



ASSESSMENT OF COPING STRATEGIES AMONG PARENTS HAVING CHILDREN WITH EPILEPSY

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Abstract

Background: Epilepsy is the most common neurological brain disorder seen in children, parents of children with epilepsy face a number of challenges including the stigma of disclosure of epilepsy in addition to the lack of sound information about how to cope with the problem, and need psychosocial and emotional support.

The aim of study: to assess coping strategies among parents having children with epilepsy.

Research design: A descriptive research design was used in this study.

Setting: The study was conducted at the neuropsychiatry outpatient clinic at El- Fayoum General Hospital

Sample: Convenience sample will be selected available parents having children with epilepsy.

Tools: 1st tool structured questionnaire format to assess the children and their parents characteristics as well as knowledge of parents about epilepsy 2nd tool Parents burden scale to assess parents burden 3rd tool coping pattern scale to assess adaptive attitude of parents toward their epileptic children.

Results: This study represent mean age of children is 8.03 ± 0.365 , more than half of children in primary school, less than half of studied parents had secondary education, more than half of parents had poor knowledge, more than half have severe burden, Additionally less than three quarters of parents had low coping

Conclusion: It can be concluded that, Parents of children with epilepsy have poor knowledge about epilepsy, parents facing several burdens resulting from epilepsy they are continually worried about the child diagnosis, long-term costs of treatment and follow-up and have low coping pattern with their epileptic children

Recommendation: Its recommended for the importance of applying educational program for parents on improving their knowledge and coping strategies

Keywords: Children, Coping strategies, Epilepsy, Parents

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1. INTRODUCTION

Epilepsy is a brain disorder characterized by a predisposition to produce epileptic seizures with neurobiological, cognitive, psychological and social consequences. Estimates show that the incidence of children diagnosed with epilepsy (CDE) ranges from 41–187/100,000, with a higher incidence in underdeveloped countries. Epilepsy is about twice as common in children as in adults (about 700 per 100,000 in children under the age of 16 years compared to 330 per 100,000 in adults (Andersen & Quintana, 2022).

Parents are mostly the primary caregivers of children with epilepsy. Caring for a child with a chronic life threatening illness such as epilepsy carries major physical and psycho-logical burdens on the parents. Those parents face a number of challenges including the stigma of disclosure of epilepsy in addition to the lack of sound information about how to cope with the problem, and hence need psychosocial and emotional support (Shahin & Hussien, 2021).

Parents face difficulty in making decisions about their child's care and future. The burden of a new epilepsy diagnosis will play an important role in the day-to-day lives of families with epileptic children. Most parents are extremely upset when their child is diagnosed with epilepsy, mainly because of the disease-related stigma. Shock, grief, anger, disappointment, sorrow and depression are common parental reactions (Ghaith & Mohammed, 2020).

Children with epilepsy are at increased risk for psychologic, behavioral, cognitive, neurologic, academic, and social problems caused by their chronic neurologic condition, which may have a significant impact on quality of life independent of the seizures. Frequent subclinical or subtle seizures may also have a direct impact. Depression and suicidality, there is a high burden of mood disorders in children with epilepsy (Engel et al., 2021)

Childhood epilepsy affects the family significantly. The condition is associated with a range of cognitive and behavioral difficulties that are often

unrecognized and under-treated, and have a significant effect on health-related quality of life. Difficulties in school include increased risk of academic underachievement and school attendance problems, which may also affect parental wellbeing (Tsehay et al., 2022).

Epileptic seizures are unpredictable; they increase the risk of injury, hospitalization, and even mortality. Coping with the consequences of epilepsy, especially its typical burden of the accompanying social stigma depends on the individual's personality traits. Different episodes of discrimination, coping strategies, and personality may be important in feeling the stigma of epilepsy. Stigmatization leads to discrimination against PWE in multiple aspects of life (Mlinar, Renner, Primec and Petek, 2021)

Families caring for children with medical problems are at risk for physical illness, mental illness, divorce, job loss, and financial problems. Parents of children with chronic diseases such as epilepsy may experience burnout as a result of uninterrupted care needs and uncertain outcomes. They may feel unprepared or lacking in resources to care for their child (Donohue et al, 2018). In addition, they also face unreasonable costs for resources that are compatible with their child's medical needs. Raising a child with epilepsy often involves a state of uncertainty, anxiety, and the need for continued monitoring. Parents need to learn to cope with special diets, medications, school challenges, frequent hospitalizations, behavioral problems (Jafarnejad & Khosravi, 2021)

nurses need to assess the impact of epilepsy on all members of family, identify their knowledge and attitudes towards seizures, understand family structure and dynamics, and determine family's reaction about having epileptic child. Then, nurses can determine the obstacles and stressors affecting the family that can disturb the caring for epileptic child. Later, nurses should provide suitable support, counselling sessions, information about epilepsy, workshops regarding effective coping skills, available community resources, and self management strategies to increase the adaptation and improve overall performance (Elmohalem, Ismail and Bayomi, 2020).

Aim of the Study:

The study was aimed to assess coping strategies among parents having Children with Epilepsy.

This aim was attained through:

- 1-Assess knowledge of parents having children with epilepsy
- 2-Assessing burden of parents having children with epilepsy.
- 3-Assess coping strategies of parents having children with epilepsy.

4- Assessing the relationship between knowledge of parents about epilepsy with their burden and coping strategies.

Research Questions:

- What are the burden facing parents of children with epilepsy?
- What are the coping strategies of parents having children with epilepsy?
- Is there any relationship between knowledge of parents about epilepsy with their burden and coping strategies?

2. SUBJECTS AND METHODS

1) The technical design:

A) Research design:

A descriptive research design was used to achieve the objective of the study.

B) Setting:

The study was conducted at the neuropsychiatric outpatient clinic at the EL - Fayoum General Hospital.

C) Subject:

Sample types and size:

Convenience sample technique was utilized in the present study. The study was included all parents from the previous mentioned settings. The total numbers of parents were 70.

D) Tools for data Collection:

Three tools were used for data collection in the present study as the following:

I. Tool I: A Structured Questionnaire Format: A structured Arabic self-administered questionnaire sheet was designed by the researcher, after reviewing the related current and previous literature, to collect data which cover the aim of the study, and it consists of two parts as follows:

The first part: A-Socio-demographic characteristics of parents as age, sex, educational level, occupation, residence and family income.

B-Socio-demographic characteristics of children such as age, sex, and educational level of the child.

The Second part: It was concerned with parents knowledge about childhood epilepsy it includes items regarding to: -

-Definition of epileptic attack.

- Types of epileptic attack.

-Causes of epilepsy

-Contributing factors for epileptic seizure

-proper action to prevent contributing factors

Scoring System for parents Knowledge about **Childhood Epilepsy:-** The total scores for the parent's knowledge regarding epilepsy divided into three levels: these levels are poor knowledge, fair knowledge and good knowledge

-Poor knowledge <50%

-Fair knowledge 50- <75%

- Good knowledge > 75%

II. Tool II: Burden scale developed by (Zarit et al, 1980).

to assess burden of parents having children with epilepsy, measures the extent to which the parents emotional and physical health, social life and financial status are affected by caring for their child with epilepsy, it is formed of 29 statements.

Scoring System for parent's burden scale:- Parents burden is four point scale, according to the degree of parents burden, the numerical values allotted to each response as following:

Score were used (3) for always, score were used (2) for sometimes, score were used (1) for rarely, score were used (0) for never.

- The total degree of burden :-

* Score from 0-29 referred to mild burden.

* Score from 29-58 referred to moderate burden

* Score from 59-87 referred to severe burden.

III-The third tool: Coping Pattern Scale: that was developed by (Jalowiec and Powers, 1991), this scale is used to assess parents coping strategies toward their children suffering from epilepsy. It contains 60 statement coping behavior. It were classified into eight modes of adaptive behavior. It including confrontive, evasive, optimistic, fatalistic, emotive, palliative, supportant and self reliant modes. Scoring of the coping pattern scale.

The coping pattern scale is a four point scale according coping, the numerical values allotted to each response was the always, sometimes, rarely and never

The overall scale for coping strategies is 0-180. A total score is obtained by summing up scores of the items of each area. A higher summed score indicates greater use of coping strategies.

These scores were converted into percent score. The parents coping strategies were considered high or appropriate if the percent score was 75% or more and low if less than 75%.

Tools validity and reliability:

The data collection tools were reviewed by a panel of three experts in Psychiatric Mentalhealth nursing field to test the face and content validity.

Ethical consideration

The researcher approval was obtained from a scientific, ethical committee in the faculty of nursing, Helwan University before starting the study. Before data collection, an oral consent was obtained from every participant in the study after a clear explanation of the purpose and importance of the study. the researcher assured that the obtained information would be confidential and used only the purpose of the study. Parents were informed about their rights to refuse or withdraw at any time. It haven't any harmful effect on them.

II. Administrative design:

Official letters, including the title and purpose of the study were issued from the faculty of Nursing Helwan University and submitted to the Director of the pre-mentioned Hospitals for conducting the study.

III. Operational design:

The study, to be completed, has passed through different phases as follows: the preparatory phase, then the pilot study phase and lastly the field of work phase.

Preparatory phase:

During this phase the researcher reviewed the current, local and international related literature using books, periodicals journals, magazines and internet. The review was helpful in developing the tools used in the study, and increasing the researcher's depth of knowledge in the study area.

Pilot study:

It was conducted on 7 parents of children with epilepsy representing 10% of the total study sample, the aim of the pilot study was to evaluate clarity, visibility, applicability and content validity as well as the time required to fulfill the developed tools There were no major modifications found after the pilot study. The pilot showed very high levels of reliability. Parents in the pilot study were excluded from the study sample due to the availability number of calculation study sample.

Field work:

After securing the official requirements for carrying out the study, the researcher started the data collection. At the start of the interview, each subject was met individually by the researcher. The aim and nature of study were explained, with reassurance about confidentiality of parents information, and that it will be used for scientific research only.

Interviews were done individually the outpatient clinic on the previously mention setting. During the interview, the researcher established good relationship with each patient to gain trust and confidence. The data collection was carried out through interviewing the studied parents 3 days-week (Saturday, Monday, Thursday) visiting from 8 am-12 pm, the time needed by each participant to complete the questionnaire ranged between 30-45min. The questionnaires was distributed on parents and completed by the researcher assessment. All studied subjects filled questionnaire sheet by themselves except illiterate's parents by researcher according their answer.

IV. Statistical design:

The data was collected, coded and entered to a personal computer. It was analyzed with the program statistical package for social science (SPSS) version 20. The collected data were organized, revised, analyzed and presented in numbers and percentage in tables and figures. Proper and suitable statistical tests were used to test the significance of results obtained. Using the mean, standard Deviation, chi-square and Linear Correlation Coefficient [r] tests.

3. RESULTS

Table (1): shows that, mean age of children is 8.03 ± 0.365 , while the distribution of children

according to their gender shows that, (60%) of children were males and (45.7%) of children ranking as first among his brothers . As regarding the educational level of children, (54.2%) of children in primary school, while (22.9 %) of them not attached of school

Table (2) illustrates that, the mean age of the studied parents are (33.14±7.5). Regarding parents education (42.9%) had secondary education (74.3%) living in rural areas. As regarding income, (57.1%) of parents had insufficient income. Meanwhile, regarding marital status of parents, (85.7%) reported that married.

Figure (1) shows that, (55.7%) of parents have poor knowledge, while (12.9%) of them had good knowledge.

Figure (2) shows that, (62.9%) had severe burden, while (27.1%) had moderate burden and (10%) had mild burden.

Figure (3) show that, (70%) of studied parents had low coping, while (30%) of them had high coping.

Table (3) shows that, there was negative statistical correlations between parents knowledge about the disease and their burden, there was highly positive statistical correlations between parents knowledge related to epileptic disease and their coping pattern and there was negative correlation between parents burden and their coping.

Table (1): Distribution of children under the study according to their socio-demographics characteristics (N=70)

Items	N	%
Age (years)		
<5	16	22.9
5- <10	32	45.7
10 or more	22	31.4
Mean±SD	8.03±0.365	
Gender		
Male	42	60
Female	28	40
The arrangement of the child among his siblings		
First	32	45.7
Second	20	28.6
The third	6	8.6
Last mentioned	12	17.1
The child's educational stage		
Nursery	14	20.0
Primary	38	54.2
Preparatory	2	2.9
Not attached to the study	16	22.9

Table (2): Distribution of parents under the study according to their socio-demographics characteristics (N=70)

Items	N	%
Age (years)		
<30	24	34.3
30- <40	34	48.6
40 or more	12	17.1
Mean±SD	33.14±7.5	
Educational level		
Illiteracy	7	10.0
Primary Education	9	12.9
Preparatory education	14	20.0
Secondary education	30	42.9
University education	10	14.2
Job		
Works	18	25.7
Doesn't work	52	74.3
Place of residence		
Rural	52	74.3
Urban	18	25.7
Type of housing		

Own	46	65.7
Rent	24	34.3
Monthly family income		
Enough	28	40.0
Not enough	40	57.1
enough and overflowing	2	2.9
Number of family members		
3 to 5	54	77.1
6 to 8	16	22.9
Marital Status		
Widow	8	11.4
Married	60	85.7
Divorced	2	2.9

Figure (1) Distribution of the study group according to their total knowledge score regarding epilepsy (N=70)
Total knowledge score regarding epilepsy (N=70)

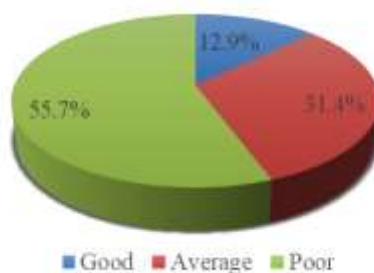


Figure (1) show more than half (55.7%) of parents have poor knowledge, while less than one quarter (12.9%) of them had good knowledge.

Figure (2) Distribution of total burden levels among parents having children (N=70)
Total burden levels among parents having children (N=70)

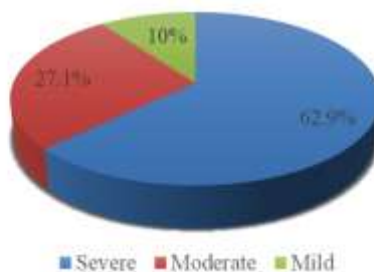


Figure (2) shows that, (62.9%) had severe burden, while (27.1%) had moderate burden and (10%) had mild burden.

Figure (3) Distribution of total level of coping pattern among parents having children with epilepsy(N=70)
Total level of coping pattern among parents having children with epilepsy

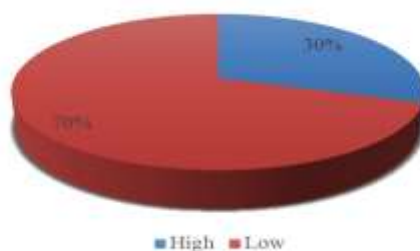


Figure (3) show that, (70%) of studied parents had low coping, while (30%) of them had high coping

Table (3): Correlation between studied parents knowledge, their burden and coping pattern

	Total Knowledge		Total Coping Pattern	
	r	P-value	r	P-value
Total Coping Pattern	0.427	<0.001*		
Total parents Burden	-0.375	0.005*	-0.519	<0.001*

4. DISCUSSION

Epilepsy is the most common neurological brain disorder seen in children. According to the World Health Organization, approximately 7.60 per 1000 individuals experience epilepsy during their lifetime, with the condition affecting around 70 million people of all ages worldwide. The maximum incidence of epilepsy, i.e., 102 per 100,000 cases annually, occurs in the first year of life, similar to the age range of 1 to 12 years. The incidence of epilepsy in children aged 11–17 is 21–24 per 100,000 cases. (Rozensztrauch & Kołtuniuk, 2022).

Management of a child with epilepsy is very difficult and, despite medication, some of the epileptic seizures are uncontrollable. On the other hand, children with epilepsy and other neurological disorders cannot control attacks, and this is often the responsibility of parents and, especially, the mothers. This uncertainty causes burden that reduces parents' belief in their skills and causes anxiety, depression, and eventually a function change. (Chehrzad et al., 2020).

The current study showed that, more than two fifth of children age 5- <10 with mean age (8.03±0.365). This finding agreement with the finding of Kinkar et al., (2020), who carried out study entitled ,Parental knowledge, attitudes, and behaviors toward their epileptic children at King Abdulaziz University Hospital and illustrated that, mean age of children was 9.0 years .

Regarding the characteristics of children, the current study showed that, more than half of children were males. This finding was in accordance with the finding of Ghaith & Mohammed, (2020) , who carried out the study entitled , Depression and coping patterns in mothers caring for children with epilepsy and illustrated that, 62% were males.

As regarding the educational stage of children ,the current study reported that, slightly more than half of children in primary school and as regarding arrangement of the child among the siblings , more than two fifth of children ranking as first among his brothers,. This finding was in accordance with the finding of Khalaf & Elaasar (2020) ,who carried out the study entitled , Effect of Training Program on Mothers' Self Competence Regarding Caring for Their Epileptic Children and reported that, 70% of children at primary school level. 42% arranged first among siblings.

Regarding to the characteristics of parents, the present study revealed that , slightly less than half of

studied parents 30- <40 years ,the mean age are (33.14±7.5). This finding was in agreement with Abd El-Mouty & Salem (2019), who carried out study entitled, Burden and quality of life among caregivers to children with epilepsy and illustrated that, mean age of caregivers similar to these results is 35.7±10.9. Regarding to the characteristics of parents, the present study revealed that, more than two fifth had secondary education . This finding was in accordance with Salisu et al., (2022), who carried out study entitled, Parent's Knowledge, Attitude and Pattern of Care for Children with Epilepsy in Lagos, Nigeria. and illustrated that, Most (98.2%) of the parents had at least a secondary level of education

Concerning the parents job, the present study revealed that ,slightly less than three quarters of parents are doesn't work . This finding was in accordance with, Aydın & Korkut (2022) ,Who carried out a study entitled, Examination of Parents' Knowledge, Attitudes, and Behaviors About Epilepsy and reported that, 76.9% of parents doesn't work.

Concerning parents income, the present study revealed that, more than half of parents had insufficient income . This finding supported by Shahin & Hussien (2021), Who carried out a study entitled, Knowledge, attitude, practice, and self-efficacy of caregivers of children with epilepsy: impact of a structured educational intervention program and reported that, 66.7% of parents had insufficient income

As regarding total levels of knowledge among studied parents. The current study show that, more than half of studied subjects had poor knowledge and this finding was in agreement with Girma et al., (2022), who conducted published study in Ethiopia under title " Public knowledge toward Epilepsy and its determinants in Ethiopia: A systematic review and meta-analysis and reported that, The pooled magnitude of poor knowledge toward epilepsy was 48.54% .

Also this finding supported by Shahin & Hussien (2021), and reported that the study participants had low level of knowledge about epilepsy.

As regarding the total level of burden of studied parents ,the present study illustrated that ,more than half of them had severe burden.This result was disagreement with, Pokharel et al., (2020) who carried out a study entitled , Burden and its predictors among caregivers of patient with epilepsy and reported that , only 13.9% of caregivers had high level of burden.

As regarding the total level of coping of studied parents ,the present study illustrated that ,more than two thirds of parents had low coping .This study was supported by **El-Marzky et al.,** (2019) , who carried out a study entitled Stressors and Coping Patterns of Mothers Having Children with Epilepsy and reported that , The majority of mothers were generally unable to cope with their child condition Parents had low coping with epilepsy related to parents had unsatisfactory knowledge regarding epilepsy may be related to slightly less than half of parents age (30-<40 years) that affects their attitudes towards their epileptic children. Common examples of misconceptions include overprotection of their epileptic children by preventing them from going to school and participating in sports or social activities.stressors that facing them such as financial burden, cost of treatment and parents always worried about future of the child. All these factors had negative effect on their adaptations abilities.

Regarding to Correlation between parents knowledge and their coping, the current study revealed that, there were highly statistical positive correlations between parents knowledge and their coping pattern. This finding was disagreement with **Raman et al., (2020)**, and found that, Knowledge was negatively correlated with Active Coping while being positively correlated with emotional support, instrumental support, humour and acceptance.

As regarding to Correlation between parents knowledge and their burden, the current study revealed that, there were highly statistical negative correlations between parents knowledge related to epileptic disease and their burden .This finding supported by El Malky Mohsen and Amer (2016) , and reported that , there was a negative correlation between caregiver's knowledge, practice and feeling of burden.

As regarding correlations between parent's burden and their coping pattern, the current study revealed that, there were statistical negative correlations between parent's burden and their coping pattern .This finding was in accordance with Abd Abd El-Mouty & Salem (2019), Who carried out a study entitled, Burden and quality of life among caregivers to children with epilepsy and found that, when the caregivers level of burden increases, the coping level decreases.

5. CONCLUSION

The result of the current study pointed to, more than half of parents of children with epilepsy had poor knowledge about epilepsy. Caring for children with epilepsy is really challenging and it is associated with enormous burden. More than half of studied parents had severe burden of epilepsy. These burdens include all aspects of life as physical, social, psychological and financial burden .Also less than three quarters of parents had low coping pattern with their children

with epilepsy and suffering from it. There was a statistically significant relation between parent's burden and their coping, there was statistical significant relation between burden and their level of knowledge. Also, there was highly statistical significant relation between coping pattern and their level of knowledge. There was negative correlation between burden and coping pattern among parents.

6. RECOMMENDATIONS:

In the light of the finding of this study, the following recommendations are suggested;

1-Emphasize the importance of availability and distributions of pamphlets and booklet containing the basic knowledge for parents about epileptic disease of their children.

2-Health awareness, educationl program for all people in the community personnel to identify epilepsy risk factors, decrease the incidence of epilepsy complication by adopting a healthy lifestyle and adherence to therapeutic regimen

3-Apply further research in large sample and other setting for generalization

3- National mass media survey to detect early cases and prevent risk factors using T.V, face book, social media...etc

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