

# Quality of Life in Patients with Epilepsy

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## ABSTRACT

**Introduction:** Epilepsy is a chronic condition with physical and psychological consequences and hence quality of life is generally considered to be poor in patients suffering with epilepsy. There is limited number of studies investigating the quality of life in patients with uncomplicated epilepsy, with good seizure control and without obvious structural brain damage. The objective of the current study is to evaluate the quality of life in patients with adequate seizure control, without obvious brain damage and to compare with healthy first degree relatives.

**Material and Methods:** This is a cross sectional case control clinical study conducted in Father Muller Medical College Mangalore. A total of 80 subjects, 40 patients attending the outpatient and inpatient facilities of the department of neurology with a clinical diagnosis of idiopathic generalized tonic clonic epilepsy and 40 healthy age matched first degree relatives were evaluated. Demographic data was collected using special designed Performa. Quality of life was assessed using 36 item Short Form Survey. The various findings were statistically analyzed using chi-square test, Student T test and ANOVA.

**Results:** Patients with epilepsy scored less on the physical and mental component of the SF-36 indicating worse quality of life in comparison to control.

**Conclusions:** Adult individuals with well controlled idiopathic generalized tonic clonic epilepsy without obvious structural brain damage have worse quality of life compared to healthy first degree relatives.

**Keywords:** Epilepsy; Quality of Life.

## INTRODUCTION

Quality of life is the degree of well being felt by an individual or group of people and consists of physical and psychological components. The physical aspect includes health, diet, and protection against pain and disease. The psychological aspect includes worry, stress, pleasure and other positive or negative emotional states.<sup>1</sup> WHO defines quality of life as “a state dependent on physical and functional status and the degree of family support, social activity and friendship, personal achievement and philosophy; and financial adequacy and work achievement.”<sup>2</sup> The Center for Disease Control and Prevention defined quality of life as the perception of physical and mental health over time. Health related-quality of life pertains to the effect of chronic illness on patient’s subjective experience in physical, psychological and social domains. The focus of quality of life is on the patient’s perception and experience of the disease rather than on medical determinations of physiological functioning such as seizure control. The three different areas in the concept of quality of life in epilepsy are physical health, psychological health and social health. Physical health is the outcome measures for patients with epilepsy traditionally include seizure frequency and severity and adverse effects of treatment. In addition seizures increase the risk of bruises, fractures, dislocation and pain as well as

unexplained death. Psychological health is when patients with epilepsy usually experience psychiatric and emotional disorders such as depression, fear of the public, loss of self esteem etc. Social health is the area that deals with a range of aspects of relationships with people both inside and outside the family nucleus, the ability to comfortably and appropriately relate, the occupational status, and economic self sufficiency.<sup>3</sup>

The domains of quality of life in epilepsy that has been suggested as relevant outcomes of health and medical care are the symptoms, functional status, self care, mobility, physical activity, role performance, work, household management, social functioning, personal interactions, intimacy, community interactions, emotional status, general life satisfaction.<sup>4</sup> Patients with epilepsy had significantly lower scores compared with healthy persons in 6 domains of the SF-36, general health, mental health, vitality, role limitations in a prospective observational study of patients with partial or GTCS.<sup>5</sup> In a large population survey in Ontario, Canada which evaluated more than 60,000 people among whom 313 were epileptics and found quality of life to be worse in patients with epilepsy.<sup>6</sup> In comparison with other chronic diseases, patients affected by epilepsy and multiple sclerosis reported significantly lower health related quality of life scores than patients with diabetes on emotional well being, role limitation, physical, energy and social functioning scales of SF-36.<sup>7</sup> Children with epilepsy had a relatively more compromised quality of life in the psychological, social and school domains in comparison with children or adolescents with asthma.<sup>8</sup> Quality of life, family function and social support were worse in patients with epilepsy. Patients with epilepsy had more disability days, limitations in activity and lower annual income, and were high users of health care resources than all other groups including chronically ill.<sup>6,9</sup>

In adults and children with well controlled epilepsy, studies have shown no difference in quality of life when compared with the general population.<sup>10</sup> Seizure free adults can have health related quality of life levels comparable with those of general population.<sup>11</sup> The extent of seizure control had the strongest effect on quality of life as was seen in a cohort of adults with intractable epilepsy.<sup>12</sup> Reducing adverse effects and achieving better seizure control were key to improving the quality of life in epilepsy, as was reducing the stigma and handicap associated with it.<sup>13</sup> A retrospective cross sectional study conducted in France, Germany and the UK that quality of life worsens with an increase in seizure frequency particularly as regards daily

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activities, mental health, social life and feeling about health.<sup>14</sup> The occurrence of seizures even in low frequencies was associated with psychosocial handicap.<sup>15</sup> As seizure frequency increases patients have impaired quality of life regardless of time since last seizures, gender and comorbid status. Frequency of seizures was the most significant parameter related to quality of life and duration of disease also correlated with quality of life score.<sup>16</sup> Quality of life determinants in people affected by epilepsy are seizure frequency, seizure type, medication side effects, psychological and medical co morbidity, stigma and discrimination.<sup>17-19</sup>

Depression is the only co morbidity which was investigated in quality of life studies of epilepsy. It was frequently diagnosed among patients with complex partial seizures and quality of life was reported as being poorer compared with that of patients without current/lifetime depression.<sup>20</sup> Health Related - quality of life and depressive disorder were strongly inter related indicating that patients with depressive symptoms report lower quality of life and specific patterns of activities of daily living.<sup>21-23</sup> It was found that patients with pseudo seizures experienced a similar impact on their seizure disorder as patients with chronic partial seizures on many aspects of cognitive function and mental health, except the physical health domain where they reported lower scores.<sup>24</sup> Assessment of quality of life in temporal lobe epilepsy showed that seizure frequency, presence of auras, time since the last seizure, intake of antiepileptic drugs and the severity of antiepileptic drugs side effects were significantly correlated with poor quality of life. Furthermore, employment status, tumors and hippocampus sclerosis pathology, psychiatric and medical co-morbidities were significantly correlated with poor quality of life.<sup>25</sup>

The positive effect of antiepileptic drugs therapy on quality of life in patients with epilepsy is control of seizures, generally achieved in 80% of patients; the remaining 20% might be expected to develop chronic epilepsy which is more difficult to treat, often requiring intensive drug treatment with a consequent onset of adverse effects and a worsening of quality of life.<sup>26,27</sup> The purpose of treating epilepsy is not necessarily seizure eradication rather the aim should be at obtaining maximal improvement of patients quality of life, therefore a multi disciplinary approach to epilepsy is required.<sup>28</sup> Patients with epilepsy have relatively higher risk for psychopathology and poor quality of life. There are only a limited number of studies investigating the quality of life in uncomplicated Epilepsy, with good seizure control and without obvious structural brain damage.

The aim of the study was to evaluate the quality of life in patients with epilepsy and to evaluate the relationship between sociodemographic and clinical variables and quality of life in patients with epilepsy.

## MATERIAL AND METHODS

The clinical study was conducted in Father Muller Medical College, Mangalore. All patients attending the outpatient and inpatient facilities of the department of neurology with a clinical diagnosis of idiopathic generalized tonic clonic epilepsy constituted the population for the study. The study was conducted from the 1<sup>st</sup> of September 2007 to the 31<sup>st</sup> of August 2009. The sample for the study consisted of forty consecutive patients with idiopathic generalized tonic clonic epilepsy who

satisfied the inclusion and exclusion criteria. Inclusion Criteria were male and female patients between the ages of 18 and 50yrs with at least primary school education. Patients diagnosed with idiopathic generalized tonic clonic epilepsy with duration of illness less than 10 years. Exclusion Criteria were patients with co morbid neuro psychiatric disorders, patients with epilepsy secondary to other causes, intractable epilepsy or with poor seizure control and patients with epilepsy who have undergone neuro surgical interventions, patients with epilepsy having medical disorders like diabetes mellitus, thyroid and other endocrine disorders and other chronic debilitating medical conditions, patients on long term regular treatment other than anti epileptic drugs.

Forty first degree male and female non affected relatives of the patients between the ages of 18-50 years without comorbid psychopathology constituted the control for the study. A written informed consent was obtained from all patients and the first degree relatives recruited for the study. This study has been cleared by the ethical committee of the institution. The socio demographic and clinical variables were recorded in a specific Proforma prepared for this clinical study. All the patients and control underwent a thorough clinical examination to rule out psychopathology and medical disorders if any. Quality of life was assessed using short Form Health Survey 36 (SF36). The patients with epilepsy were evaluated during the inter ictal period at least six weeks after the last seizure.

## STATISTICAL ANALYSIS

The data was analyzed using chi - square test, Student T test and ANOVA using SPSS version 21.

## RESULTS

40 cases of idiopathic generalized tonic clonic epilepsy and 40 age matched first degree relatives were assessed. Table 1 shows the distribution of demographic characteristics in both groups. No statistically significant difference was noted in sociodemographic data.

55% of patients had epilepsy for duration of 1-2 years forming the largest group, followed by 32.5% of patients that had epilepsy onset within one year. There is no significant difference between the groups. 55% of patients were seizure free for a period of 1-2 years, 32.5% of patients were seizure free for > 6 weeks but less than 1 year and 12.5% of patients were seizure free for longer durations (2-10 years). There is no significant difference between the groups. (p=0.562) [Table 2]. There is no statistical significance found for the duration of epilepsy and duration of seizure free interval. Increasing age had a negative effect on the physical component, but the same results were found in the control group as well.

There is highly significant difference in the domains of general health, vitality and mental health (p=0.000<0.001). The mean scores of the case group are lower than that of the control group on these domains. There is no significant difference between groups on the domains of physical functioning, role physical, bodily pain, social functioning and role emotional [Table 3].

There is highly significant difference between groups on the physical component summary (p=0.000<0.001). The mean value obtained by the cases group (87.53) is significantly lower than control group (94.66). There is highly significant

Demographic Data	Cases	Control	Total	P value
<b>Age</b>				
18-30 yrs	30(75%)	27(67.5%)	57(71.3%)	0.643
30-40 yrs	8(20%)	9(22.5%)	17(21.3%)	
40-50 yrs	2(5%)	4(10%)	6(7.5%)	
<b>Gender</b>				
Male	22(55%)	26(65%)	48(60%)	0.361
Female	18(45%)	14(35%)	32(40%)	
<b>Religion</b>				
Hindu	22(55%)	22(55%)	44(55%)	0.929
Christian	14(35%)	14(35%)	14(35%)	
Muslim	4(10%)	4(10%)	4(10%)	
<b>Education</b>				
Primary	8(20%)	6(15%)	14(17.5%)	0.694
High school	12(30%)	13(32.5%)	25(31.3%)	
Puc/Graduation	17(42.5%)	15(37.5%)	32(40%)	
Post Graduation	3(7.5%)	6(15%)	9(11.3%)	
<b>Occupation</b>				
Unemployed	1(2.5%)	3(7.5%)	4(5%)	0.760
Unskilled	5(12.5%)	4(10%)	9(11.3%)	
Skilled	4(10%)	6(15%)	10(12.5%)	
Clerk/office	7(17.5%)	5(12.5%)	12(15%)	
Agriculturist	3(7.5%)	6(15%)	9(11.3%)	
Others	17(42.5%)	13(32.5%)	30(37.5%)	
<b>Marital status</b>				
Single	22(55%)	23(57.5%)	45(56.3%)	0.466
Married	18(45%)	16(40%)	34(42.5%)	
Separated/divorced	0(0%)	1(2.5%)	1(1.3%)	
<b>Type of Family</b>				
Nuclear	30(75%)	32(80%)	62(77.5%)	0.861
Extended Nuclear	6(15%)	5(12.5%)	11(13.8%)	
Joint	4(10%)	3(7.5%)	7(8.8%)	
<b>Domicile</b>				
Urban	29(72.5%)	30(75%)	59(73.8%)	0.954
Rural	7(17.5%)	6(15%)	13(16.3%)	
Others	4(10%)	4(10%)	8(10%)	
<b>Socio Economic class</b>				
Lower	11(27.5%)	11(27.5%)	22(27.5%)	0.756
Middle	28(70%)	28(70%)	56(70%)	
Upper	1(2.5%)	1(2.5%)	2(2.5%)	

Table-1: Sociodemographic Characteristic

	Cases	Total	P value
<b>Duration of epilepsy</b>			
<1 yr	13(32.5%)	13(32.5%)	0.686
1-2 yrs	22(55%)	22(55%)	
2-5 yrs	4(10%)	4(10%)	
5-10 yrs	1(2.5%)	1(2.5%)	
<b>Seizure free period</b>			
<1 yr	13(32.5%)	13(32.5%)	0.562
1-2 yrs	22(55%)	22(55%)	
2-5 yrs	4(10%)	4(10%)	
5-10 yrs	1(2.5%)	1(2.5%)	

Table-2: Clinical Data

difference between groups on the mental component summary ( $p=0.000<0.001$ ). The mean score obtained by cases (88.80) is significantly lower than control group (92.82). Results indicate overall worsening of quality of life in cases, with certain domains being primarily affected [Table 4].

## DISCUSSION

Quality of life measures serve as a common denominator for comparing the overall impact of different health interventions, both at the individual and community level. Illness and its treatment can have a major impact on many aspects that are highly relevant to the individual's quality of life, such as cognitive, emotional and sexual functioning, life satisfaction and the ability to fulfill economic and other social roles. The performance of basic social roles and activities of daily living (ADL) is often used as a standard for the impact of a disease entity on quality of life.

Epilepsy is a chronic condition with numerous social and psychological consequences. Quality of life is generally accepted to be poor in epileptics especially when seizures are not well controlled and is worsened by the presence of co-morbid depression. It has been widely pointed out that the purpose of treating epilepsy is not necessarily seizure eradication;

SF-36	Group	N	Minimum	Maximum	Mean	Std deviation	p
Physical functioning (PF)	Cases	40	75	100	96.63	6.444	0.519
	Control	40	67	100	97.54	6.199	
	Total	80	67	100	97.08	6.299	
Role Physical (RP)	Cases	40	100	100	100	.000	0.236
	Control	40	100	100	100	.000	
	Total	80	100	100	100	.000	
Bodily Pain (BP)	Cases	40	62	100	95.95	9.979	0.000
	Control	40	68	100	98.21	6.628	
	Total	80	62	100	97.08	8.494	
General Health (GH)	Cases	40	20	77	57.55	14.627	0.000
	Control	40	70	97	82.90	9.179	
	Total	80	20	97	70.23	17.604	
vitality	Cases	40	55	90	75.00	8.843	0.000
	Control	40	65	100	83.25	8.515	
	Total	80	55	100	79.13	9.572	
Social functioning (SF)	Cases	40	75	100	99.38	3.953	0.656
	Control	40	88	100	99.69	1.976	
	Total	80	75	100	99.53	1.709	
Role Emotional (RE)	Cases	40	100	100	100	0.000	0.000
	Control	40	100	100	100	0.000	
	Total	80	100	100	100	0.000	
Mental Health	Cases	40	52	92	81.23	7.969	0.000
	Control	40	72	96	88.35	5.691	
	Total	80	52	96	84.79	7.759	

Table-3: Short Form Health Survey 36 data

	Group	N	Minimum	Maximum	Mean	Std deviation	P
Physical Component summary (PCS)	Cases	40	74.75	94.25	87.53	5.409	0.000
	Control	40	76.02	99.25	94.66	4.322	
	Total	80	74.75	99.25	91.09	6.045	
Mental Component Summary (MCS)	Cases	40	77	95	88.80	4.166	0.000
	Control	40	84	98	92.82	3.539	
	Total	80	77	98	90.81	4.341	

Table-4: Physical and mental Component Summary of SF-36 data

rather the aim should be at obtaining maximal improvement in patient's quality of life. Earlier studies aimed at studying behavioral, emotional and psychiatric consequences of epilepsy as important aspects of health related quality of life (HR-QOL), later more specific instruments like Quality of Life in Epilepsy (QOLIE) and the Liverpool HR-QOL were provided to assess quality of life in epilepsy patients. A comprehensive definition of quality of life in epilepsy that is generally accepted now was provided by Dodson and colleagues: 'quality of life in epilepsy is an individual's perception of the impact of their condition and its treatment. It reflects the discrepancy between the person's actual and desired physical and psychological health level of independence and social relationships'.<sup>29</sup>

Earlier studies using the SF-36 for quality of life in epilepsy have found that epilepsy patients had worse HR-QOL, they scored worse on general health perceptions, mental health, vitality, role limitations and emotional well being.<sup>5-7</sup> Other studies have shown that the most consistent relationship observed between clinical/demographical and psychosocial variables was that between current level of seizure frequency and measures of psychological well being and aspects of daily functioning<sup>11-13</sup> and the occurrence of seizures even at low frequencies was associated with psychosocial handicap.<sup>14,15,18</sup> Epileptics were also found to be less likely to be married, employed or full time

students.<sup>30</sup>

In this study SF-36 data revealed that epileptics scored worse on general health, vitality, mental health and the physical and mental component of the sf-36 health survey which is consistent with earlier studies and there is no deterioration found in physical health, role physical, role emotional and social functioning domains. Earlier studies had found impairment in social functioning. The duration of epilepsy or seizure free interval did not have any effect on the quality of life. Increasing age had a negative effect on the physical component, but the same results were found in the control group as well.

The present investigation has some limitations and certain relative merits. The samples as well as the control are not representative of the general population. Recruitment of consecutive patients ensures that there is no sample bias. The exclusion and inclusion criteria are specific. Hence the sample consists of generalized tonic clonic epilepsy patients who are otherwise not compromised, but this has not been verified by using neuroimaging to exclude presence of such factors. The effect of anti epileptics and other medications has not been considered in this study. The size of the sample and control is sufficient to assess quality of life, but a larger sample size will be required to enhance the reliability and validity of the results. A larger sample size is required to calculate the exact

relationship of cognitive impairment and socio-demographic and clinical variables. The present study is a cross sectional case control study to evaluate quality of life. A longitudinal study would enable to assess the continuum of quality of life. The tools used have adequate established reliability and validity. All the tools are rater friendly, easy to administer, less time consuming thereby causing no discomfort to the patients.

## CONCLUSIONS

The current study concludes that in adult patients with well controlled generalized tonic clonic epilepsy, without obvious structural brain damage have poor quality of life. This study has found that adult patients with well controlled generalized tonic clonic epilepsy, without obvious structural brain damage have poor quality of life. Hence assessment of quality of life is warranted for comprehensive management of patients with epilepsy.

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