete abstinence of alcohol dependence, thereby improving the patient and caregiver's quality of life may be possible. Findings stress the need of public health officials to incorporate quality of life as an important measure to evaluate treatment outcome in alcohol dependence whose natural course consists of relapses. Treatment of epilepsy and alcohol dependence with a favorable outcome is possible with minimal financial resources, regular follow up, and the involvement of caregivers. There is a need to create general awareness in public about epilepsy and alcohol dependence that requires immediate attention and treatment.

## 6. References

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