Psychosocial Stressors among Epileptic Children

Manar Gamal Mohamed El Maghraby, Prof. Dr / Ghada Mohamed Mourad, Assist. Prof. / Rania Abdel-Hamid Zaki

Department of Mental Health Nursing, Faculty of Nursing, Ain Shams University

Abstract

Background: Epilepsy is one of the most common chronic neurological disorders in children that have a negative impact on the children's psychosocial development, cognition, behaviors, schooling, finally resulting to high stressors experiencing. Aim: The aim of this study was to assess the psychosocial stressors of epileptic children. Research design: A descriptive study design was conducted. Setting: This study was conducted at Neurological clinic of Children's University Hospital at Ain Shams University. Sample: Convenience sample was selected which included (100) epileptic children. Tools of data collection: Interviewing questionnaire tool for children was used which included two parts: Sociodemographic characteristics and medical history of the epileptic children and their parents, and the psychosocial stressors inventory. Results: More than three fifths of studied epileptic children had high psychological stressors and more than three quarter of studied epileptic children had high social stressors. Moreover, there were statistically significant relation between psychosocial stressors and socio-demographic features and medical history such as their age, area of residence, and medications compliance. Conclusion: The epileptic children have high psychosocial stressors in relation to their socio-demographic data and medical history. Furthermore, the majority of these stressors are due to illness precautions, medications side effects, epileptic fits, and the school. **Recommendation:** Develop and apply nursing intervention programs for epileptic children, their parents, and teachers to improve the knowledge, awareness, and attitudes towards epilepsy.

Key words: Epilepsy, Children, Stressors

Introduction

Pediatric epilepsy is the most prevalent and chronic neurological condition worldwide, characterized by epileptic seizures attack owing to excessive and abnormal neuronal electrical discharges in the brain that leads to alteration in cognition, sensation, or motor activity transiently (*Patel and Moshé*, 2020).

Actually, these abnormal neuronal discharges may originate from the central areas in the brain affecting the consciousness, may be restricted to one area of the cerebral cortex that produce manifestations features related to the affected area, or may also initiate in a part of the cortex and extent to

other areas of the brain leading to generalized epileptic seizures (*Devinsky*, 2016).

In fact, the epilepsy prevalence rate in children for the developed countries is 3.2-5.5/1000 and for the developing countries is 3.6-44/1000. The epilepsy incidence rate in children is 41-187/100000 (Pellock et al., 2017). In Egypt, some researchers reported that the prevalence of epilepsy in children is (9/1000) and the gender-specific prevalence rate is slightly higher in boys (10.5/1000) than girls (7.4/1000) (Farghaly et al., 2012).

Moreover, the causes of epilepsy are multi factorial and various according to age, but it is unknown for about half of epileptic patients. In Upper Egypt, the most common etiology of seizures attack in children and adolescents was the unknown type (59.4%), while the most frequent cause for structural/metabolic epilepsy was perinatal complications (Farghaly et al., 2018).

About 90 % of epileptic patients had seizure triggers and the most common triggers in children include stress, excitement, fever, illness, missed medication, and tiredness; consequently it is important to follow lifestyle modifications and stress management for seizures control (Connolly, 2014).

Although epilepsy is a medical disorder, it has a negative impact on the children's cognitive, behavioral, psychological, and social functioning related to its unexpected and chronic nature, negative public attitudes toward epilepsy, and stigmatization attached to seizures. Therefore, it could be reflected on children's performance concerning several aspects as emotional, social, school, and family, and give rise to more stressors for them and their families (Ahmed, 2019).

In other words, epilepsy is a medical and psychosocial disorder characterized not only by seizures attack but also by psychological and social stressors and coping related problems. As a result, the comprehensive care should be directed to determine and manage the medical and psychosocial problems related to epilepsy for epileptic children and their caregivers to improve their cognitive, behavioral, psychological, and, social functioning (Rani and Thomas, 2019).

Significance of the Study

WHO at 2019 reported that about 50 million people currently live with epilepsy world-wide, five million people are diagnosed with epilepsy yearly, and the epilepsy prevalence rate is 6/1000 for the developed countries and 18.5/1000 for the developing countries. At least 50% of the cases are children or adolescents;

however, it affects 10.5 million under the age of fifteen years old and 65 million in total *(WHO, 2019)*.

In Egypt, some researchers reported that the life time prevalence of epilepsy is 12.46/1000 while the incidence rate is 123/100000, and the age-specific prevalence rate is much higher in infancy and early childhood group (62.5 and 37.04/1000) (Fawi et al., 2015).

According to the Statistical Office of Neurological Out-Patient Clinic of Children's Hospital at Ain Shams University, the prevalence of epilepsy in children for the two years (2012: 2013) was about 300 children (*El-Marzky et al.*, 2019).

Moreover, epilepsy has significant psychosocial impacts on children and their families due to several factors as chronicity and unpredictability of seizures, long term therapy, and stigmatization attached with epilepsy. However, there is lack of researches concerning psychosocial epileptic facing children. stressors Therefore, it would be useful to determine these stressors as it may assist health care providers, especially psychiatric nurses, in developing health educational and nursing intervention programs about children's psychosocial stressors management and its effective coping strategies.

Aim of the study

The aim of the Study was to:

Assess the psychosocial stressors among epileptic children.

Research Question:

What are the psychosocial stressors among epileptic children?

Subjects and Methods

Research Design:

A descriptive design was conducted in this study.

Research Setting

The study was conducted at the neurological clinic of Children's Hospital at Ain Shams University.

Subjects

A purposive sample of 100 epileptic children of both sexes was selected from the neurological clinic of Children's Hospital at Ain Shams University who fulfilled these criteria (age range from 8-13 years old, diagnosed with epilepsy within a period of 1 year and more, free from any other psychiatric/ chronic medical disorders, able to communicate, and willing to participate and cooperate).

According to The Epi-Info 7.0 program, the minimum sample size is 91 subjects which the population size= 200 over 6 months. Therefore, the researcher increased this number to 100 subjects to increase the reliability of the study.

Tools for data collection

Interviewing questionnaire:

An Arabic questionnaire was developed by the researcher and revised by supervisor after review of related literature and data were collected after the patient interview using the following tools:

A- Socio-demographic characteristics and medical history:

- Socio demographic characteristics of the epileptic child and his parents such as child's age, child's gender, child's education, area of residence, father's education,etc.
- 2. Medical history of the epileptic child such as duration of disease, seizure

frequency, common seizures attack's place,etc.

B- The psychosocial stressors inventory for epileptic child:

This tool was designed by the researcher as statements and interviewed the epileptic child to measure the frequency of the psychosocial stressors of the epileptic children. It was classified into two main parts:

- 1. The first part represents psychological stressors and contains thirty-eight items; which includes the following subscales of psychological stressors related to: epileptic fits (twelve items), treatment and its side effects (eight items), precautions of illness (six items), school (seven items), and periodic follow-up (five items).
- 2. The second part represents social stressors and contains twenty-two items; which includes the following subscales of social stressors related to: family (twelve items) and school (ten items).

❖ Scoring system

Each item taken one scores, never= 1, sometimes =2, and always =3. Psychosocial stressors questionnaire contained 56 sentences so score of psychosocial stressors items regarding total psychosocial stressors. According to children's responses, their stressors were categorized into three categories: the total scores less than 50% had mild stressors, score of 50% up to 75% had moderate stressors, and score of 75%-100% had high psychosocial stressors.

Preparatory phase

This phase includes reviewing past, current, local and international related literature and theoretical knowledge of various aspects of the study using books, articles, internet, periodicals and magazines to develop tools for data collection then the

content validity and reliability were reviewed and assessed by expert persons.

Validity and Reliability

Tο achieve the criteria oftrustworthiness of the tools of data collection in this study, the tools were tested and evaluated for their face and content validity, and reliability by five expertises in two different specialties; in Psychiatric and Mental Health Nursing Department at Nursing faculty/Ain Shams University and Biostatistics Department at High Institute of Public Health at Alexandria University. The items on which 85% or more of the experts have agreed were included in the proposed tool. The required corrections modifications were done.

The reliability of the tools was assessed through measuring their internal consistency by Cronbach Alpha Coefficient test, Reliability test result was 0.814.

Pilot study

The pilot study was conducted on ten epileptic children. They represent 10% of total sample from above mentioned setting to ensure the clarity of questions, applicability of the tools and the time needed to complete them. The necessary modifications were done as a result of pilot study; those patients were excluded from the actual study sample.

Field work

The actual fieldwork for the process of data collection has consumed six months started at the beginning of February 2017 and was completed by end of July 2017. Data were collected in two days per week average. With two patients a day, the researcher conducted an interview at the neurological clinic of Children's Hospital at Ain Shams. The caregivers of epileptic children were asked to give a verbal agreement to participate in the study; the investigator explained the aim and objectives to the participants and their

caregivers and that data will only be used for the purpose of the study. Confidentiality of any obtained information was assured and the participants and their caregivers were informed about their right to participate or not in the study.

Patients were interviewed individually using the developed tool. This interview took about approximately 40 to 45 minutes to complete for each patient.

Ethical Consideration

An official approval was obtained from Research Ethics Committee in Faculty of Nursing, Ain Shams University and Children's Hospital at Ain Shams University. The approval of each subject and his caregiver to share in this study was obtained after assuring for their anonymity and confidentiality.

Administrative design

An official letters were issued from Faculty of Nursing, Ain Shams University to get permission from the director of neurological clinic of Children's Hospital at Ain Shams for gathering data of research.

Statistical design

The collected data were revised, coded, tabulated, and statistically analyzed using Computer Software for Excel program and the statistical package for the social science (IBM SPSS) software package version 20.0 Data were presented using descriptive statistics in form of frequencies and percentage. Chisquare test and p-value was used to test the association between variables.

Results:

Table (1): illustrates that, more than half of studied epileptic children were males, in age from 11 years to 13 years old, which constitute (55% and 61% respectively). Regarding education, more than two thirds of them (69%) were primary school, and (37%) of them having two or more of siblings. Concerning child's order of birth, one third of studied epileptic children (33%) reported being only child in their family, while half of them (50%) were first and last (25% equally for each one).

Table (2): clarifies that, more than half of fathers' studied epileptic children had university education and the majority of them had work and lived in urban area, while nearly half of their mothers had preuniversity education and more than three fifths of them had work; which constitute (55%, 93%, 65%, 47%, and 62% respectively).

Table (3): shows that, more than half of studied epileptic children had epilepsy one to three years ago and had no seizure attack over the last month; also the common seizure attack's place was at home (59%, 57%, 52% respectively). Concerning periodic follow-up regularity, more than two thirds of studied epileptic children (68%) had regular follow-up visits to the clinics. It was clear that more than three fifths of studied epileptic children (63%) followed the medical instructions.

Additionally, slightly three quarters of them (74%) had compliance with the medications that was prescribed for them.

Table (4): clarifies that, more than three fifths of the studied epileptic children represented high psychological stressors, which nearly two thirds of them represented high psychological stressors related to precautions of illness, three fifths of them represented high psychological stressors related to the treatment and its side effects, and more than half of them represented high psychological stressors related to epileptic fits (63%, 64%, 60%, and 51% respectively).

Table (5): shows that, more than three quarter of the studied epileptic children represented high social stressors, which more than two third of them represented high social stressors related to school (78% and 71% respectively).

Table (6): shows that, there are statistical significant relations between the total psychological stressors among studied epileptic children and their age and number of siblings with P-value (< 0.05).

Table (7): reveals that, there are statistically significant relations between the total social stressors among studied epileptic children and their compliance of medications and medical instructions with P-value (< 0.05).

Table (1): Distribution of the studied children according to their socio-demographic characteristics (n=100).

Item	No.	%
Age (years):		
8 < 11	39	39.0
11 - 13	61	61.0
Gender:		
Male	55	55.0
Female	45	45.0
Child's education:		
Primary school	69	69.0
Preparatory school	31	31.0
Number of siblings:		
None	33	33.0
One	30	30.0
Two or more	37	37.0
	51	37.0
Order of the child:		
Only		
First	33	33.0
Middle	25	25.0
Last	17	17.0
	25	25.0

Table (2): Distribution of the studied children according to their family socio-demographic data (n=100).

Items	No.	%
Area of residence:		
Urban	65	65.0
Rural	35	35.0
Father's education		
Illiterate	3	3.0
Pre-university education	38	38.0
University education	55	55.0
Postgraduate education	4	4.0
Father's job		
Work	93	93.0
Not work	7	7.0
Mother's education		
Illiterate	2	2.0
Pre-university education	47	47.0
University education	42	42.0
Postgraduate education	9	9.0
Mother's job		
Work	62	62.0
Not work	38	38.0

Table (3): Distribution of the studied children according to their medical health history (n=100).

Item	No.	%
Duration of disease		
1 year- 3 years	59	59.0
More than 3 years	41	41.0
Seizure frequency/the last month:		
None	57	57.0
Once	34	34.0
Twice or more	9	9.0
Common seizures attack's place:		
Home	52	52.0
School	27	27.0
Street	21	21.0
Periodic follow-up regularity:		
Regular	68	68.0
Irregular	32	32.0
Following medical instructions:		
Yes	63	63.0
No	37	37.0
Medications compliance:		
Yes	74	74.0
No	26	26.0

Table (4): Distribution of studied children according their psychological stressor (n=100)

Psychological Stressor		Low <50%		Moderate 50%–75%		High 75%–100%	
Stressor	No.	%	No.	%	No.	%	
Related to epileptic fits	4	4.0	45	45.0	51	51.0	
Related to treatment and side effects	0	0.0	40	40.0	60	60.0	
Related to precautions of illness	5	5.0	31	31.0	64	64.0	
Related to school	6	6.0	52	52.0	42	42.0	
Related to periodic follow-up	6	6.0	53	53.0	41	41.0	
Total	2	2.0	35	35.0	63	63.0	

Table (5): Distribution of the studied children according to their social stressors (n=100).

Social Stressor	Low <50%			erate –75%	High 75%–100%	
	No.	%	No.	%	No.	%
Related to family	4	4.0	41	41.0	55	55.0
Related to school	4	4.0	25	25.0	71	71.0
Total	2	2.0	20	20.0	78	78.0

Table (6): Relation between total psychological stressors and socio-demographic characteristics among studied epileptic children (n=100).

Total Psychological Stressors								
Item		Low (N=2)		Moderate (N=35)		ligh I=63)	Chi-squ	are test
	No.	%	No. %		No. %		X^2	P Value
Age (years):								
8 < 11	0	0.0%	21	60.0%	18	28.6%	10.647	*.005
11 - 13	2	100.0%	14	40.0%	45	71.4%	10.047	1.003
Gender								
Male	2	100.0%	19	54.3%	34	54.0%	1.671	.434
Female	0	0.0%	16	45.7%	29	46.0%	1.0/1	.434
Child's education:								
Primary school	1	50.0%	25	71.4%	43	68.3%	.450	700
Preparatory school	1	50.0%	10	28.6%	20	31.7%	.430	.798
Number of siblings:								
None	0	0.0%	8	22.9%	25	39.7%		
One	1	50.0%	19	54.3%	10	15.9%	16.869	*.002
Two or more	1	50.0%	8	22.9%	28	44.4%		
Order of the child:								
Only	0	0.0%	12	34.3%	21	33.3%		
First	1	50.0%	4	11.4%	20	31.7%	0.740	126
Middle	1	50.0%	9	25.7%	7	11.1%	9.749	.136
Last	0	0.0%	10	28.6%	15	23.8%		

 $P-value > 0.05 \text{ not significant} \qquad P-value \leq 0.05 \text{ Significant (*)} \qquad P-value \leq 0.001 \text{ Highly Significant (**)}$

	Total Social Stressors								
Item		Low (N=2)		Moderate (N=20)		High (N=78)		Chi-square test	
	No.	%	No.	%	No.	%	X^2	P value	
Duration of disease:									
1 year- 3 years	1	50.0%	11	55.0%	47	60.3%	.250	.882	
More than 3 years	1	50.0%	9	45.0%	31	39.7%	.230	.882	
Seizure frequency/the last month:									
None	1	50.0%	11	55.0%	45	57.7%			
Once	1	50.0%	7	35.0%	26	33.3%	.407	.982	
Twice or more	0	0.0%	2	10.0%	7	9.0%			
Common seizures attack's place:									
Home	0	0.0%	9	45.0%	43	55.1%			
School	2	100.0%	4	20.0%	21	26.9%	8.318	.081	
Street	0	0.0%	7	35.0%	14	17.9%			
Periodic follow-up regularity:									
Regular	1	50.0%	12	60.0%	55	70.5%	1 110	572	
Irregular	1	50.0%	8	40.0%	23	29.5%	1.112	.573	

Table (7): Relation between total social stressors and medical characteristics among studied epileptic children (n=100).

P-value > 0.05 not significant P-value ≤ 0.05 Significant (*) P-value ≤ 0.001 Highly Significant (**)

40.0%

60.0%

65.0%

35.0%

53

25

61

17

8

12

13

100.0%

0.0%

0.0%

100.0%

2

0

Discussion

Yes

No

No

Following medical instructions:

Medications compliance:

Epilepsy is pervasive neurological disorder in children that contains not only of epileptic fits, but also has a significant impact on their cognitive, psychological, behavioral, and social functioning. As a result, epileptic children encounter numerous psychological and related social stressors to the unpredictability, disability, chronicity, episodic, and stigma attached to the illness nature. So, the knowledge and early assessment about these stressors facing epileptic children has a vital part in promotion the ability of nurses to provide and apply appropriate nursing intervention programs that will enhance effective coping strategies (Alshahawy, 2018).

The present study has been designed to assess the psychological and

social stressors among children with epilepsy.

67.9%

32.1%

78.2%

21.8%

6.533

7.251

*.038

*.027

The current study was carried out on hundred children with epilepsy (n=100) at the neurological clinic of Children's Hospital at Ain Shams, who were accessible at the study time, and free from any other chronic medical or psychiatric diseases.

The present study showed that more than half of studied children were in the age 11-13 years old. This may be due to increasing activities and the risk of accidents and infection exposure in this age stage which may affect the nervous system and lead to epilepsy. This finding is in agreement with Mansy et al., (2012) whose study on Maternal practice and its effect on Quality of Life of their Epileptic Children. and reported that age-specific prevalence of epilepsy in children is less than 12 years old.

The present study presented that the majority of the studied children were in primary school. This may be due to the study age-group is ranged from 8- 13 years old and the almost of this age-group in primary school. This result is in agreement with *Abd El Moneim*, (2010) whose study on A counseling intervention for family caregivers of children with epilepsy, and showed that more than three fourths of them were in primary school.

The present study presented that more than half of studied children were males. This result goes on line with many studies as the *Saleem et al.*, (2015) whose study on Prevalence and pattern of active epilepsy in school going children's in Kashmir valley, and clarified that boys had higher prevalence of epilepsy than girls. However, these results are in disagreement with *Ayar et al.*, (2020) whose study on the association between seizure self-efficacy of children with epilepsy and the perceived stigma, and reported that more than half of them were female.

As regard to child's order of birth, one third of studied children stated being only child in their family and this may be owing to parent's fear of having other children with epilepsy; while half of studied children were first and last child in their family; one quarter equally for each one. These results are disagreement with Badawy, (2015) whose study on Maternal knowledge and management of their children with epilepsy, and mentioned that the majority of studied children were the first child in their families.

Regarding the educational level of parents' epileptic children, the present study illustrated that more than half of their fathers had university education and nearly half of their mothers had preuniversity education. These results are in agreement with *Ahmed*, (2019) whose

study on the burden and coping strategies among caregivers having children with epilepsy, and founded that more than one third of their mothers had secondary education.

In addition, the present study demonstrated that the majority of them lived in urban area. This may be due to the fact that all of the epileptic children under the study were gotten from the same hospital that is responsible for provision its services to the nearby areas. and also the study was conducted at Cairo which is considered an urban area. This finding is in agreement with Emran et al., (2011) whose study on A survey of public knowledge familiarity. and attitude towards epilepsy in Lahore, in Pakistan, and estimated that the higher rate of epilepsy in urban than rural areas. However, this finding is incongruent with El-Senousev et al., (2009) whose study on Infantile and Childhood Epilepsies in Middle Delta: Types, Risk Factors and Etiology, and found that higher rate of pediatric epilepsy in rural areas.

Concerning the job of parents' epileptic children, the majority of their father had work and more than three fifths of their mothers had work. This result is incongruent with *Abd El-Mouty*, (2019) whose study on burden and quality of life among caregivers to children with epilepsy, and showed that two third of epileptic children's mothers were housewives.

Concerning the medical history of studied children, the present study mentioned that more than half of studied children had epilepsy one to three years ago and no seizure attack over the last month. This result is in agreement with *Vestergaard*, (2011) whose study on Changes in bone turnover, bone mineral and fracture risk induced by drugs used to treat epilepsy, and estimated that studied subjects had low seizures frequency.

The present study reported that the majority of them were compliant with medications, medical instructions, and regular follow-up. This finding is supported by Badawy, (2015) whose study on Maternal knowledge and management of their children with epilepsy, found that majority of the epileptic children were compliant with medications. While this finding is inconsistent with El-Sharkawv et al., (2006) whose study on Attitudes and practices of families and health care personnel toward children with epilepsy in Kilifi/ Kenya, estimated that the majority of epileptic children had medication non-compliance.

The present study revealed that the common seizure attack's place of more than half of studied children was at home. This is may be due to staying at home for long times. This is in agreement with *Sajjan, Jain, Sharma, Seth, and Aneja, (2016)* whose study on Injuries in Children with Epilepsy: A Hospital-based Study, showed that the most prevalent place for seizures injuries in epileptic children is home.

The present study revealed that more than three fifths of the studied epileptic children had high psychological stressors which nearly two thirds of them perceived high psychological stressors related to precautions of illness, three fifths of them perceived psychological stressors related to the treatment and its side effects, and more than half of them perceived high psychological stressors related epileptic fits. Meanwhile, more than half ofthem perceived moderate psychological stressors related to periodic follow-up and school.

This result is supported by **Speechley**, et al., (2012), whose study on Quality of life in children with new onset epilepsy: A 2-year prospective cohort

study, and illustrated that studied subjects had high levels of psychological stress.

The present study illustrated that more than three quarter of the studied epileptic children had high social stressors which more than two third of them suffered from high social stressors related to school and more than half of them suffered from high social stressors related to family.

This finding is consistent with *Ahmed, (2019)* whose study on Burden and coping strategies among caregivers having children with epilepsy, and illustrated that majority of studied subjects had severe social stress.

The present study revealed that there were statistically significant relations between the total psychological stressors of studied children and their socio-demographic characteristics such as age and number of siblings.

Moreover, the present study clarified that there were statistically significant relations between the total social stressors among studied epileptic children and their medical characteristics such as compliance of medications and medical instructions.

This finding is supported by *Rani*, *Varughese*, *Shankar*, *and Kannan*, *(2013)* whose study on Assessment of quality of life of patients with epilepsy in the neurology out-patients departments of a tertiary care hospital, and showed that there was a significant relation between age and psychosocial impacts of epilepsy.

This finding is incongruent with *Riechmann, et al., (2019)* whose study on Quality of life and correlating factors in children, adolescents with epilepsy, and their caregivers: A cross-sectional multicenter study from Germany, and revealed that there was no significant

relation between age and psychosocial consequence of epilepsy.

Conclusion

In the light of this study results, it can be concluded that:

The epileptic children have high psychosocial stressors in relation to their socio-demographic features and medical history such as their age, number of siblings. residence area. fathers' education, common seizures attack's place, and medications compliance. the majority of these additionally stressors are due to illness precautions, side effects of medications, epileptic fits, and the school.

There were statistically significant relations between the psychological stressors among epileptic children under the study and their age, number of siblings, residence area, and common epileptic attack's place.

There were statistically significant relations between the social stressors among epileptic children under the study and their age, father's education, and compliance of treatment and medical recommendations.

Recommendations

According to the findings, it is recommended that:

- Develop a routine screening of stressors for epileptic children by health professionals during their visits at outpatient clinics.
- Develop and apply support groups, health educational and nursing intervention programs, and workshops for epileptic children, their parents, and teachers about epilepsy, care of children, community resources, children's psychosocial stressors, and effective coping strategies.

- Establish campaigns through mass media and the Ministry of Health to improve public awareness and attitudes towards epilepsy.
- Further researches are required to develop health educational and nursing intervention programs for epileptic children, their parents, and teachers to manage children's psychosocial stressors and determine the effective coping strategies.
- Future studies are needed to utilize psycho-educational programs for nurses regarding counseling, reassurance, and psychosocial support for epileptic children and their families.

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