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Assessment of quality of life, stigma associated and self-management practices among patients suffering from epileptic seizures: A cross sectional study

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Epileptic patients are often neglected in our society. This hospital based cross sectional study was done among epileptic patients in Mangalore city of south India in February 2011. Epileptic patients aged 7 or more were interviewed using a pretested semi-structured questionnaire. Standardised scales were used for assessing the quality of life (QOL), stigma and self-management practices of patients. Association of these parameters was done with various socio demographic factors of patients. Of the 56 patients, 55.4% patients had GTCS and 80.4% had multiple episodes of seizures. QOL and self-management practices were good in 44.6% and 71.4% patients, respectively. Self-management practices was found to significantly improve with age of patients (P=0.012). Educational status of patients was found to significantly improve their QOL and self-management practices (P=0.031). Stigmatization was reported by 66.1% patients and it was significantly more in patients in the age groups 30 to 50 years (P=0.043). Gender and occupation of patients was not significantly associated with any of the parameters. Self-management practices were good in most patients but this was not so with QOL or experience of stigma. These aspects could be improved by educating the people in order to generate greater social support for epileptic patients in future.

Key words: Epileptic seizures, quality of life, stigma, self-management practices.

INTRODUCTION

Epilepsy which means a tendency to have seizures is a common neurological condition, frequently associated with psychosocial difficulties (Baker, 2002). The occurrence of psychosocial problems related to epilepsy in certain situations could be even more troublesome than the effect of the seizure disorder themselves (Shibre et al., 2006). The fear of impending seizures among patients leads to a feeling of insecurity, which in turn adversely affects their healthy social development (Moffat et al., 2009a,b). They also experience a feeling of shame and guilt compared with individuals without epilepsy (Jacoby et al., 1996). People with epilepsy are thus prone to have poorer self-esteem, higher levels of anxiety and depression

(Rodin, 1968). The diagnosis of epilepsy challenges their self-perception and causes concern about ability to function in normal social roles, such as getting a job or having a family (Scambler and Hopkins, 1990). Epilepsy causes serious problems among children too. Children with epilepsy have been found to be behaviorally disturbed and develop poorer academic attainment than children with diabetes or asthma (Austin et al., 1994).

Epilepsy is also a known stigmatizing condition. Due to its unpredictable nature society may fear dealing with someone who is having an epileptic seizure. Misconception about etiological factors, curability, cause and outcome are other factors which have contributed to the social stigma (Suurmeijer et al., 2001).

Because of its clinical uncertainty and its social meaning and consequent stigmatization, the impact of epilepsy on a person's quality of life (QOL) can be significant (Moffat et al., 2009a,b). Studies in Europe (Baker,

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2002) and North America (Dilorio et al., 2003) suggest that the stigma of epilepsy is one of the most important negative influences on the quality of life of people with epilepsy. Paradoxically, this facet of epilepsy is rarely studied, especially in limited resource countries (Li and Sander, 2003), where the burden of epilepsy is higher. Of the 50 million people with epilepsy worldwide, around 80% reside in resource-poor countries, which are ill-equipped to tackle the enormous medical, social and economic challenges posed by epilepsy. The capability to identify people with epilepsy and provide cost-effective care is compromised by widespread poverty, illiteracy, inefficient and unevenly distributed health-care systems, and social stigma and misconceptions surrounding the disease. The high cost of treatment, lack of availability of antiepileptic drugs, side effects of medication and superstitious and cultural beliefs contribute to a large epilepsy treatment gap. A substantial proportion of the current burden of epilepsy in resource-poor countries could be minimized by educating the public about positive features of life with epilepsy. This will minimize the stigma associated with this disease. This together with improvement in self-management practices of epileptic patients will help in the betterment of their quality of life. There is thus a need of a comprehensive epilepsy care model which considers the marked heterogeneity of the disorder and its variable effects on the patient, family and community (Radhakrishnan, 2009).

We therefore conducted this study in an urban area where clinic and outreach services for treating people with epilepsy are well established with the main goal of assessing the quality of life of epileptic patients, their self-management practices, stigma experienced by them and to find out association of each of these with various socio demographic factors.

MATERIALS AND METHODS

This cross sectional study was done in various tertiary care hospitals in Mangalore, a coastal city of Karnataka state of south India in February 2011.

The ethical clearance for the conduct of this study was taken from the Institutional Ethics Committee. Permission to do the study in the hospital was taken from the respective medical super-intendents of these hospitals. Following this, epileptic out and in patients were approached and were taught about the importance of the study. All the patients who gave written informed consent for participation were enrolled in this study. In case of minors (aged less than 18 years) consent for participation was taken from their accompanying parents or guardians. Epileptic patients below the age of 7 years and those with mental handicap or with severe psychiatric disturbances were excluded from this study. A total of 56 such patients could be enrolled by convenient sampling over the data collection period. Each of the participants were interviewed using a pretested semi-structured questionnaire by a team of investigators. Information with respect to socio demographic profile of patients such as age, gender, marital status, occupation, educational status, family income and place of residence were recorded. For assessing quality of life, Quality of life in childhood epilepsy (QOLCE) (Sabaz et al., 2000), quality of life in epilepsy inventory for adolescents (Cramer et al., 1999) and QOLIE 31 for

adults (Grudzinski et al., 1998) was used. For assessing stigma, explanatory model interview catalogue stigma scale was used (Weiss et al., 1992) and for assessing self management practices, epilepsy self management scale (Dilorio et al., 1994) was used. The questions in quality of life scale comprised of perception about seizures, feeling of loneliness or nervousness or tiredness due to the disease, adjustment with the disease, state of mental health, level of concentration with routine work and experience of side effects due to anti epileptic drugs (AED) therapy. The questions in stigma scale comprised of whether patient preferred secrecy about the disease, feeling of shame due to the disease, whether they attend social gatherings following diagnosis of being epileptic, whether they experienced avoidance or disrespect from peer groups and relatives and whether they had any problems in getting married or had experienced any discord in marital life. Good self-management practices include measures like taking medication on time, maintaining a record of seizure episodes, carrying an identity card, periodic consultation with treating doctor, adequacy of sleep, avoiding food substances and activities that may precipitate seizures and avoidance of dangerous works like cooking or swimming.

All the data collected were entered and analyzed using version 11.5 of the statistical package for social sciences software package (SPSS Inc., Chicago, IL) into categories and percentages. Chi-square was used for testing association and P value less than 0.05 was considered as statistically significant.

RESULTS

Of the 56 patients, most (46.5%) were of the age group 20 to 40 years. The mean age of all participants in this study was 30.95 ± 18.19 years. Majority was males (55.4%) and most of them were educated up to high school (25%). Most of the study participants were students (21.4%). Few of them (3.6%) were separated from their spouses because of epilepsy. The number of married individuals was 69.6% (Table 1). Out of the 44 patients who knew the type of seizures they developed, 24 (54.5%) said that it was of generalized tonic clonic type (GTCS), 16(36.4%) said it was partial seizures (simple/complex) while 4 (9.1%) said it was absence seizures.

Majority of patients 28 (50%) had 2 to 6 episodes of seizures followed by 11 (19.6%) with single episode followed by 10 (17.9%) with 12-24 episodes of seizures and lastly 7 (12.5%) with 6 to 12 episodes of seizures. Out of 56 epileptic patients 46 of them could recollect when they developed seizures for the first time. The mean age of first episode among these 46 epileptic patients was 25.3 ± 16.6 years (Table 2).

The quality of life was good in 25 (44.6%), average in 17 (30.4%) and was poor in 14(25%) of epileptic patients. Quality of life in patients was found to be significantly associated with educational status (P=0.031). Patients educated from pre degree and beyond were found to have a better quality of life than the rest. Quality of life was found to be better among patients aged between 40 to 50 years, males, among professionals and house wives. However these observations were not statistically significant (Table 3).

Stigmatization was reported by 37 (66.1%) patients in

Table 1. Socio demographic distribution of epileptic patients.

Age group	Number	%
7-10 years	8	14.3
10-20	8	14.3
20-30	16	28.6
30-40	10	17.9
40-50	4	7.1
50-60	6	10.7
>60	4	7.1
Gender		
Male	31	55.4
Female	25	44.6
Marital status		
Single	15	26.8
Married	39	69.6
Divorced	2	3.6
Educational status		
Illiterate	6	10.7
Primary school	11	21.4
Middle school	10	19.6
High school	14	25
PUC	8	14.3
Graduation & above	7	8.9
Occupation		
Professional	3	5.4
Semi-professional	4	7.1
Businessman	11	19.6
Skilled	10	17.9
Unskilled	10	17.9
Housewife	6	10.7
Student	12	21.4
Total	56	100

Table 2. Distribution of patients based on age at first episode of developing seizures.

Age in years	Number	Percentage
7-10	7	12.5
10-20	16	28.7
20-30	11	19.7
30-40	3	5.3
40-50	3	5.3
50-60	3	5.3
>60	3	5.3
Total	46	100

management practices were seen more among male patients, house wives and students. Professionals and semi-professionals had a greater percentage of poorer self-management practice as compared to others. However these observations were not statistically significant (Table 5).

DISCUSSION

People with epilepsy in developing countries are known to experience problems with marriage, education, social isolation and employment (Baker, 2002). This study analyses these aspects in a less prioritized disease, by health care providers, like epilepsy. In this study 4% participants were separated from their spouses because of seizures which were similar to other studies (Baker et al., 1997; Baker et al., 1997). The marriage rate of about 70% in this study was higher than that observed in a study done in Kanpur where it was only about 46% among epileptic patients (Agarwal et al., 2006).

Even though most participants (80.4%) had multiple episodes of seizures in this study none of them were unemployed because of their illness. However a European study reported unemployment rate of 23% among epileptic patients due to seizures (Baker et al., 1997).

Several other studies too reported unemployment among epileptic patients (Baker, 2002; Bahou et al., 2011; Fraser et al., 1983; Herodes et al., 2001; Kleinman et al., 1995). Unemployment and lower rates of marriage among epileptic patients leads to greater social isolation which will further depress the lives of these patients.

Commonest type of seizure was GTCS which was seen in more than half of the participants. This observation has also been supported by other studies (Baker et al., 1997; Bahou et al., 2011; Goodridge and Shorvon, 1983). Mean age of first episode of seizure in this study (25.3 years) was slightly higher than that observed in a Atlanta based study where it was 22 years (Dilorio et al., 2003).

The quality of life was found to be good only in 44.6% of patients. This was lesser than the findings of a Jordanian

this study. Patients in the age group of 30 to 50 years reporting greater stigmatization than other age groups (P=0.043). Stigmatization was reported by more number of male patients, students and semi-professionals. However these observations were not statistically significant (Table 4).

Among the 56 patients, 40 (71.4%) had good, 8 (14.3%) had average and rest 8 (14.3%) had poor self-management practices. The quality of self-management practice was found to improve with age of the patients with best performance by patients aged between 40 to 50 years (P=0.012). Educational status was also found to significantly influence self-management practices with performance being better among those patients educated at least up to middle school (P=0.031). Good self-

Table 3. Association between age, gender, occupation and educational status with quality of life in epileptic patients.

Age group	Quality of life			
	Poor (%)	Average (%)	Good (%)	Total (%)
7-10 years	4 (50)	2 (25)	2 (25)	8
10-20	1 (12.5)	4 (50)	3 (37.5)	8
20-30	3 (18.8)	5 (31.2)	8 (50)	16
30-40	1 (10)	5 (50)	4 (40)	10
40-50	0 (0)	0 (0)	4 (100)	4
50-60	4 (66.7)	1 (16.7)	1 (16.7)	6
>60	1 (25)	0 (0)	3 (75)	4
			X^2=19.5, DF=12, P=0.076	
Gender				
Male	5(16.1)	10(32.3)	16(51.6)	31
Female	9(36)	7(28)	9(36)	25
			X^2=3.02, DF=2, P=0.22	
Occupation				
Professionals	1(33.3)	0 (0)	2 (66.7)	3
Semi-professionals	1 (25)	1 (25)	2 (50)	4
Businessman	3 (27.3)	3 (27.3)	5 (45.4)	11
Skilled	3 (30)	2 (20)	5 (50)	10
Unskilled	5 (50)	4 (40)	1 (10)	10
Housewife	1 (16.7)	1 (16.7)	4 (66.6)	6
Student	3 (25)	6 (50)	3 (25)	12
			X^2=10.4, DF=12, P=0.58	
Educational status				
Illiterate	4 (66.6)	1(16.7)	1 (16.7)	6
Primary school	8 (72.7)	1 (9.1)	2 (18.2)	11
Middle school	4 (40)	5 (50)	1 (10)	10
High school	2 (14.2)	6 (42.9)	6 (42.9)	14
P.U.C	1 (12.5)	2 (25)	5 (62.5)	8
Graduates	2 (28.6)	1 (14.3)	4 (57.1)	7
			X^2=19.8, DF=10, P=0.031	
Total	14	17	25	56

Table 4. Association between age, gender, occupation and educational status of patients with experience of stigmatization.

Age group	Stigmatization		
	Present (%)	Absent (%)	Total (%)
7-10 years	2 (25)	6 (75)	8
10-20	4 (50)	4 (50)	8
20-30	12 (75)	4 (25)	16
30-40	8 (88.9)	1 (11.1)	9
40-50	5 (100)	0 (0)	5
50-60	3 (50)	3 (50)	6
>60	3 (75)	1 (25)	4
Total	37	19	56
		X^2=13, DF=6, P=0.043	
Gender			
Male	21 (67.7)	10 (32.3)	31

Table 4. Contd.

Female	16 (64)	9 (36)	25
			X^2=0.0864, DF=1, P=0.769
Occupation			
Professional	2 (66.7)	1 (33.3)	3
Semi-professional	3 (75)	1 (25)	4
Businessman	8 (72.7)	3 (27.3)	11
Skilled	7 (70)	3 (30)	10
Unskilled	5 (50)	5 (50)	10
Housewife	3 (50)	3 (50)	6
Student	9 (75)	3 (25)	12
			X^2=2.7, DF=6, P=0.846
Educational status			
Illiterate	2 (33.3)	4 (66.7)	6
Primary school	7 (63.6)	4 (36.4)	11
Middle school	8 (80)	2 (20)	10
High school	8 (57.1)	6 (42.9)	14
P.U.C	7 (87.5)	1 (12.5)	8
Graduation and above	5 (71.4)	2 (28.6)	7
			X^2=5.99, DF=5, P=0.307
Total	37	19	56

Table 5. Association of age, gender, occupation and educational status with quality of self-management practices among epileptic patients.

Age group	Self-management practices				
	Poor (%)	Average (%)	Good (%)	Total (%)	P value
7-10	5 (62.5)	0 (0)	3 (37.5)	8	
10-20	1 (12.5)	1 (12.5)	6 (75)	8	
20-30	2 (12.5)	2 (12.5)	12 (75)	16	
30-40	0 (0)	2 (22.2)	7 (77.8)	9	
40-50	0 (0)	0 (0)	4 (100)	4	
50-60	0 (0)	3 (42.9)	4 (57.1)	7	
>60	0 (0)	0 (0)	4 (100)	4	
				X^2=25.7, DF=12, P=0.012	
Gender					
Male	4 (12.5)	4 (12.5)	24 (75)	32	
Female	4 (16.7)	4 (16.7)	16 (66.7)	24	
				X^2=0.467, DF=2, P=0.792	
Occupation					
Professionals	1 (33.3)	1 (33.3)	1 (33.3)	3	
Semi-professionals	1 (25)	1 (25)	2 (50)	4	
Businessman	1 (9.1)	2 (18.2)	8 (72.7)	11	
Skilled	1 (10)	2 (20)	7 (70)	10	
Unskilled	2 (20)	1 (10)	7 (70)	10	
Housewife	0 (0)	0 (0)	6 (100)	6	
Student	2 (16.7)	1 (8.3)	9 (75)	12	
				X^2=6.85, DF=12, P=0.868	
Education					
Illiterate	1 (16.7)	2 (33.3)	3 (50)	6	
Primary school	5 (45.4)	3 (27.3)	3 (27.3)	11	

Table 5. Contd.

Middle school	1 (10)	0 (0)	9 (90)	10
High school	1 (7.1)	1 (7.1)	12 (85.8)	14
P.U.C	0 (0)	1 (12.5)	7 (87.5)	8
Graduates	0 (0)	1 (14.3)	6 (85.7)	7
				X^2=19.8, DF=10, P=0.031
Total	8	8	40	56

study which reported that 84% did not have any restriction of daily activities due to epilepsy and substantial proportions (range 52 to 88%) did not perceive any impact of epilepsy on the aspects of daily living (Bahou et al., 2011). Other studies have found that because of the clinical uncertainty and social meaning associated with this disease, the impact of epilepsy on a person's quality of life can be significant (Dilorio et al., 2003; Dilorio et al., 1994; Begley et al., 2010; Collings, 1990). The European study had reported that 44% of respondents worried a lot of possible side effects of their medication, 47% reported that it substantially affected their plans and ambitions for the future (Baker et al., 1997). Quality of life of patients in this study was found to significantly increase with educational status. This could be because well-educated patients are well aware of self-management practices and are better educated about the disease and also know that by being regular with treatment can avoid seizures and hence lead a normal life. Stigmatization was reported by about 66% of patients in this study. High rate of stigmatization was also reported by a European study where more than half of all epileptic patients (51%) experienced this sometime in their lives (Baker et al., 1997). The rate of stigmatization was found to be lesser in a Jordanian study where it was reported by 14% of patients (Bahou et al., 2011).

Epilepsy being a stigmatizing condition has also been reported in other studies as well (Jacoby et al., 2005; Ablon, 2002; Scambler and Hopkins, 1990).

Superstitious beliefs among people that evil spirits or curse God as the cause of seizures could be one reason for its presence in our society. Even educated people are found to stigmatize epileptic patients probably because these patients have a poor social life due to poor marriage and employment rates. Stigmatization could also arise because of their fear or helplessness in dealing with these patients during an epileptic attack.

Consequently an attitude of non-acceptance of self or reluctance in disclosing their disabilities to others has developed among epileptic patients as observed (Goodridge and Shorvon, 1983). The stigmatization due to epilepsy was significantly associated with age of patients. Patients in the age group of 30 to 40 years reported greater stigmatization than patients of other age groups. No association of stigma was seen with gender, occupation and educational status of participants. In a

study done in Atlanta it was found that the perceived stigma was similar for men and women, ethnic groups and age groups. Here it was also observed that the participants reporting higher levels of perceived stigma also reported lower levels of self-efficacy to manage epilepsy; more negative outcome expectancies related to treatment and seizures and lower levels of medication management, medication adherence and patient satisfaction (Dilorio et al., 2003).

The social cause of epilepsy depends on economic and social factors, and, for this reason, the stigma can be heterogeneous and changeable (Kleinman et al., 1995). The perception of epilepsy is often negative, which impairs the patient's quality of life and reinforces the stigma (Scambler and Hopkins, 1990).

Studies have reported that prejudice and discrimination often have a greater impact on the daily lives of people with epilepsy than seizures (Suurmeijer et al., 2001; Fisher et al., 2000). In a Glasgow based study few children reported episodes of bullying, teasing or being laughed at because of their epilepsy. The study also reported that few epileptic children were not permitted by their teachers to join activities, however few others reported that teachers were helpful and supportive. These children also reported difficulty to concentrate during lectures more since epilepsy onset (Moffat et al., 2009a, b).

All children are likely to encounter issues and concerns during the course of their development, which are further complicated by the presence of epilepsy or other chronic illnesses of childhood. Hence stigma associated with epilepsy need to be eliminated by whatever possible means such as creating awareness among people for the betterment of plight of epileptic patients. Mass media campaigns should target these social segments to fight prejudice and improve society's acceptance of people with epilepsy (Fernandes et al., 2007).

Of late, positive attitude has been witnessed among epileptic patients in certain parts of the world. The Glasgow based study for example reported that few epileptic patients have decided to tell others about their illness so that they could feel safer if they had seizures (Moffat et al., 2009a,b).

Self-management practices are another area which has been found to be good in about 71% patients in this study. Significant association of this was seen with age of

patients particularly of the age group 30 to 50 years. Self-management practice was also found to significantly increase with educational status of patients. However no significant association was seen between gender and occupational status of patients. Similar observation was made in a Texas based study where epileptic patients with higher levels of self-efficacy and social support also reported higher self-management (P<0.01) regardless of demographics, seizure frequency and socio-economic status (P<0.05). These findings provide little support for age, gender and socio economic status related disparities in self-management and suggest that the focus of strategies to improve self-management may be similar across diverse populations (Begley et al., 2010). Thus educating patients is all that is required to improve their self-management practices so as help them to cope up with epilepsy. The association of economic status with various parameters could not be studied as family income was not revealed by most participants.

Conclusion

Quality of life was significantly associated with educational status of patients. Poor quality of life being reported by more than half of patients indicates the importance of empowering people to adjust with epilepsy so that they can better accommodate their condition. Reducing side effects and achieving better control of seizures are also key to improving the quality of life of people with epilepsy, as is reducing the stigma and handicap associated with it. Stigmatization being reported by more than 65% of patients and being significantly more among patients in the age groups 30 to 50 years indicates the gravity of this issue. Stigma can be alleviated by better family and social support. For this, general public need to be educated so that they get the right perspective of this disease. They also need to be taught the required skills to help an epileptic patient during an attack. Self-management practices being good in more than 70% patients indicate that most patients know the dos and don'ts practices associated with epilepsy quite well. These beneficial practices were found to significantly improve with increasing age of patients and also were significantly associated with educational status of patients. Hence if quality of life of epileptic patients is improved and stigma associated minimized it will improve their self-esteem and help them lead a normal life like any other individuals.

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