Original Article

The quality of life among Sudanese children with epilepsy and their care givers

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ABSTRACT

In the past few years, there has been a progressive increase in appreciation of the importance of quality of life (QOL) especially among patients with epilepsy. This issue had not been addressed in Sudanese children with epilepsy. We here aim to assess the quality of life in Sudanese children with epilepsy and their family care giver. This study was conducted in 2011 at the Epilepsy and Neurodisablity Out-patient Clinic at Saad Abualila University Hospital, Sudan. The study included 100 Children with epilepsy, and their care givers, whose age was between 6-18 years and had seizure for more than one year. The questionnaire used contains 27 questions; it was divided into four sections: impact of epilepsy and treatment, impact on the child development, impact on parents and impact on the family. For each question there were two dimensions: the frequency of the problem and the concerns that it causes. The total score ranges from 0 to 54. A combined total scale scores were calculated. The commonest concern regarding epilepsy was that the child may injure oneself, followed by that the child may stop breathing or develop brain damage or even die. The commonest concern regarding treatment was that medication may cause reduced alertness. The relevant mean scores in frequency and concern were 5.77 and 5.83 out of 10 respectively. In the child development domain, the commonest concern was that the child may become more moody and the related mean scores in frequency and concern were 9.36 and 9.32 out of 18. The commonest concern to parent was decreased ability for self care with relevant mean scores in frequency and concern of 3.14 and 3.16 out of 10. The commonest concern to the family was that the child needs to be more closely watched than other children .The mean scores here in frequency and concern were 5.37 and 5.44 out of 14. The group with epilepsy and associated co morbidities, longer seizure and treatment duration had consistently higher mean scores which were proved to significantly lower their QOL. There is a significant decline in the quality of life among Sudanese children with epilepsy and their family care giver. Psychosocial consultation, family support programs and health education for parent, teachers and publics about different aspects of epilepsy need to be addressed through mass media.

Key words:

Epilepsy; Quality of life; Sudanese children.

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INTRODUCTION

The goal of management of children with epilepsy is to enable the child and his family to lead a life as free as possible of the medical and psychosocial complications of epilepsy. This comprehensive care needs to go beyond simply trying to control seizures with minimal adverse drug reactions. Other factors including social, psychological, behavioural, educational, and cultural dimensions affect children with epilepsy, their families and their close social networks [1]. The term QOL refers to the physical, psychological, and social aspects of health [2]. In the past few years, there has been a progressive increase in appreciation of the importance of QOL and there were many studies that attempted to measure the QOL among epileptic patients using either generic or specific instruments. To our knowledge no study had been done in Sudan addressing this issue among children with epilepsy The main aim of this study is to assess the quality of life in Sudanese children with epilepsy &their family care givers.

PATIENTS AND METHODS

This is a descriptive cross sectional study conducted at the Epilepsy and Neurodisablity Outpatient Clinic at Saad Abualila University Hospital in 2011. The study included 100 Children with epilepsy and their caregivers attending the clinic and whose age was between 6-18 years and their seizure duration was more than one year. Children with severe disabilities, global developmental delay or other known chronic illnesses were excluded from the study. The questionnaire used was designed by Petter Hoare [3]. It contains 27 questions (the original questionnaire was formed of 30 questions but modified to fit with our Sudanese culture). It was divided into four sections. The first addressed the impact of epilepsy and treatment (questions 1-5), the impact on the child's development (questions 6-14), the impact on parents (questions 15-19), and lastly the impact on the family (questions 20-27). For each question there were two dimensions: the frequency of the problem, and its importance or degree of concerns that it causes. The two dimensions for each question scored 0, 1, or 2, so the total ranges from 0 to 54. Zero score implies never or rarely true, 1= sometimes true, 2 = often or nearly always true. In the importance or degree of concern: 0= no much concern, 1= of little of concern, 2= a lot of concern. A combined total scale score was calculated from the response to all the 27 questions. Descriptive analysis was used to measure means, standard deviations and range of different subscales and combined total scales score of epilepsy impact. Chi square test was used to determine the degree of association between diagnosis and other variables, association was considered significant when P value is less than 0.05.

RESULTS

One hundred patients and their caregivers were included in this study. Sixty one (61%) children were males and 39 (39%) were females. Fifty five (55%) were living in Khartoum state, While 45(45%) were from outside Khartoum state. Fifty three were off school of whom 41(77.4%) were not attending school due to their illness. Only 11(23.9%) had excellent school performance as shown in table (1). The majority of caregivers were mothers 94(94%), four (4%) fathers and two other caregivers. Eighty seven (87%) of them were married, nine (9%) divorced and four (4%) widows. Regarding their educational level, 52 (52%) had basic education, 26(26%) secondary, 28(28%) university and 14(14%) with no education. The majority 66 (66%) were of low socioeconomic class as shown in table (2). Fifty three (53%) of children had epilepsy for more than 5 years. Sixty two (62%) had generalised epilepsy, 31 (31%) had focal and only seven (7%) had specific epileptic syndromes.

Forty nine (49%) of them were receiving treatment for more than 5 years. Seventy two (72%) were on mono therapy, 14 (14%) were on two drugs while nine (9%) were on poly therapy. Forty four patients (44%) had no disabilities or any co- morbidity, while 36 (36%) had learning difficulties and nine (9%) had motor disability (Table 3).

The commonest concern regarding epilepsy was that the child may injured oneself, followed by that the child may stop to breathe or develop brain damage or even die. The commonest concern regarding treatment was that medication cause reduced alertness, followed by concern about behavioural problems. The mean in frequency was 5.77 and the mean in concern was 5.83 out of 10. In the child development domain, the commonest concern was that the child may become more moody, this was followed by that he may be easily embarrassed, acquires few friends, develops fewer hobbies, learning difficulties and he may not marry or have a family. The mean scores in frequency here were 9.36 and the mean in concern was 9.32 out of 18. Regarding the impact on parents, the commonest concern was difficulty in using public transport followed by decreased ability for self care, difficulty explaining child's illness to others and to the child problems with the administration of medications. The mean in frequency in this domain was 3.14 and the mean in concern was 3.16 out of 10. The impact of epilepsy on the family revealed that the commonest concern was that the child needs to be more closely watched than other children, followed by difficulty giving other children enough attention, limitation to what his brothers and sisters can do, having fewer social relationships and activities, limitations in frequency of family outings and turning down opportunities at work. The mean in frequency was 5.37 and the mean in concern was 5.44 out of 14, in this domain. The Subscale scores for the total group were recorded (Table 4).

The group with epilepsy who had longer seizure and treatment duration and on polytherapy had consistently higher mean scores which were proved to be significantly affecting their QOL (P value < 0.0.) (Tables 5, 6, and 7).

Table 1- Socio-demographic variables among children with epilepsy

Subject		%
Age		
	6-10 years	56.00
	10-15 years	40.00
	>15years	04.00
Sex		
	Male	61.00
	Female	39.00
	Total	100
	Schooling	
	Not attending schools	56
	Ordinary schools	42
	School for special needs	02
	School performance	
	Excellent	11
	Good	24
	Poor	11

Table 2 - Demographic variables among caregivers (N=100)

Variables	%
Educational level	
Basic	42
Secondary	26
University	18
No education	14
Income	
Low	66
Moderate	31
High	03
Marital Status	
Married	87
Divorced	09
Widow	04

Table 3- Epileptic variable among study group (N=100)

Epileptic features	%
Duration of seizure (years)	
> 5	53
5-2	33
<2	14
Classification of epilepsy	
Generalized	62
Focal	31
Syndromes	07
Medications	
Monotherapy	72
Two drugs	14
Polytherapy	09
Duration of treatment (years)	
> 5	49
5-2	34
<2	17
Additional disabilities	
Learning difficulties	36
Motor disability	09
Others	11

Table 4 - Sub-scale scores for total group

Subscale	Frequency			Concern		
	Mean	Std. D.	Range	Mean	Std. D.	Range
Treatment	5.77	2.4	0 – 10	5.83	2.38	0 – 10
Development	9.36	6.41	0 – 18	9.32	6.46	0 – 18
Parent	3.14	3.16	0 – 10	3.11	3.16	0 – 10
Family	5.37	4.80	0 – 16	5.44	4.84	0 – 14
Combined total scales score	47.34	28.70	0 – 95			

Std. D. - Standard deviation

Table 5 - Correlations between duration of the seizure and sub-scale scores (N=100)

Subscale	Duration of seizures	Frequency					Concern				
		N	Mean	Std. D.	Range	P. value	N	Mean	Std. D.	Range	P. value
Treatment	< 1	14	5.64	2.65	2-10	P > 0.05	14	5.71	2.55	2-10	P > 0.05
	2 - 5	33	5.30	3.15	0-10		33	5.48	3.12	0-10	
	> 5	53	6.09	1.80	0-10		53	6.08	1.73	0-10	
Development	< 1	14	5.64	5.64	0-16	P < 0.05	14	5.79	5.89	0-17	P < 0.05
	2 - 5	33	8.45	5.91	0-18		33	8.42	6.07	0-18	
	> 5	53	10.91	6.50	0-18		53	10.81	6.49	0-18	
Parent	< 1	14	2.00	2.94	0-8	P > 0.05	14	2.14	3.08	0-8	P > 0.05
	2 - 5	33	2.58	2.65	0-10		33	2.58	2.65	0-8	
	> 5	53	3.79	3.40	0-10		53	3.70	3.39	0-10	
Family	< 1	14	3.50	4.42	0-12	P > 0.05	14	3.57	4.54	0-12	P > 0.05
	2 - 5	33	5.24	5.21	0-14		33	5.36	5.30	0-14	
	> 5	53	5.94	4.59	0-14		53	5.98	4.58	0-14	

Std. D. - Standard deviation

Table 6 - Correlations between duration of treatment and total sub-scale score (N=100)

Subscale	Duration of treatment (years)	Frequency					Concern				
		N	Mean	Std. D.	Range	P. value	N	Mean	Std. D.	Range	P. value
Treatment	< 1	17	6.06	2.66	2-10	P > 0.05	17	6.12	2.57	2-10	P > 0.05
	2 - 5	34	5.21	3.15	2-10		34	5.38	3.13	2-10	
	> 5	49	6.06	1.66	2-10		49	6.04	1.58	2-10	
Development	< 1	17	6.82	6.15	0-16	P < 0.05	17	6.94	6.43	0-17	P < 0.05
	2 - 5	34	7.85	5.85	0-18		34	7.79	5.96	0-18	
	> 5	49	11.29	6.40	0-18		49	11.20	6.38	0-18	
Parent	< 1	17	2.24	2.91	0-8	P > 0.05	17	2.35	3.02	0-8	P > 0.05
	2 - 5	34	2.44	2.63	0-8		34	2.44	2.63	0-8	
	> 5	49	3.94	3.42	0-10		49	3.84	3.42	0-10	
Family	< 1	17	4.65	5.09	0-14	P > 0.05	17	4.71	5.16	0-14	P > 0.05
	2 - 5	34	4.91	4.92	0-14		34	5.03	5.02	0-14	
	> 5	49	5.94	4.66	0-14		49	5.98	4.64	0-14	

Std. D. - Standard deviation

Table 7 - Relation between monotherapy versus polytherapy antiepileptic drugs and total subscale score (N=100)

Subscale	Groups	Frequency			Concern			P. value
		Mean	Std. D.	Range	Mean	Std. D.	Range	
Treatment	Monotherapy	5.25	2.71	0 - 10	5.39	2.63	0 - 10	P > 0.05
	Polytherapy	6.18	2.14	0 - 10	6.18	2.12	0 - 10	
Development	Monotherapy	3.901	3.70	0 - 18	13.64	4.56	1 - 18	P < 0.001
	Polytherapy	13.64	4.56	0 - 14	3.70	3.30	0 - 18	
Parent	Monotherapy	0.39	0.99	0 – 4	0.39	0.99	0 – 10	P < 0.001
	Polytherapy	5.30	2.52	0 – 4	5.25	2.57	0 – 10	
Family	Monotherapy	1.86	2.72	0 – 12	1.93	2.87	0 - 14	P < 0.001
	Polytherapy	8.13	4.29	0 - 11	8.20	4.26	0 - 14	

Std. D. - Standard deviation

DISCUSSION

The concept of quality of life is difficult to define because of its multi-dimensional aspects and it is difficult to quantify. According to WHO the main domains of QOL are the physical domain, which includes independence in activities of daily living and symptoms of disease; the psychological domain, involving emotional, cognitive and behavioral status; and the social domain, how people perceive their role and relationship with other people [1,2]. Because many of the components of QOL cannot be observed directly, they are typically assessed according to classical principles of item-measurement theory [4]. Psychometric tools are used to explore each domain using group of questions (items). Answers are converted into numerical scores that are, then, combined to yield 'scale scores', which may be further combined to yield domain scores or other summary scores of statistical interest [4]. Measuring QOL is difficult in children and adolescents, and this is reflected in the few suitable tools available. Several instruments rely on the opinions of parent or career, but self-assessment by the child is preferable wherever possible. In the past few years, there has been a progressive increase in appreciation of the importance of including patient preferences and values into healthcare management [5,6]. Although there are many studies reporting the psychosocial outcome of children with epilepsy, there was only a few that attempted to measure the QOL using either generic or specific instruments. This study was conducted in 100 Sudanese children with epilepsy and their caregivers using a questionnaire designed by Petter Hoare [3]. The questionnaire was found to be suitable because it was designed for the same age group; however some adaptations were made to suit our Sudanese culture.

During the past 20 years, major clinical and research efforts have sought to characterise the status of health-related quality of life (HRQOL) in epilepsy [12]. The research to date has focused predominantly on the impact of clinical seizure features and the effects of treatment on HRQOL [13-23]. Our studied group was found to have a significantly poor QOL and especially so in the group with epilepsy and longer seizure and treatment durations, as well as those on polytherapy which is similar to what had been mentioned by Yong Li et al in his report from China using a questionnaires for Quality of Life in Childhood Epilepsy (QOLCE) [24]. Miller V et al reported that co-morbid impairment

was the best predictors for poor QOL [25]. The risk factors for poor QOL in 197 adolescents with epilepsy was evaluated by Devinsky et al, they found that increased seizure severity, and AED neurotoxicity were associated with poorer QOL [26]. The QOL life was measured in adult epileptic patients from Sudan using the WHO 26-item QOL The study concluded that Poor QOL in epilepsy reflects the impact of side effects of treatment, illness chronicity and social underachievement [27]. Seventy seven percent of our patients were not attending school regularly due to their illness and very few had excellent school performance. This adds on to affect their QOL [7-11].

CONCLUSION AND RECOMMENDATIONS

There is a significant decline in the QOL among Sudanese children with epilepsy and their family caregivers, which is similar to what had been mentioned in the literature. Implementation of family support programmes, clinics for psychosocial consultations and health education for parents, teachers and publics about different aspects of epilepsy need to be addressed through mass media.

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