

Effect of Epilepsy on The Quality of Life of Children and Their Family Caregivers

¹Magda Ali Mohamed, ²Mona Abd Elsabour Hassan, ³Manal Farouk Mohamed

^{1*}Lecturer, of Community & family Health Nursing, Faculty of Nursing, Port-said University, Egypt.

²Assistant Professor of Family and Community Health Nursing, Faculty of Nursing, Port Said University, Egypt

³Lecturer of Pediatric Nursing, Faculty of Nursing, Suez Canal University

*Corresponding author: Magda Ali Mohamed

Abstract

Abstract: Background: Epilepsy is one of the chronic illnesses that have a great impact on the life of the epileptic children and their family caregivers. The **aim** of the study was to: Assess the quality of life of epileptic children and their family caregivers. **Subjects and Method:** Correlation descriptive research design was used in the current study. **Setting:** This study was conducted at the Outpatient Clinic at Psychiatric Hospital & El-Nasr hospital affiliated to Ministry of Health in Port-Said. A purposive sample of 169 epileptic children with one of their family caregivers were recruited (169 caregivers). **Tools:** Data was collected using the following two tools: **First tool:** included, sociodemographic data & Health Related Quality of Life Scale for child and **second tool:** included WHO quality of life brief scale for the family caregivers. **Results:** The overall score of QOL for the epileptic children was 52.58 ± 12.89 and it was 33.24 ± 14.17 for the family caregivers of children with epilepsy, a statistically significant correlation was detected between family caregivers Quality of Life and their epileptic children Quality of Life. **Conclusion:** It was concluded from this study, that, family caregivers of children with epilepsy showed a decrease in QOL, the study also provides important evidence that the illness of epileptic children had an impact on their family caregivers' quality of life. **Recommendation:** Family care givers living with epileptic children must be adequately educated on how to cope with psychological, physical, environmental and social stress and improve on their overall quality of life.

Keywords: Children, Epilepsy, Family Caregiver, Quality of Life .

Date of Submission: 24-09-2018

Date of acceptance: 11-10-2018

I. Introduction

Epilepsy is a chronic neurological disorder characterized by seizures originating from abnormal electrical signals in the brain. About 50 million people worldwide have epilepsy, and nearly 80% of epilepsy occurs in developing countries. ^[1] Epilepsy is a frequent chronic illness in children. The psychosocial impact of epilepsy on the child and family's everyday life depends on several factors: the severity of the epilepsy; complexity of the clinical management, the meaning of the illness to the child, family, and society as a whole, restrictions in the child's and families, the child's and family's innate coping abilities; and the level of social support and extent of resources available to deal with the epilepsy. Each of these factors contributes to the real or perceived adjustment to this chronic illness. ^[2]

Quality of life (QOL) is an especially important health outcome to assess in children with epilepsy because they are a high-risk group and in critical development period during which many cognitive and social skills have to be learned. Despite its importance, there is relative lack of research on quality of life among children with epilepsy from the developing countries. There is also little evidence about the parent's view on the effects of epilepsy on their functioning and management of their children. Keeping this in view, the present study assessed the quality of life of children with epilepsy using an epilepsy specific instrument in order to provide a basis for comprehensive treatment program for children with epilepsy and their families. ^[3]

It is clear that epilepsy can have a negative impact on many aspects of the life of the child and his or her family. ^[4] **Mehndiratta**, ^[5] reviewed the many emotional, psychological, and academic difficulties that children experience with epilepsy, as well as issues of self-esteem, stigma, and social interactions. Greater social support has been linked to better quality of life in patients with chronic diseases. Social support is defined as the perception that an individual is a member of a network in which one can give and receive help, affection and obligation. ^[5,7] Social support can be received from family members, friends, colleagues, and medical personnel. ^[8] Emotional support coming from family members has been found to have positive effects on mental health, family cohesion

and marriage quality while support coming from people outside the family and instrumental support had a negative effect on family variables.^[9]

Family caregivers play a major role in providing care giving assistance to ill persons and their families. The effect of stressors on family members caring for an ill person in the family has been referred to as caregiver's burden. Caregiver's burden is a multidimensional phenomenon reflecting physical, psycho-emotional, social and financial consequences of caring for an impaired family member. Family members are acting as caregivers as the individual in the family of suffering from chronic diseases and continue his treatment at home. In many chronic diseases it places considerable burden for family caregivers who takes the sole responsibility in taking care of chronically ill patients.^[6]

Nurses' knowledge was allowed for better treatment and care of children with epilepsy and their families. Because family may be an important constant in the child's life, it is extremely important for the advanced-practice nurse to provide family centered care to children and families coping with epilepsy. Nurses have a responsibility to educate individuals with epilepsy and their families and are involved in the assessment, management and treatment interventions.^[10]

It is important for nurses to understand the possible negative effects of epilepsy, such as decreased familial coping and adaptation abilities, and increased family stress levels.^[11] The role of the community health nurse in epilepsy is to care for the child and his or her family. Advanced practice nurses are often responsible for diagnosing epilepsy and managing the care of children with epilepsy and their families. Advanced practice nurses must have knowledge of interventions for families coping with epilepsy in order to provide strategies for stress management, positive adaptation, and effective coping mechanisms.^[12]

1.1 Significance of the study:

WHO,^[13] reported that more than 70% of the adult population with epilepsy had the onset of their disease in childhood. The 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.^[14] In Egypt, the highest prevalence rate is recorded in the early and late childhood group (69.78/100,000 and 43.78/100,000).^[15] The determination of incidence rate is still to be studied in Egypt.

The presence of child with epilepsy in the family affects various aspect of family, like leisure time activities, family and social relationship and finances. Presence of child with epilepsy creates problems not only to the person who is suffering from epilepsy but their immediate family caregiver's members too. Prolonged epilepsy attack can become a threat to the socio-occupational repertoire of the family caregiver's members. Family's all caregivers be the necessary or secondary, can become inadequate or inappropriate due to this problem. Family's important caregivers like interpersonal relationship; general family atmosphere may become pathological because of this problem. Hence the present study was carried out to find the relation between Quality of Life of Children with Epilepsy & their family caregiver Quality of Life.

1.2 Aim of this study was to:

Assess the quality of life of epileptic children and their family caregivers through:

1. Describe the quality of life of children with epilepsy and their family caregivers.
2. Find the relation between family caregivers' quality of Life and their epileptic children Quality of Life.

1.3 Research questions:

1. What is the score of the quality of life of epileptic children and their family caregivers?
2. Is there is a relation between family caregivers' quality of Life and their epileptic children quality of Life?

II. Subjects and Method:

2.1 Research design

Correlational descriptive research design was used in the current study.

2.2 Setting:

This study was conducted at the Outpatient Clinic at Psychiatric Hospital & El-Nasr hospital affiliated to Ministry of Health in Port-Said.

2.3 Sample:

A purposive sample of 169 epileptic children with one of their family caregivers for every child (total=169 caregivers) were chosen with the following *inclusion criteria*:(a) children between 6- 18 years of age (b) have been willing to participate in the study (c) care givers were attending with the child at the clinic for routine follow up. Children with known co-morbid diseases were excluded.

Tools of data collection:

Data of this study was collected using the following two tools:

First tool: structure interview questionnaire. It included two parts:

- **First part:**

Included Socio-demographic data of family and child, it includes: age, sex, education, etc.

- **Second part:**

Included Health Related Quality of Life (HRQOL) scale for child, it divided into eight (8) domains: **Epilepsy impact** (12 items) explores the quality of the child's related to mood disturbances and 8 items related to anxiety and depression, **Memory/concentration** (10 items)explores the quality of the child's regarding explored an ability to reason, memories important aspects or concentrate on key activities, **Attitudes toward epilepsy** (4 items) explores the quality of the child's regarding extent of worry over epilepsy and seizure, **Physical functioning** (5 items)explores the level of physical activity, energy and fitness of the child and to what extent they feel unwell or complain of poor health, **Stigma** (6 items)explores the quality of the child's regarding hide their disorder or minimize social contact because of the associated stigma, **Social support** (4 items)explores the quality of the child's social relations and interactions with friends and peers, and the extent of their perceived support, **School behavior** (4 items) explores the perceptions that a child holds regarding their cognitive capacity, learning and concentration in the school environment, **Health perceptions** (3 items) explores the health perceptions that a child regarding general health. A total of 40 HRQOL items were included in this tool. [16]

- **Scoring System:**

Health Related Quality of Life (HRQOL) scale for child consists of 8domains. Each domain has number of items or questions with responses as Very often=1, often=2, Sometimes=3, Not often=4, Never=5. Calculate the mean value of the items in each domain, Convert the pre-coded numeric values of items to 0-100-point scores. Calculate the mean value of the items in each domain. Multiply the mean by the relative weight for the subscale of each domain, add the weighted values for all subscales to determine the total score, with higher converted scores always reflecting better quality of life.

Validity and Reliability

Test-retest reliability has been reported with Pearson's correlation to be $r > .70$ and cronbach's at between .72 and .88. [17,18]

Second tool: included WHO Quality of life brief scale (WHOQOL-BREF)^[13,19] this tool was translated into Arabic version and tested for reliability in many Arabic studies.^[20]It includes **four** domains: **Physical health (seven items)** (Energy and fatigue, Pain and discomfort, Sleep and rest, Mobility, Activities of daily living, dependence on medicinal, substances and medical aids, work capacity, **psychological domains (six items)** (Bodily image and appearance, Negative feelings, Positive feelings, Self-esteem, Thinking, learning, memory and concentration, Religion/ Spirituality/ Personal beliefs), **Social relations activity (three items)** (Personal relationships, Social support, Sexual), and **environment domains (eight items)** (Financial resources, Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills, Participation in and opportunities for recreation/ leisure, Physical environment (pollution/ noise/ traffic/ climate),Transport and general subjective wellbeing (general facet on health & QOL). The response options range from 1 (very dissatisfied/very poor) to 5 (very satisfied/very good). A total of WHOQOL 24 items were included in this tool.

- **Scoring system:**

The four domain scores denote an individual perception of quality of life in each particular domain. Domain scores are scaled in a positive direction (i.e. higher scores denote higher quality of life). The mean score of items within each domain is used to calculate the domain score. Mean scores are then multiplied by 4 in order to make domain scores comparable with the scores used in the WHOQOL-100. Explicit instructions for checking and cleaning data, and for computing domain scores, the transformation method converts domain scores to a 0-100 scale.

Reliability and Validity

Measures of WHOQOL-Brief at the test-retest evaluation, intraclass coefficients and 95% confidence intervals per each of the four domains were respectively: "Physical": 0.92 (0.85-0.96); "Psychological": 0.94 (0.88-0.97); "Social Relationships":0.89 (0.80-0.93); "Environment": 0.80 (0.75-0.85); all correlations were statistically significant ($p < 0.05$). Cronbach alfa for each dimension was: (0.82 for Physical, 0.81 for Psychological, 0.76 for Environment and 0.71 for social relationships dimensions). [21, 22]

Ethical Consideration: Permission to conduct the study was obtained from the Psychiatric Hospital& El-Nasr hospital directors Port Said. Informed consent and assent were obtained from the participants and their parents. 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.

Pilot Study:

A pilot study was carried out on 10 % of epileptic children (N= 19) and family caregivers (N= 19) representing the study sample to test the feasibility and clarity of the used tools; modifications were done based on the results. The sample included in the pilot study was excluded from the final study sample.

Field work:

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 June 2017., children & their family caregivers were assessed using the prementioned tools, the researcher met the children individually and explained to them and their family caregiver the purpose of the study, also the consent of each child and his family member was obtained before their participation. Children and their family caregivers were interviewed individually to fill the sheet. The time needed for filling each questionnaire ranged from 35 to 40 min for child and the same time for their families.

Statistical analysis:

Initially, the data was analyzed using SPSS version 23.0 Frequencies were calculated for socio-demographic data. The total QOL mean scores and standard deviations for epileptic children were obtained at baseline data. The Means scores were compared using-test (independent & paired) to test the significant differences. 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.

III. Results

Table 1: The study results revealed that 68.9% were males, 55.1% aged between 6 to 10 years; 77.6% were interned the school. 48.0% were in 1-4 class. As regards to a family caregivers of child with epilepsy 51% of them aged between 37 to 46 years. More than one third of caregivers (32.7%) were illiterate.

Table 2: *According the research question No. one.* Represented the scores of subscale of QOL, In all domains for children and their family care giver, the vitality domain had the highest score for children(66.65±28.97),the lowest one was mental health domain(28.88±17.33),for the family caregivers, the highest domain was Social relations activity(41.28±18.07),the lowest one was environment domain(25.02±16.34),the table also showed that the total QOL of the family caregivers (33.24 ± 14.17) is lower than the total QOL of their epileptic children (52.58±12.89).

Table 3: *According the research question No. tow.* This table revealed that there was a statistical significant positive correlation between child physical, social function domains, total QOL and psychological domain of the family caregivers($p=0.025^*$, 0.013^* , 0.011 ,respectively),moreover, a statistical significant positive correlation was found between family caregivers physical health, general health, and bodily pain and total QOL of child($p=0.005^*$, 0.030^* , 0.004 respectively), also, the same table showed that there was a statistical significant positive correlation between social relations activity, vitality, general health and total QOL of child ($p= 0.008^*$, 0.001^* , 0.001^* respectively), additionally, the environment domain of the family had a statistical significant positive correlation with the child total QOL and domains namely bodily pain, general health ($p=0.019^*$, 0.001 · 0.001 respectively),Overall family caregivers QOL showed a statistical significant positive correlation with the child total QOL and domains namely bodily pain, general health($p=0.014^*$, 0.001^* , 0.001 respectively).

Table 4: Multivariate linear regression model showed that the family QOL is a predictor had significant effect on child QOL ($p < 0.001^*$). Also, the model showed that the child QOL affecting family QOL significantly ($p < 0.001^*$).

Table (1): Distribution of the studied epileptic children and their family caregivers according to demographic data (n = 196)

Child	No.	%
Age of child		
6 – 10	108	55.1
11 – 14	64	32.7
15 – 18	24	12.2
Sex of child		
Male	135	68.9
Female	61	31.1
Interning the schooling		
Yes	152	77.6
No	44	22.4
level of education of the child		
1 – 4 Class	94	48.0
5 – 8 Class	43	21.9
High school	15	7.7
Not inter school	44	22.4
Family		
Age of family caregivers		
25 – 30	42	21.4
31 – 36	32	16.3
37 – 41	48	24.5
42 – 46	52	26.5
47 – 51	22	11.2
Sex of family caregivers		
Male	53	27.0
Female	143	73.0
Level of Education of family caregivers		
Illiterate	64	32.7
Basic/ primary	47	24.0
Intermediate	29	14.8
Higher school	34	17.3
University	22	11.2

Table (2): The quality of life (QOL) score of the studied children& their family care givers (n = 196)

Domains	Min. – Max.	Mean ± SD
Score of QOL epileptic children		
Physical functioning:	0.0 – 100.0	41.74±26.18
Physical roles limitation:	0.0 – 100.0	35.27±30.26
Emotional roles limitation:	2.27-72.73	37.73±17.21
Social functioning	0.0 – 100.0	41.45±22.07
Bodily pain:	0.0 – 100.0	54.04±34.94
Mental health:	0.0-82.14	28.88±17.33
Vitality	0.0 – 100.0	66.65±28.97
General health	0.0-87.50	45.79±21.18
Overall	25.64-82.05	52.58±12.89
Score of QOL of family caregivers		
Physical health	0.0-75.0	40.32±17.05
Psychological	0.0 – 75.0	32.44±17.27
Social relations activity	0.0 – 75.0	41.28±18.07
Environment	0.0 - 71.43	25.02±16.34
Overall	1.92 – 68.27	33.24 ± 14.17

Table (3): Correlation between quality of life (QOL) of epileptic children and QOL of their family caregivers (n = 196)

QOL of child		Family Quality of Life				
		Physical health	Psychological	Social relations activity	Environment	Overall family caregivers QOL
Physical functioning	r	-0.049	0.161*	0.014	0.048	-0.046
	P	0.491	0.025*	0.844	0.502	0.521
Physical roles limitation	r	-0.078	-0.100	-0.061	-0.096	-0.103
	P	0.274	0.161	0.394	0.182	0.151
Emotional roles limitation	r	-0.107	-0.107	0.023	0.010	-0.056
	P	0.136	0.136	0.753	0.893	0.439
Social functioning	r	-0.129	0.177*	0.106	-0.115	-0.094
	P	0.071	0.013*	0.141	0.108	0.190
Bodily pain	r	0.155*	0.133	0.115	0.167*	0.175*
	P	0.030*	0.062	0.108	0.019*	0.014*
Mental health	r	0.103	-0.041	-0.020	0.039	0.024
	P	0.151	0.572	0.780	0.589	0.741
Vitality	r	-0.058	-0.043	0.190*	-0.105	0.000
	P	0.420	0.552	0.008*	0.143	0.997
General health	r	0.202*	0.079	0.267*	0.287*	0.257*
	P	0.005*	0.272	<0.001*	<0.001*	<0.001*
Overall QOL of child	r	0.207*	0.182*	0.273*	0.369*	0.296*
	P	0.004*	0.011*	<0.001*	<0.001*	<0.001*

r: Pearson coefficient

*: Statistically significant at $p \leq 0.05$

Table (4): Multivariate Linear regression for QOL of child and QOL of Family of child with epilepsy quality of life

	B	T	P	R ²
Family of child with epilepsy quality of life	0.525	4.316*	<0.001*	0.088
QOL of child	0.167	4.316*	<0.001*	0.088

B: Unstandardized Coefficients

R²: Spearman coefficient

*: Statistically significant at $p \leq 0.05$

IV. 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 it. [23]

According to the socio-demographic characteristics in this study, the children with epilepsy were predominantly less age, and different educational levels. This was in line with the expectations from the literature. [24] Accordingly, most family caregivers were females. These characteristics indicate that our subjects were typical of the clinical samples reported for QOL studies in epilepsy. [25, 26, 27] The higher proportion of females and younger age groups indicate that children had similar characteristics with the general population of epilepsy patients reported in the epidemiological studies from Arab countries. [28]

The present study revealed that family caregivers had low QOL, and had low scores in all domains of quality of life, in this context, **Senthil**, [29] reported that, epilepsy can affect the lives of other family members besides the persons with epilepsy. The caregivers of persons with epilepsy undergo severe physical, psychosocial, emotional, coping, adjustment within marital relationship, issues surrounding children, employment, economic burden and stigma about the disease. Family caregivers also face enormous problem of caring who is having epilepsy is an enduring stressor and causes considerable amount of burden. The results agree with **Anna**, [30] who reported that, epilepsy had an impact on caregivers' QOL and imposed a mild to moderate burden as a consequence of caregiving. This could be because; a caregiver is in a position to have a significant influence on the quality of life of the children with epileptic for whom they are caring. Although living the children with epileptic can result in personal challenges, it does not have to result in an inability to have a full and rewarding life.

Moreover, the study reported that, the family caregivers had lowest scores in domains of environment, psychological domains; this is agreement with previous evidence where family caregivers of children with epileptic reported a higher risk of poor mental health and depression compared to family caregivers of children without epilepsy. ^[31, 32] **American Epilepsy Society et al.**, ^[33] noted that, the HRQOL may seriously be affected by the attitudes of their other family members and environment, if the people around were also unaware or uneducated about this illness. This result is probably for the reason; Family caregivers can be instrumental in helping the children with epilepsy to learn about the condition, to share that information with others, to find effective medical treatment, to develop a support network of family, and to pursue what brings joy into their life.

The finding of the present study could be attributed to that family caregivers (particularly the parents) were struggling with great difficulties to admit and accept the child' diagnosis. They were also very concerned about the unpredictable nature of epilepsy, prognosis and the side effects of anti-convulsant as well as the "epilepsy" label itself. All these issues may have imposed anxiety, psychological and social problems, uncertainties and ultimately problems in attempting to positively adapt to the challenging situation.

Furthermore, the present study, also indicated that, the family had low scores in domains of social relation, activities and physical health, this in the line with: **Yamazaki et al.**, ^[34] reported in their study in Japan, that family caregivers of epileptic children had low QOL in relation to their social functioning. ^[35] Reported similar findings where the caregivers of childhood epilepsy reported higher levels of family conflict, ^[36] while a qualitative study by **Khalifa et al.**, ^[37] in a study carried in Egypt, noted that stronger marital relationships tend to contribute positively towards better coping as a caregiver. ^[38]

According to **Saburi et al.**, ^[39] Family caregivers who are able to adjust to the illness situation themselves can cheer up the patients and empower them to cope with the illness. Moreover, family reactions such as openness, acceptance, and support, were positively correlated with the quality of life. A statistically significant positive correlations were detected between children total QOL and their family caregivers QOL, also some of the subscale of the children had a significant correlation with their caregivers' subscales, which is mean that QOL of the epileptic children had a strong effect on their family caregivers QOL (**Table 3,4**).

Poor QOL in families with epileptic children may be due to the noted impact of life-long social stigma and possibly, the absence of fee –subsidy services, also due to their negative or poor psychological response to the challenge of care giving and decrease family physical capacity and poor coping due to physical ,psychological and social burden of the disease as a life-long disease impacted on their daily life routines., this opinion is supported by **Begley et al.**, ^[40] in the study carried in the United States, reported that, living with epilepsy patients exposes one to challenges at home, school, workplace and other outdoor places since epilepsy can impose immense burden on both patients and their family caregivers, causing loss in quality of life (QOL) and daily productivity.

The association between children's quality of life and family functioning was confirmed by **Hodaňová et al.**, ^[41] who studied the quality of life in children aged 11–15 years and their subjective perception of family functioning in Czechoslovakia, the results of their survey indicate that higher quality of family relations is related to an increase in children's quality of life. The study carried out by **Sikorová & Bužgová**, ^[42] showed a weaker correlation between family functioning and children's quality of life. A study by **Moreira et al.**, ^[43] highlighted an interrelation between the child's illness and family functioning as well as an interrelation between family functioning and the child's psychosocial status.

Moreover, **Ana**, ^[44] reported that, epilepsy had an impact on caregivers' QOL and imposed a mild to moderate burden as a consequence of caregiving. Recent reports in Sudan have indicated that family caregiver's impression of the patient's QOL is a significant predictor of the overall QOL of that of the patient and that of the caregiver. ^[45] The finding of the present study is also in the line with **Awadalla et al.**, ^[46] who found in a study in Sudan that, caregivers' proxy rating of the patients' QOL was a significant predictor of the QOL of the patients and the QOL of caregivers. **Adewuya**, ^[47] in a study in Nigeria, indicated that, patient - caregiver characteristics do impact on each other's QOL.

V. Conclusion:

The current study and research questions concluded that that family caregivers of children with epilepsy showed a decrease in QOL, moreover, the total QOL of the family caregivers is lower than the total QOL of their epileptic children, a statistical significant correlations were found between total QOL and some of subscales of QOL of children and of their family caregivers total QOL and subscales, the study also provided an important evidence that the illness of epileptic children had an impact on their family caregivers' quality of life.

VI. Recommendation:

▪ **For family:**

1. Parents should provide a safe psychological and physical environment from which the child can explore the world and master the developmental tasks of childhood and adolescence.
2. Encourage epilepsy support groups for giving children with epilepsy and their family members' ways to share their experiences, frustrations, as well as tips for coping with the disorder.
3. Raising awareness and improving education of epileptic children and their family through up-to-date, accurate information about epilepsy, treatment options, and associated comorbidities and risks, as well as information about available vocational and community resources and health care services upon diagnosis regardless of their socioeconomic status, demographic group, culture, or geographic location.
4. Parents should work with the school system to find reasonable ways to handle any special educational or environmental supports their epileptic children may have.

▪ **For children:**

1. Involvement of epileptic children in school activities is paramount to fostering a sense of emotional well-being well as, promoting social and physical development.
2. Provide counseling services can help children cope with epilepsy in a positive manner.
3. All children with epilepsy should have a health plan on file at their school which tells teachers what to do if the child seizures during the school day which might include supporting the child, giving emergency medications, calling the parents.
4. Provide epileptic children, families, and caregivers with high-quality, validated epilepsy education, vocational rehabilitation programs to build the skills needed to achieve optimal self-management.

▪ **Further studies:**

1. Identify effective interventions for epilepsy accompanied by mental health comorbidities, risk factors for injuries, suicide, status epilepticus, and sudden unexpected death in epilepsy.
2. Prospective studies that examine the effects of epilepsy on cognitive function.
3. Studies that develop and evaluate educational programs to improve the knowledge of epileptic children, their family and health providers about epilepsy.
4. Evaluation of behavioral interventions programs on health outcomes and quality of life for children with epilepsy.
5. Development of interventions programs to identify academic problems and improve academic achievement in students with epilepsy.

References

- [1] Taylor, J., Baker, G. A., and Jacoby, A. (2011). Levels of epilepsy stigma in an incident population and associated factors", *Epilepsy Behav.* 21 (3), 255-60.
- [2] Yemadje LP, Houinato D, Quet F, Druet-Cabanac M, Preux PM. (2011): Understanding the differences in prevalence of epilepsy in tropical regions. *Epilepsia.* 52:1376-81.
- [3] Rudzinski LA, Meador KJ. (2013): Epilepsy and neuropsychological comorbidities. *Continuum (Minneapolis)*. 19(3 Epilepsy):682-96.
- [4] Hesdorffer, D.C., Beck, V., Begley, C.E., Bishop, M.L., Cushner- Weinstein, S., Holmes, G.L., Shafer, P.O., Sirven, J.I., Austin, J.K. (2013). Research implications of the institute of medicine report, epilepsy across the spectrum: promoting health and understanding. *Epilepsia* 54 (2), 207-216.
- [5] Mehndiratta P, Sajatovic M. (2013): Treatments for patients with comorbid epilepsy and depression: A systematic literature review. *Epilepsy Behav.* 28:36- 40.
- [6] de Lima C, de Lira CA, Arida RM, Andersen ML, Matos G, de Figueiredo Ferreira Guilhoto LM, et al. Association between leisure time, physical activity, and mood disorder levels in individuals with epilepsy. *Epilepsy Behav.* 2013; 28:47-51.
- [7] Ohaeri JU, Awadalla AW, Farah AA. (2009): Quality of life in people with epilepsy and their family caregivers. An Arab experience using the short version of the World Health Organization quality of life instrument. *Saudi Med J.* 30:1328-35.
- [8] LaFrance Jr WC, Alosco ML, Davis JD, Tremont G, Ryan CE, Keitner GI, et al. (2011): Impact of family functioning on quality of life in patients with psychogenic nonepileptic seizures versus epilepsy. *Epilepsia.* 52:292-300.
- [9] Kotov AS. (2013): Anxiety in epileptic patients. *ZhNevrolPsikhiatrIm S SKorsakova.* 113(4Pt 2):41-4.
- [10] Shakir M, Al-Asadi J (2012). Quality of Life and its Determinants in People with Epilepsy in Basrah, Iraq. *Sultan Qaboos University Med J.* 12(4):449-457.
- [11] Ramsey R. R., Loiselle K. A., Rausch J. R., Harrison J., Modi A. C. (2016). Predictors of trajectories of epilepsy-specific quality of life among children newly diagnosed with epilepsy. *Epilepsy and Behavior.* 57, 202-210.
- [12] Arya V, Gehlawat VK, Kaushik JS, Gathwala G. (2014). Assessment of parent reported quality of life in children with epilepsy from Northern India: A cross-sectional study. *J PediatrNeurosci.* 9:17-20.
- [13] World Health Organization (2010). Regional Office for the Eastern Mediterranean. *Epilepsy in the WHO Eastern Mediterranean Region Bridging the gap.*
- [14] Neni WS, Latif AZA, Wong SY, Lua PL. (2010). Awareness, knowledge and attitudes towards epilepsy among rural populations in East Cost Peninsular Malaysia: a preliminary exploration. *Seizure.* 19:280-90.
- [15] Khedr, E.M., et al., (2013): A community based epidemiological study of epilepsy in Assiut Governorate/Egypt. *Epilepsy research.*103(2): p. 294-302.
- [16] Joyce A.et al. (1999): Development of the Quality of Life in Epilepsy Inventory for Adolescents: *Epilepsia* 40(8):1 1 114-1121, Inc., Philadelphia, international League Against Epilepsy.

- [17] LaVasseur SA, Talmann GS. (2005). SEIQoL-DW is a valid method for measuring individual quality of life in stroke survivors attending secondary prevention clinic. *Quality of Life Research* 14(3):779-88.
- [18] Neudert C, Wasner M, Borasio GD. (2001). Patients' assessment of quality of life instruments: a randomised study of SIP, SF36, and SEIQoL-DW in patients with amyotropical lateral sclerosis. *Journal of Neurology Science*; 191(1-2):103-9.
- [19] Cheryl P, shore, Susan M, Perkins, Joan K. Austin. (2007): The Seizures and Epilepsy Education (SEE) Program for families of children with epilepsy: A preliminary study. *Epilepsy & Behavior*. 2 (12):157-164.
- [20] Mohammed N, Abdel Moneim M, Rahman A1. (2010): The profile of childhood epilepsy in Sudan. *Khartoum medical journal*. 3; (2):444 - 447.
- [21] Berlim M.T., Pavanello D.P., Caldieraro M.A. & Fleck M.P. (2005). Reliability and validity of the WHOQOL-Bref in a sample of Brazilian outpatients with major depression. *Quality of Life Research*14, 561-564.
- [22] Naumann V.J. & Byrne G.J. (2004). WHOQOL-bref as a measure of quality of life in older patients with depression. *International Psychogeriatrics*16, 159-173.
- [23] Christianson AL, Zwane ME, Manga P, Rosen E, Venter A, Kromberg JG. (2013). Epilepsy in rural South Africa children-prevalence, associated disability and management. *S Afr Med J*. 90:262-6.
- [24] Mahrer-Imhof R, Jaggi S, Bonomo A, Hediger H, Eggenschwiler P, Krämer G, et al. (2013). Quality of Life in Adult Patients with Epilepsy and Their Family members. *Seizure*. 22(2):128-35.
- [25] Baker GA, Jacoby A, Gorry J, Doughty J, Ellina V, SIGN Group. (2005). Quality of life of people with epilepsy in Iran, the Gulf, and Near East. *Epilepsia*; 46: 132-140.
- [26] Piperidou C, Karlovasitou A, Triantafyllou N, Dimitrakoudi E, Terzoudi A, Mavraki E, et al. (2008). Association of demographic, clinical and treatment variables with quality of life of patients with epilepsy in Greece. *Qual Life Res*; 17: 987-996.
- [27] Shackleton DP, Kasteleijn-NolstTrenité DG, de Craen AJ, Vandenbroucke JP, Westendorp RG. (2013). Living with epilepsy: long-term prognosis and psychosocial outcomes. *Neurology*; 64-70.
- [28] Cianchetti C, Messina P, Pupillo E, et al. (2015). The perceived burden of epilepsy: impact on the quality of life of children and adolescents and their families. *Seizure*. 24:93-101.
- [29] Senthil (2016): Relationship between family interaction, family burden and quality of life among caregivers of patients with epilepsy, *Senthil, Vol.4 (Iss.4)*.
- [30] Anna, C.W. (2012): Quality of Life and Burden in Caregivers of Patients with Epilepsy, *Journal of Neuroscience Nursing*, 39(6), 354 - 360.
- [31] Yamazaki S, Sokejima S, Mizoue T, Eboshida A, Fukuhara S. (2005): Health-Related Quality of Life of Mothers of Children with Leukemia in Japan. *Quality of life research*.14(4):1079-85.
- [32] Khalifa AS, Bishry Z, Tantawy AAG et al. (2014): Psychiatric morbidity in Egyptian children with acute lymphoblastic leukemia and their care providers. *Hematol Oncol Stem Cell Ther*. 7(2):76-84.
- [33] American Epilepsy Society, Centers for Disease Control and Prevention, Chronic Disease Directors, Epilepsy Foundation, National Association of Epilepsy Centers (2012): Living well with epilepsy II: report of the 2003National Conference on public health and epilepsy: priorities for a public health agenda on epilepsy. Available from: http://www.cdc.gov/epilepsy/pdfs/liv_ing_well2003.pdf.
- [34] Bayen, P. Pradat-Diehl, C. Jourdan et al., (2013). "Predictors of informal care burden 1 year after a severe traumatic brain injury: results from the Paris-TBI study," *The Journal of Head Trauma Rehabilitation*, vol. 28, no. 6, pp. 408 - 418.
- [35] Pai ALH, Greenley RN, Lewandowski A, Drotar D, Youngstrom E, Peterson CC. (2007): A Meta-Analytic Review of the Influence of Pediatric Cancer on Parent and Family Functioning. *Journal of Family Psychology*.21(3):407-15.
- [36] Mrabet H, Mrabet A, Zouari B, Ghachem R. (2014). Health-related quality of life of people with epilepsy compared with a general reference population: a Tunisian study. *Epilepsia*; 45: 838-843.
- [37] Khalifa AS, Bishry Z, Tantawy AAG et al. (2014): Psychiatric morbidity in Egyptian children with acute lymphoblastic leukemia and their care providers. *Hematol Oncol Stem Cell Ther*. 7(2):76-84.
- [38] Sinha S, Siddiqui KA. (2011): Definition of intractable epilepsy. *Neurosciences* 16:3-6.
- [39] Saburi GL, Mapanga KG, Mapanga MB. (2006): Perceived family reactions and quality of life of adults with epilepsy. *Journal of Neuroscience Nursing* 38(3):156-65.
- [40] Begley CE, Famulari M, Annegers JF (2000): The cost of epilepsy in the United States: an estimate from population based clinical and survey data. *Epilepsia*; 41(3):342-51.
- [41] Hodaňová L, Hlaváčová E, Čermáková E, Csémy L, Šmejkalová J. Sledování kvality života u českých dětí. In: Koukola B, Mareš J, editors. (2008): *Psychologie zdraví a kvalita života*. Brno: MSD; s. 70-74. (in Czech)
- [42] Camfield P, Camfield C. (2015). Incidence, prevalence and etiology of seizures and epilepsy in children. *Epileptic Disord*. 17 (02) 117-123
- [43] Moreira H, Frontini R, Bullinger M, Canavarro MC. (2014): Family cohesion and health-related quality of life of children with type 1 diabetes: the mediating role of parental adjustment. *Journal of Child and Family Studies*.;23(2):347-359.
- [44] M. A. Ferro and K. N. Speechley, (2012). "Examining clinically relevant levels of depressive symptoms in mothers following a diagnosis of epilepsy in their children: a prospective analysis," *Social Psychiatry and Psychiatric Epidemiology*, vol. 47, no. 9, pp. 1419-1428.
- [45] Awadalla, A.W., Ohaeri, J.U., Salih, A.A., Tawfiq, A.M. (2005): Subjective quality of life of family caregivers of community living Sudanese psychiatric patients. *Social Psychiatry & Psychiatric Epidemiology*, 40,755-763.
- [46] Awadalla, A.W., Ohaeri, J.U., Tawfiq, A.M., Al-Awadi, S.A. (2006): Subjective quality of life of outpatients with diabetes: comparison with family caregivers' impressions and control group. *Journal of National Medical Association*. 98, 737 -745.
- [47] Adewuya, A.O. (2006): Parental psychopathology and self-rated quality of life in adolescents with epilepsy in Nigeria. *Development & Medical Child Neurology*, 48, 600- 603.

Magda Ali Mohamed. "Effect of Epilepsy on The Quality of Life of Children and Their Family Caregivers" *IOSR Journal of Nursing and Health Science (IOSR-JNHS)*, vol. 7, no.5, 2018, pp. 55-63.