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Effect of Family Support Program on Quality of Life of Epileptic Children In Khartoum City

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ABSTRACT

Epilepsy is a chronic illness that has a great impact on the life of the epileptic children. The aim of this study was to evaluate the effect of family support program on quality of life of epileptic children. An experimental study design was used in this study. Forty five (45) epileptic children from Soba University Hospital Outpatient Clinic were selected randomly as intervention group and, another Forty five (45) epileptic children from Fathelrahman El Basher Outpatient Clinic, selected as a control group. Data was collected on three occasions from the experimental and control group as follows: before the implementation of the program, one and 3 months after the program completion. Program activities implemented through four sessions, one hour session per week for one month. The program covered all the points evaluated by the scales, using different methods and materials such as lectures, pictures, discussion, videotapes and Hand out. Mean total quality of life significantly improved in the experimental group, at baseline data, 1 and 3 months after the program (52.85%,65.60% ,79.56%) respectively (P-value<.0005). Unlike quality of life in control group no significant change has been observed. A significant difference in all Health related quality of life sub domains in experimental group from baseline data, 1 and 3 months after the program (p-value <.0005).Unlike quality of life in control group where no significant change has occurred. The study has shown the effectiveness of the role played by family support program in improving quality of life of epileptic children in experimental group compared to control group where no significant change has occurred. It will recommended that, educational programs must be carried out periodically for parents and their children to provide them with proper knowledge and skills necessary for improving the quality of life of epileptic children.

Keywords: Quality of life - Epileptic children- Family Support

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INTRODUCTION

The brain is made up of billions of nerve cells or neurons that communicate through electrical and chemical signals. When there is a sudden excessive electrical discharge that disrupts the normal activity of the nerve cells, a change in the person's behavior or function is potential. This abnormal activity in the brain that results in a change in the person's behavior or function is a seizure. ¹Today more people are living with chronic illnesses than before. Epilepsy can affect anyone at any age. ²Two thirds of epileptic cases are children, with the majority developing epilepsy during infancy or early childhood. ³Aziz reported that more than 70% of the adult population with epilepsy had the onset of their disease in childhood. ⁴The diagnosis of a seizure disorder in children is associated with worries and fears in both the affected child and the parents. Adaptation to epilepsy is similarly problematic; with both children and their parents reporting unmet needs for information and support for months and years after the seizure disorder is diagnosed. ⁵Quality of life (QOL) is the individuals' perception of life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns. ⁶Despite the advance in pharmacological treatment, management of childhood epilepsy is often not optimal and adversely affects the quality of life of epileptic children. ⁷ While seizures are the most common physical symptom of epilepsy, treatment must include far more than medical intervention for seizure control. The health status and quality of life in epileptic children study results have shown that all aspects of life are affected by disorder including personal relationships, employment and perception of self and overall quality of life. ⁸ In Sudan the prevalence of epilepsy varies between 0.7 to 4.8%. For instance, among the school students in the capital city of Sudan, Khartoum, the prevalence of epilepsy is 0.9 per 1000. ⁹ Study carried out by Abbas has indicated serious declining in quality of life for the Sudanese children with epilepsy which makes a big concern. ¹⁰ Children are supported by educational programs generally intended to increase knowledge about epilepsy, improve skills in self-management, communication about epilepsy to others, and developmental tasks such as increasing independence and optimize the quality of life. They are also supported by psychological programs intended to improve attitudes, coping, adjustment, self-esteem and behavior. ¹¹

MATERIALS AND METHOD

An experimental design with pre- and post test was used in the present study. Two groups of study sample were involved in this study: the first group was experimental group consists of 45 epileptic children and the second one is control group consists of another 45 epileptic children the study approved by two ethical committees. Official ethical clearance was

obtained from Medical & Health Studies Board, Graduate College-University of Khartoum, Soba university hospital director and Fathelrahman El Basher Outpatient Clinic director. Informed consent was obtained from the participants and their parents. The researcher has made it clear that the participation in the study is not connected to the care provided to the children. The participants were told that they can withdraw at any time and their privacy will be protected. High confidentiality was observed during filling the questionnaires.

Inclusion criteria for both groups:

Children age between 6- 18 years, willing to participate in the study.

Exclusion criteria for both groups:

Children with known co morbid diseases.

Sampling technique:

Forty five (45) epileptic children were chosen by using simple random sampling and allocated as intervention group in Soba University Hospital Outpatient Clinic, and another forty five (45) epileptic children in Fathelrahman El Basher Outpatient Clinic were also chosen randomly and allocated as control group.

Data collection:

The data was collected using two tools:

First tool: An interview questionnaire: it includes two parts:

First part:

socio-demographic data of the studied children as age, sex, residence and education

Second part:

Medical history of the child, as duration of the disease, frequency of fit, treatment taken, etc.....

Second tool:

Health Related Quality of Life (HRQOL) scale, it divided into eight (8) domains: Epilepsy impact, Memory/concentration, Attitudes toward epilepsy, Physical functioning, Stigma, Social support, School behavior, Health perceptions. A total of 40 QOL items were included in this tool.

Study maneuver:

After obtaining the official permission to conduct the study and after finalization of the data collection tool, data were collected over a 6-month period from 1 April to the end of September 2014. Before the starting sessions, children of both groups were assessed (pretest) using the prementioned tools, the researcher met the children individually and explained to them and their parents the purpose of the study, also the consent of each child and his parents

was obtained before their participation. Children were interviewed individually to fill the sheet. The time needed for filling each questionnaire ranged from 35 to 40 min.

The educational program was developed based on the baseline information gathered in the assessment phase and related literature. After the implementation of the program for the experimental group, a posttest was immediately conducted for children then 3 months later. The same tools were used in posttest and in follow up for the control group.

The program was presented in clear and concise form, and focused on the point of learning, using different teaching methods such as lectures, discussions, and suitable audiovisual aids. The content of the session included the definition of epilepsy and all items knowledge practices of epilepsy. The program activities were implemented through four sessions, one hour session per week for one month. The program covered all the points evaluated by the scales, using different methods and materials such as power point lectures, pictures, demonstrations, role play, discussion, videotapes and handout.

Statistical analysis:

Initially, The data was analyzed using SPSS version 20. Frequencies were calculated for socio-demographic data. The total QOL mean scores and standard deviations for epileptic children were obtained at baseline data, one month and 3 months after program implementation. The Means scores were compared using T-test (independent & paired) to test the significant differences in all the study groups for both intervention and control groups. Correlations analyses were performed to study significant variable relations using spearman's rank correlation coefficient. Correlation is significant if the p-value $< (\alpha = .05)$. If the correlation is significant and $r > 0$, it means there is positive linear relation. If $r < 0$, it means that there is a negative linear relationship. To compare epileptic children QOL sub domains for experimental and control group. When the groups follow the normal distribution Friedman test was used to test the significant change between baseline, 1 month and 3 months. When the groups not follow the normal distribution Mann-Whitney test was used to test the difference between QOL sub domains between baseline, 1 month and 3 months).

RESULTS AND DISCUSSION

Table 1: The distribution of socio-demographic characteristics of the studied epileptic children at baseline data

Variables	Experimental (n=45)		Control (n=45)	
	No.	%	No.	%
Age				
6-10 years	25	55.6	21	46.7
11-14	15	33.3	16	35.6
15-18	5	11.1	8	17.8
Sex				

Male	30	66.7	31	68.9
Female	15	33.3	14	31.1
Residence				
Khartoum	20	44.4	16	44.4
Khartoum north	5	11.1	8	17.8
Omdurman	5	11.1	9	20.1
Outside Khartoum state	15	33.3	12	26.7
Level of education				
1-4 class	22	48.9	17	37.8
5-8 class	10	22.2	8	17.8
High school	3	6.7	4	8.9
Had never been going to school	10	22.2	16	35.6
Duration of illness				
1-5 years	36	80.0	37	82.2
6-10 years	8	17.8	6	13.3
11-15 years	1	2.2	2	4.4

More than half of the participants in the intervention group (55.6%) were between 6-10 years old compared to 46.7% in control group in the same age group. 66.7% of experimental group were male, Compared to 68.8% of control were male. 35.6 of intervention group and 44.4% of control group were live in Khartoum. While 22.2% of intervention group and 35.6% of control group had never been going to school, Moreover 80% of children in the intervention group and 82.2% of the children in control group had been ill for 1-5 years.

Table 2: Health related quality of life through the three phases of the program for experimental epileptic children

variable	QOL of experimental epileptic children			
	pretest	1 Month	3 Month	Significant difference
Epilepsy impact	53(14.60)	66(13.58)	81(12.51)	<.0005
Memory/concentration	51(20.93)	64(18.36)	75(18.24)	<.0005
Attitude towards epilepsy	59(22.10)	68(18.8)	80(17.90)	<.0005
Physical functioning	48(17.79)	64(13.43)	81(12.14)	<.0005
Stigma	54(20.12)	64(17.28)	81(15.84)	<.0005
Social support	52(15.14)	70(15.14)	84(12.10)	<.0005
School behavior	64(21)	73(20)	81(18.10)	<.0005
Health perception	54(13.60)	65(13.93)	81(13.67)	<.0005

Table 2: This table illustrated the QOL for experimental group at pre test, 1 month and 3 months after program implementation. The result shows that there is an improvement in all sub-domains of QOL from pre to 1 month and 3 months post program, this improvements were statistically significant, where p value ≤ 0.0005 .

Table 3: Meanscores of QOL of both studied epileptic children of experimental and control groups

Study groups	pretest		1 months		3 months	
	Mean	SD	Mean	SD	Mean	SD
Experimental	52.85	13.26	65.60	12.12	79.56	11.91
Control	50.09	12.23	52.56	11.85	55.51	10.1

Table 3 The mean score of QOL for the epileptic children in experimental group before the implementation of the program was 52.85 ± 13.26 , it increased to be 65.60 ± 12.12 1 month after implementation of the program and still increase to reach to 79.56 ± 11.91 three months later. Where the QOL for control group was 50.09 ± 12.23 in pre- test, while it was 52.56 ± 11.85 after 1 month, and was 55.51 ± 10.1 after three months.

DISCUSSION:

Epilepsy is a chronic medical condition with many co-morbid features. It has been observed that children with epilepsy (CWE) have a compromised quality of life (QOL). Epilepsy can significantly affect the quality of life (QOL) not only because of its chronicity, need for regular medications, and their side effects, but also due to prejudices and social conventions that still surround it¹²

Children having seizures may bother their parents, who do not receive specific training during their education. Moreover, parents feel desperate not knowing how to handle the situation. Not only the disease itself, but also the drugs used may lead to certain cognitive, psychosocial and behavioral problems.¹³ So, the aim of this study was to evaluate the effect of family support program on quality of life of epileptic children.

In the present study, an educational program about epilepsy directed to a sample of parents with their children in Khartoum city to improve the quality of life of their epileptic children, program included audiovisual material other teaching methods on the basic aspects of epilepsy. After one month of implementation of the program and retesting of children about their quality of life, they appeared significantly improved in all explored domains of quality of life (Epilepsy impact, Memory/concentration, Attitude towards epilepsy, Physical functioning, Stigma, Social support, School behavior and Health perception). This improvement might be attributed to the program effect.

The result of the present study is disagreed with Abbas et al¹⁰ who found that there is a significant decline in the quality of life among Sudanese children with epilepsy and their family care giver. They added that 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.

An improvements in all sub-domain of QOL (as epilepsy impact, memory/concentration, attitude towards epilepsy, physical functioning, stigma, social support, school behavior and health perception) from pre to 1 month and 3 months post program had been detected, this improvements were statistically significant.

This result is in contrast with Pal et al.¹⁴ who reported that, studied the social activities of children with epilepsy(CWE) and their peers in rural India and found all groups of CWE had significant social deficit. Parental attitudes toward their children were found to be negative in 25%. Social stigma was found to be present more in CWE of rural area. In another study carried by Pal et al.,⁽¹⁵⁾ involving the same families, the same research group measured mothers' satisfaction with social support from informal sources and correlated it with a parental adjustment measure. They found positive independent correlation of satisfaction with social support. Furthermore, Jayashree, et al ¹⁶, found that impaired QOL of CWE with greater number of antiepileptic, longer duration of treatment and focal seizure, also the result is congruent with Thomas et al.¹⁷, Sabez et al.¹⁸ and Devinsky et al.¹⁹ who reported a negative effect of poly-therapy on QOL in CWE. Moreover, Rochelle Caplan *et al.* who reported that epileptic children had more language impairment and a wider range of linguistic defects.

Additionally, Abbas,et al.¹⁰,found that, longer seizure and treatment duration proved to significantly lower the epileptic children QOL, they added that, the commonest concern to parent was decreased ability for self care.

Arya,et al.²⁰,revealed that, the lowest mean scores of QOL were observed in self-esteem subscale and subscales with higher QOL scores included control/helplessness, anxiety and social stigma, frequency of seizure or type of epilepsy did not significantly affect the overall QOL among children with epilepsy.

CONCLUSION

Considering the findings, this study has shown the effective role played by family support program in improving QOL of epileptic children.

RECOMMENDATIONS

Based on finding of the present study, It will recommended that , educational programs must be carried out periodically for parents and their epileptic children to provide them with proper knowledge and skills necessary for improving the quality of life.

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