

# Determinants of Quality of Life in Nigerian Children and Adolescents with Epilepsy: A Hospital-based Study

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## Abstract

**Purpose:** Though studies abound on the quality of life (QoL) in chronic illnesses, there has been little focus on children and adolescents. This study investigated the determinants of QoL in children and adolescents with epilepsy in a Nigerian Tertiary Mental Health Institution.

**Methods:** The study involved 67 adolescents between 11 and 18 years of age, diagnosed with epilepsy. Depression was assessed using the Centre for Epidemiology Study Depression Scale, and their QoL was assessed using the Comprehensive QoL Scale (ComQoL-S). Data was analysed using Spearman's Correlation Coefficients and linear regression ( $p < 0.05$ ).

**Results:** The mean age of the participants was  $14.5 \pm 4.0$  years. Twenty-two (32.8%) of them were depressed. Participants scored significantly higher ( $p < 0.00$ ) in health, productivity, community participation and emotional domains and total QoL scores in the subjective axis than in the objective axis of QoL. When controlled for age and gender, the lower the educational attainments of the participants, the higher was their depression scores. Depression, seizure frequency at presentation at the clinic, seizure frequency at onset and age predicted poor QoL. Parents' socio-economic status predicted seizure frequency.

**Conclusion:** There is a high prevalence of depression in Nigerian adolescents with epilepsy. Epilepsy has a negative impact on their QoL. Therefore, it is necessary to pay more attention to the condition in order to reduce the frequency of seizures and improve their psycho-social well-being.

**Key words:** Depression, quality of life, Nigerian children and adolescents, epilepsy.

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## INTRODUCTION

There is growing interest in research on the subject of children with epilepsy. A number of psychiatric syndromes such as anxiety, depression, and behavioural, affective and conversion disorders have been identified in people with epilepsy (Adewuya and Ola, 2005; Hankin, 2006; Oguz et al, 2007; Wood et al, 2008). Studies on clinical and socio-demographic correlates of psychiatric disorders in children and adolescents with epilepsy abound, both in Nigeria and in other parts of the world (Adewuya and Ola, 2005; Hankin, 2006; Oguz et al, 2007; Wood et al, 2008). Several factors have been identified in the development of psychiatric disorders in people with epilepsy related to the epileptic syndrome, personal features or the nature of the psychiatric disorder (Thome-Souza et al, 2004; Adewuya and Ola, 2005; Hankin, 2006; Oguz et al, 2007; Wood et al, 2008). Generally, the risk for psychiatric disorders has been observed to be higher in children and adolescents with epilepsy than in the age-matched apparently healthy population (Adewuya and Ola, 2005; Hankin, 2006; Oguz et al, 2007; Wood et al, 2008). The most frequent psychiatric disorders found in epileptics were depression and attention deficit hyperactivity (Thome-Souza et al, 2004; Adewuya and Ola, 2005; Hankin, 2006; Oguz et al, 2007; Wood et al, 2008). Individuals with epilepsy are sometimes socially alienated and stigmatised (Thome-Souza et al, 2004; Adewuya and Ola, 2005; Wood et al, 2008). The psychiatric co-morbidity associated with epilepsy, and often stigma, contribute negatively to their perceived and societal norm-referenced quality of life.

Quality of life is an individual's perception of his or her position in life, in the context of the culture and value system in which he or she lives, in relation to his or her goals, expectations, standards and concerns (WHO Group, 1999). It has also been defined as a person's subjective well-being and physical health, material well-being, interpersonal relationships within and outside the family, work and other activities in the community, personal development and fulfilment (Diener and Suh, 1997; Claussen, 2004; Cadilhac et al, 2010). Quality of life has been used to evaluate service delivery, which has become a central focus for policy makers and funders (Niemi et al, 1988). Many studies have also used quality of life measures to guide programme and rehabilitation efforts, and clinicians have used these to measure the outcome of rehabilitation programmes (Cummins, 1997; Sacco, 1997; Diener and Suh, 1997; Claussen, 2004; Cadilhac et al, 2010; Owolabi, 2010).

Several studies have reported the quality of life of individuals with psychiatric disorders and other chronic illnesses (Viitanen et al, 1988; King, 1996; Kwa et

al, 1996; Cummins, 1997; Duncan et al, 1997; Sacco, 1997; Wyller et al, 1998; Claussen, 2004; Akinpelu and Gbiri, 2009; Cadilhac et al, 2010; Gbiri et al, 2010; Owolabi, 2010). A few of these have drawn comparisons between the quality of life of various chronically ill persons, and also compared them with apparently healthy individuals (Viitanen et al, 1988; Duncan et al, 1997). Others reported the quality of life of individuals with chronic illnesses as the outcomes of rehabilitation programmes (Astrom et al, 1993; Kwa et al, 1996; Sacco, 1997; Wyller et al, 1998; Gbiri et al, 2010). While only a few studies on the quality of life of children and adolescents with epilepsy are available for reference, studies on the socio-demographic determinants are not available, especially in developing countries. Since knowledge will go a long way towards addressing their needs and improving their quality of life, this study aimed at exploring the socio-demographic determinants of quality of life of children and adolescents with epilepsy, in a hospital-based study in Nigeria.

## METHODS

This study was approved by the Ethical Review committee of the Federal Neuro-Psychiatry Hospital, Yaba, Lagos, Nigeria. The assent of each of the participants and written informed consent of their parents or guardians, were obtained after the objective and procedure of the study was explained. The participants were 67 consecutively selected children and adolescents between the age of 11 and 18 years, who had been diagnosed with epilepsy. The study excluded persons with severe intellectual disability and those who were not stabilized on treatment.

The participants were diagnosed with epilepsy by consultant psychiatrists using ICD-10 at the Children and Adolescents Centre of the Federal Neuro-Psychiatric Hospital, Yaba, Lagos. The socio-demographic data and clinical history were obtained from the clients, their hospital records and their parents/guardians. Their quality of life was assessed using the fifth edition of the Comprehensive Quality of life questionnaire for children and adolescents (ComQol-S-5). The ComQol-S-5 has the advantage of assessing both the subjective and objective quality of life of children with disability. This is important because it measures the person's perception of his/her quality of life, as well as the societal comparative quality of life perception. Depressive symptoms were assessed using the Centre for Epidemiology Depression Scale for children (CESD-C). This instrument measures depression in people of all ages. Data was analysed using multivariate step-wise regression analysis.

## RESULTS

This study involved 38 males and 29 females. The mean age of the participants was  $14.5 \pm 4.0$  years. The onsets of seizure ranged between 1 and 16 years with a mode of 7 years, while the presentation in the clinic ranged between 1 and 16 years with a mode of 8 years. Twenty-two participants (32.8%) had received primary education, while thirty-three (49.3%) had received secondary education (Table 1). Twenty-four (35.8%) had personal possessions less than most children

**Table 1: Socio-Demographic Variables and Clinical History of the Participants**

Variables	Frequency	%	Cumulative %
<b>Educational Level</b>			
No formal	12	17.9	17.9
Primary	22	32.8	50.7
Secondary	33	49.3	100.0
<b>Personal Possessions</b>			
•most people	24	35.8	35.8
About average	34	50.8	86.6
<every other person	9	13.4	100.0
<b>Parents' Annual Income</b>			
<N131, 988	41	61.2	61.2
N132, 000-N99, 988	14	20.9	82.1
N600, 000-N1, 199, 988	7	10.5	92.6
•N1, 900,000	5	7.4	100.0
<b>Seizure Frequency at Presentation</b>			
Several times a day	31	46.3	46.3
Once/few times daily	15	22.4	68.7
Once/few times per week	5	7.5	76.1
Once/few times per month	16	23.9	100
<b>Seizure Frequency at Present</b>			
None	23	34.3	34.3
Once/few times per week	17	25.4	59.7
Few times per month	11	16.4	76.1
Occasionally	16	23.9	100
<b>Residence</b>			
A whole house	21	31.3	31.3
A flat/apartment	29	43.3	74.6
A room and a parlour/A room	17	25.4	100

while nine (13.4%) had less than most children (Table 1). Most of the parents (61.2%) earned less than 131, 988 Naira per annum while 7.4% earned above 1, 900,000 Naira per annum (Table 1). Thirty-one participants (46.3%) reported that the frequency of seizure occurred several times a day, while after 2 months in the clinic 23 (34.3%) reported that their frequency of seizure had reduced to none per day (Table 1). Twenty-two (32.8%) were diagnosed with depression. There was significant correlation between depression and each of educational-level and seizure frequency at presentation. Seizure frequency predicted depression and felt-stigma. Parents' socio-economic status predicted seizure frequency. Majority of the participants (66.7%) were Christians, 14.0% were Muslim and 19.3% did not specify their religion. Forty-four (65.7%) of the participants reported that their condition was disrupting their education, 16.4% had dropped out of school while 32.8% had repeated classes. Most of the participants' parents (73.1%) lived in rented accommodation while 22 (32.8%) of them owned their place of residence.

The domain specific and total quality of life scores of the participants were below average, both in the objective and subjective axis (Table 2). Participants scored significantly higher ( $p < 0.00$ ) in health, productivity, community participation and emotional domains and total QoL scores in the subjective axis than in

**Table 2: Comparison of Objective and Subjective Quality of Life Scores of the Participants**

Domain	Objective Axis		Subjective Axis		p-Value
	Mean	SD	Mean	SD	
Material	31.15	9.61	32.10	9.33	0.97
Health	28.77	8.16	40.24	10.03	0.00
Productivity	28.18	6.26	38.33	7.00	0.00
Intimacy	40.46	11.91	44.79	7.75	0.21
Safety	48.67	3.38	48.08	3.35	0.89
Community	16.08	9.19	29.89	10.82	0.00
Emotion	9.74	3.41	20.35	1.38	0.00
Spiritual	---	---	18.12	1.32	---
<b>Total QoL</b>	<b>31.98</b>	<b>2.85</b>	<b>46.24</b>	<b>1.73</b>	<b>0.00</b>

$p < 0.05$

the objective axis of QoL. When controlled for age and gender, the lower the educational attainments of the participants, the higher was their depression scores. Depression, seizure frequency at presentation at the clinic, seizure frequency at onset and age predict poor QoL. Parents' socio-economic status predicted seizure frequency.

## DISCUSSION

The prevalence of depression among the participants in this study (32.8%) is comparable with that of Adewuya and Ola (2005) with reported range of 23% to 33%. It shows that depression is a major issue among children and adolescents with epilepsy, and more attention should be paid to this.

The finding regarding the low quality of life of participants demonstrates the negative impact of epilepsy on both physical and psychological well-being of children and adolescents. This corroborates the findings of Adewuya (2006), that the domain-specific quality of life of children and adolescents with epilepsy were significantly higher in the subjective axes than that the objective axes in all but three domains (material, safety, and intimacy). The results of this study may demonstrate that people's feelings cannot be judged by external factors which are measured by the objective quality of life. It also shows that people's perceptions might not reveal the true state of the individual. This corroborates previous findings that quality of life cannot be measured from external factors because it is all about individual experience (Wilk, 1999; Akinpelu and Gbiri, 2009; Gbiri and Akinpelu, 2010). It also supports the summation of Diener and Suh (1997) that objective quality may not reflect people's experience of well-being; therefore, it should be assessed separately from subjective quality of life. From the results of this study, it may also be inferred that a person could live in an affluent community and still mention having experienced abject poverty. Similarly, a person may express high quality of life despite living in great poverty.

That the participants scored lower than average in all the domains of quality of life, both in the objective and subjective axes shows that epilepsy has negative impact on the quality of life of children and adolescents with epilepsy. The finding that participants scored low in the material domain shows that epilepsy has great impact on their material well-being.

The relationship between seizure frequency and socio-economic status of the parent is a phenomenon it may not be possible to explain. However, it reflected

the socio-economic impact of epilepsy on both the patient and the family. This corroborated other reports on the socio-economic impact of caring for children with chronic illnesses such as cerebral palsy, and sickle cell anaemia. Parental level of education also had a significant effect on the seizure frequencies. This may have been due to the fact that less educated parents are likely to have less knowledge about the condition and the appropriate care required. The authors' personal experience in the clinic has shown that children from less educated backgrounds have lower drug compliance. Hence, relapses and frequent seizures are inevitable.

## CONCLUSION

This study has been able to provide more information on the high prevalence of depression in Nigerian children and adolescents with epilepsy. It also shows that epilepsy has a negative impact on their quality of life. Therefore, there is a need to pay more attention to epileptic children, in order to reduce the frequency of seizures and improve their psycho-social well-being.

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