Mothers' Perceptions of Potential Threats Associated with Epilepsy in their Children

Sahar Mahmoud Elkhedr Abdelgawad[1], Samar Abd-elrahman Radwan[2], Zeinab El-Sayed Hafez[3]

[1]Professor of Pediatric Nursing, Faculty of Nursing, Tanta University, Egypt
[2]Assistant Lecturer of Pediatric Nursing, Faculty of Nursing, Tanta University, Egypt
[3]Assistant Professor of Pediatric Nursing, Faculty of Nursing, Tanta University, Egypt

Corresponding author: Samar Abd-elrahman Radwan

E-mail: Samar.radwan@nursing.tanta.edu.eg

Abstract

Background: Mothers are often the primary caregivers who closely monitor their children with epilepsy and manage seizures and its related complications. They often experience multiple threats that affected their children's health and ability to function normally. **Aim:** the present study aim was to assess mothers' perceptions of potential threats associated with epilepsy in their children. **Research design**: A descriptive research design was utilized. **Subjects:** Purposive sampling of 120 mothers of children complaining of epilepsy was included. **Setting:** the study was conducted at Neurological Outpatient Clinic at Tanta Main University Hospital. **Tools:** Two tools were utilized. **Tool (I)** Epilepsy Knowledge Questionnaire. **Tool (II)** Mothers Perception of Epilepsy Threats. **Results**: slightly more than half of the mothers (55%) had moderate level of total knowledge regarding epilepsy. It was evident that, most of the mothers (88.3%) had negative perception toward physical threats followed by social threats 75% and psychological threats 70%. **Conclusion:** Based on the results of the present study, it can be concluded that, the majority of the studied mothers had negative perception regarding physical threats. Nearly three quarters of the mothers had negative attitude toward psychological and social threats. **Recommendation:** Educational instructions must be designed for mothers to raise their awareness about childhood epilepsy.

Key words: Children, Epilepsy, Mothers, Perception & Threats.

Introduction

Epilepsy is one of the most common disorders of the nervous system. It is a progressive and complex disease with unpredictable and debilitating nature. It is a brain condition that causes a child to have seizures. Epilepsy leads to neuro-biological, cognitive, psychological and social consequences in children, and can have a major impact on their development **(Falco, 2020)**.

International League Against Epilepsy (ILAE) 2018 suggests that, epilepsy is a neurological disease that can be defined by the recurrence of at least two unprovoked seizures more than 24 hours apart, one unprovoked seizure and a probability of further seizures similar to the general recurrence risk after two unprovoked seizures, or diagnosis of an epilepsy syndrome **(Fisher, Cross, & French, et al., 2021)**.

Epilepsy causes repeated seizures, which are sudden burst of rhythmic discharges of electrical activity in the brain that causes an alteration in sensation, behavior, or consciousness **(Pearl, 2020)**. Epilepsy is the commonest neurological disorder affecting 11 million children worldwide. One of 150 children has epilepsy during the first 10 years of their life. The incidence is 149 / 100.000 among low to middle income countries, and 43.4 / 100.00 in developed countries **(Truls, Morten, & Ragnhild, et al., 2025).** Prevalence of childhood epilepsy in Egypt was 123 /1000 per year with higher prevalence among children less than 12 years than adolescents **(Farghaly, Abd Elhamed,& Hassan, et al., 2021)**. More than half of affected children (59.4%) had idiopathic epilepsy **(Kisk, Hosny, &Bodry, et al., 2024)**.

The causes of epilepsy in childhood vary. It may be unknown (67.6%), congenital (20%), trauma (4.7%), infection (4%), stroke (1.5%), tumors (1.5%), and degenerative (0.7%) **(Mond, Duke, & Vince, 2020)**. Epilepsy can be categorized depending on level of consciousness. Complex seizure occurs when there is a change in consciousness, and simple seizure occurs when there is no change in consciousness **(Falco, 2020)**.

Management of epilepsy requires integration and cooperation among health care team to improve child's prognosis. The goal of epilepsy treatment is to control, stop, or reduce seizures **(Striano,& Minassian, 2020)**.

Epilepsy affects children in various ways, going beyond the physical health challenges to influence their emotional and social development. Many children with epilepsy live in

constant fear of when the next seizure will occur, leading to reduced children' confidence in engaging in daily activities **(Soltanifar, Salimi,& Norbakhsh, et al., 2018)**.

Mothers are mostly the primary caregivers of children with epilepsy **(Tavares, Anderson, & Ferro, et al., 2021)**. They perceive a number of threats that may be physically due to seizures-related injuries, socially including stigma, bulling, and isolation of their children. In addition to educational threats such as learning disabilities, or reduced academic performance. Psychological threats also perceived by mothers like anxiety, depression, and fear **(Benson, Lambert, & Gallagher, et al., 2022)**.

Pediatric nurses have key role in educating mothers to manage their children's illness. Core dimensions of their role toward mothers of children with epilepsy includes performing comprehensive assessment to tailor child's care plan, engage mothers in their child's care, and provide them with necessary knowledge to enhance their perception of the disease process **(Hockenberry,& Wilson, 2023)**.

Pediatric nurses should also, assess how mothers' perceived threats that encounter epilepsy. By building trust and maintain open communication, nurses can encourage mothers to express their fears, and concerns about epilepsy, caregiving behaviors, and the child's overall wellbeing **(Higgins, Downes, &Varley, et al., 2019; Pfafflin, Schmitz, & May, 2022).**

Significance of the study:

Epilepsy is unpredictable, chronic, and debilitating childhood morbidities world-wide. It is often associated with significant developmental, physical, psychological, and social health implications. It is a disorder that affects not only the child but also their mothers **(Horaib, Alshamsi, & Zabeeri, et al., 2021)**.

Nurses play a critical role in supporting mothers of epileptic children. By understanding mothers' perception of epilepsy threats, nurses can tailor education, emotional support, and care strategies to reduce their stress, improve child's safety, and enhance quality of life **(Higgins et al., 2019)**. Therefore, this study was carried out to assess mothers' perception of epilepsy threats to their children.

Aim of the study was to:

The present study aim was to assess Mothers' perceptions of potential threats associated with epilepsy in their children.

Research Question:

What are the most common epilepsy threats perceived by mothers of children with epilepsy?

Subjects and Method:

Research Design

A descriptive research design was utilized in the current study.

Setting

The present study was conducted at Neurological Outpatient Clinic of Tanta Main University Hospital, confined to the Ministry of Higher Education and Scientific Research.

Subjects

Purposive sampling of 120 mothers accompanied their children with epilepsy, and actively involved in their care were included in the study.

Tools for data collection

Two tools were utilized to collect data in this study:

Tool (I): Epilepsy Knowledge Questionnaire:

It was developed by the researcher and it consisted of two parts:

Part (1): Mothers' socio-demographic characteristics such as: age, educational level, residence, job, marital status, consanguinity, income, number of family members.

Part (2): Mothers' knowledge about epilepsy and epileptic seizures: It was developed by the researcher after reviewing the related literatures **(Hockenberry et al., 2023; Nevin, Wakefield, & Schilstra, et al., 2020; Morrison, Glick & Yin, 2019; Fisher et al., 2021)**: It included the following sub-items:

A. Knowledge related to child's history of epilepsy as causes, and age at first seizure attack, duration, and frequency of epileptic seizure

B. Knowledge about epilepsy and epileptic seizures as meaning, causes, manifestation, complication, and treatment of epilepsy. It also, included knowledge about triggers, and duration of epileptic seizures, signs and symptoms of aura, and safety measures during seizure.

The questionnaire sheet was scored from 0-2 grades, in which correct and complete answer take score two, correct and incomplete answer take one, while wrong or not known answers had zero score.

Mothers' knowledge was calculated and classified into:

- High level of knowledge from 75% - 100%.
- Moderate level of knowledge from 50 to < 75 %.
- Low level of knowledge from zero to < 50%.

Tool (II): Mothers' attitude toward Epilepsy Threats:

It was developed by the researcher after reviewing of recent and related literatures **(Rani, Mphil, & Thomas, 2019; Shore, Austin,& Dunn, 2023; Pack, Morrell,&**

Marcus, 2021). It was used to assess mothers' perception of epilepsy threats. It included physical threats as sleep deprivation and injuries, psychological threats as anxiety and depression, and social threats as stigma and discrimination.

Scoring system for mothers' perception was scored as follows: Agree = 2, Neutral=1 & Disagree=0

The scores of these items were summed up and converted into percentage.

Mothers' attitude was calculated and classified into:

- **Negative** attitude ≥ 80%.
- **Positive** attitude < 80%.

Method:

The study was accomplished through the following steps

1-Administrative process:

An official permission for data collection was obtained from the Dean of the Faculty of Nursing, Tanta University and the responsible authorities of Tanta Main University Hospital.

2-Ethical considerations:

a. Ethical approval code No. was 234/4/2023. It was obtained from the Faculty of Nursing Scientific Research Ethical Committee.
b. Nature of the study didn't' cause any harm or pain to the participated mothers.
c. Informed consent was obtained from mothers of children with epilepsy prior to data collection.
d. Confidentiality of information was maintained.

3-Tools Development: Two tools were developed by the researcher to collect the needed data.

4-Content validity: A jury of five experts in Pediatric Nursing checked the content validity and clarity of the questionnaire.

5-Pilot study: A pilot study was carried out on 12 mothers resampling 10 % of the sample. It was conducted to test clarity, applicability, feasibility of the tools and the necessary modifications were done. Pilot study was included in the study sample.

6-Reliability of tools: To test reliability of the tools cronbach's alpha test was done. It was 0.842 for tool (I), and 0.87 for tool (II) that indicated high reliability.

Mothers were interviewed individually at the Neurological Outpatient Clinic. Data was collected within 3 months.

Statistical analysis:

Statistical analysis using SPSS software was done. For quantitative data, Numbers and percentage were used. Mean and standard deviation was calculated.

Results:

Table (1) illustrates socio-demographic characteristics of the studied mothers. It was observed that, 40% of the studied mothers, aged between 30 < 40 years old, with mean ± SD 33.616 ± 8.22 years. It was evident that, 38.3% of the mothers had secondary education and nearly equal percentage (26.7%) of them had primary and university education.

It was found that, about two thirds (61.7%) of the studied mothers lived in rural areas, and 63.3% of them weren't a working mothers. More than half of the studied mothers (53.3%) had 5-6 members in their family with mean ± SD 5.016 ± 1.333.

Table (2) explains percentage distribution of the studied mothers' knowledge about child's epilepsy. It was clear that, more than two-thirds of the mothers (70%) reported that their children had epileptic seizures at any time of the day, and 60% of the seizures occurred once weekly. Most of the mothers (85%) mentioned that their children experienced generalized seizures and 43.3) had aura. Less than half of the mothers (46.1%) mentioned visual disturbances as a symptom of aura followed by hearing sounds 30.8% and 23.1% for feeling intense fear or joy.

Figure (1) explains mothers' knowledge about causes of epilepsy in their children. It was found that, nearly half of the studied mothers (48.3%) mentioned genetic causes, followed by 26.7% for infections of the nervous system and a minority of them (8.3%) didn't know the cause of epilepsy in their children.

Mothers' knowledge about duration of children's epileptic seizures was illustrated in **figure (2)**. It was revealed that, 43.3% of the mothers reported that the attack of seizure had lasted from 2-3 minutes, more than one-quarter (28.3%) their seizure attack lasted from 3-4 minutes and 11.7% had seizure attack for 1-2 minutes.

Regarding seizure triggering factors, it was noticed that, 40% of the mothers mentioned that their children exposed to seizure attack after missing treatment dose, 35% had seizure attack during watching T.V. and other screens, while excitement was the triggering factor in 11.7% of the studied children as illustrated in **figure (3)**.

Figure (4) presents mothers' knowledge about age of first seizure attack in their children. It was clear that, 50% of the children their first seizure attack had occurred before the first two years of life while more than one third of them (35%) reported first seizure attack during 2-

4 years of life and a minor percentage (6.7%) had first seizure attach at 6-8 years.

Total knowledge scores of the studied mothers regarding epilepsy and epileptic seizures were displayed in **table (3)**. It was observed that, more than one-third of the studied mothers (36.7%) had high level of knowledge about epilepsy and epileptic seizures while 55 % of them had moderate knowledge with Mean ± SD 13.033 ± 2.79.

Table (4) illustrates mothers' perception of epilepsy threats. Regarding physical threats, it was observed that**,** the majority of the studied mothers (90.8%) experienced sleep problems. An equal percentage of the mothers (95.9%) had reported stress and anxiety affected children's physical health, and children had difficulties in meeting their own health needs.

Concerning psychological threats, it was clear that, all the studied mothers (100%) and 97.5% mentioned that their children experienced sadness or depression and feeling worried as psychological threats respectively. Few percentages of the studied mothers (12.5%) had mentioned seeking psychological counseling or therapy for psychological threats to children.

As regards social threats, most of the studied mothers (81.7%, 85.8%) faced stigma or negative reactions, and had difficulties in accessing community or government support services. Nearly three quarters of the mothers (74.2%) had mentioned that epilepsy of children affected the ability to achieve their career goals and 58.3% of them reported that children's epilepsy had affected family relationship.

Table (5) explains mothers' total perception regarding epilepsy threats. It was evident that, most of the mothers (88.3%) had negative perception toward physical threats followed by social threats 75% and psychological threats 70%.

Table (1): Mothers' Socio-Demographic Characteristics (No. =120).

Socio-demographic characteristics	No. =12)	
	No.	%
Age in years:		
< 20	2	1.7
20<30	38	31.7
30<40	48	40.0
≥ 40	32	26.6
Mean ± SD	**33.616 ± 8.22**	
Educational level		
Illiterate	10	8.3
Primary education	32	26.7
Secondary education	46	38.3
University education	32	26.7
Residence		
Rural	74	61.7
Urban	46	38.3
Job		
Not working	76	63.3
Working	44	36.7
Number of family members		
3 - 4	44	36.7
5 - 6	64	53.3
7 - 8	12	10.0
Mean ± SD	**5.016 ± 1.333**	

Table (2): Mothers' Knowledge regarding Children's Epilepsy (No. =120).

Mothers' knowledge about child's epilepsy	No. =120	
	No.	%
Timing of epileptic seizures		
Morning	36	30.0
Any time of the day	84	70.0
Frequency of seizure		
Daily	48	40.0
Once weekly	72	60.0
Health problems associated with epilepsy		
Behavior disorders	40	33.3
Memory impairment	18	15.0
Attention deficit	10	8.3
All the above problems	52	43.4
Type of seizure		
Partial seizure	18	15.0
Generalized seizure	102	85.0
Presence of aura		
Yes	52	43.3
No	68	56.7
Symptoms of aura		
Visual disturbances	24	46.1
Feeling intense fear or joy	12	23.1
Hearing sounds such as buzzing	16	30.8

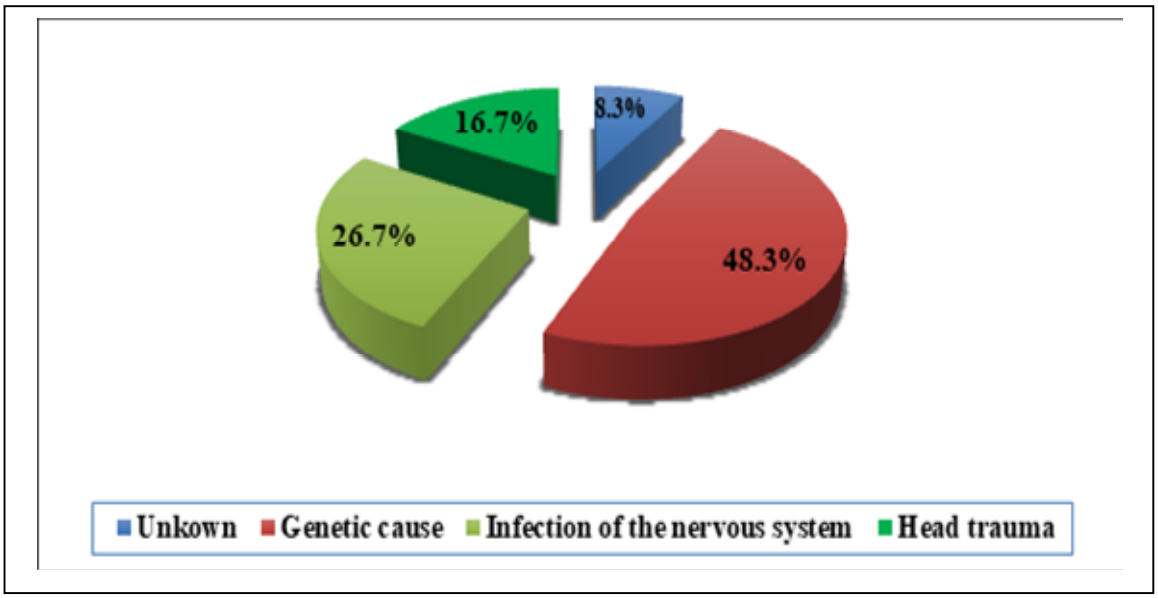

Figure (1): Mothers' Knowledge about Causes of Epilepsy in their Children.

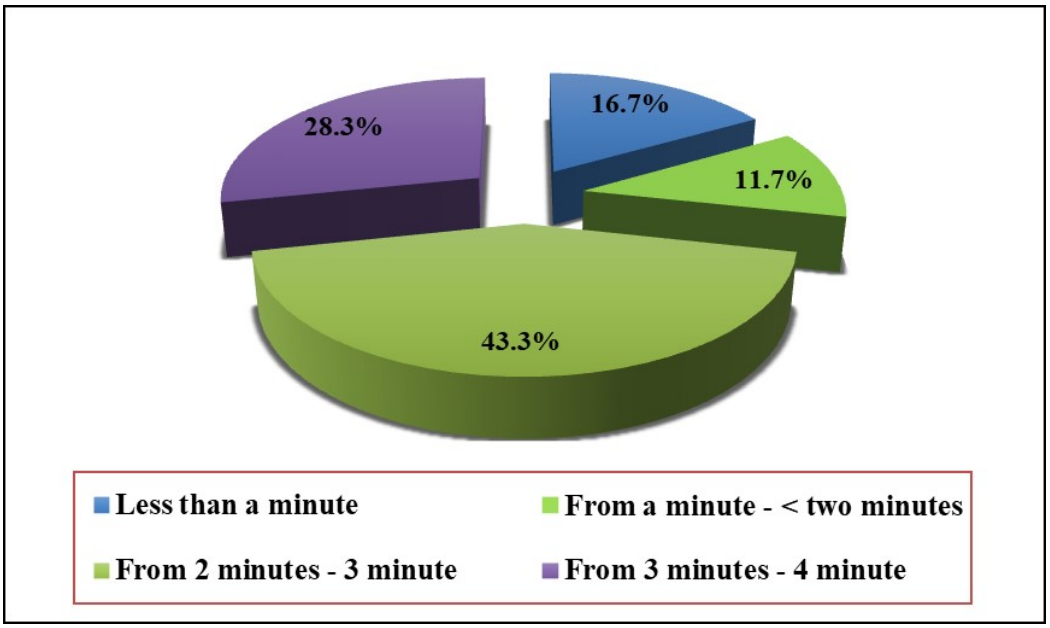

Figure (2) Duration of Epileptic Seizures as Mentioned by Mothers / Minutes

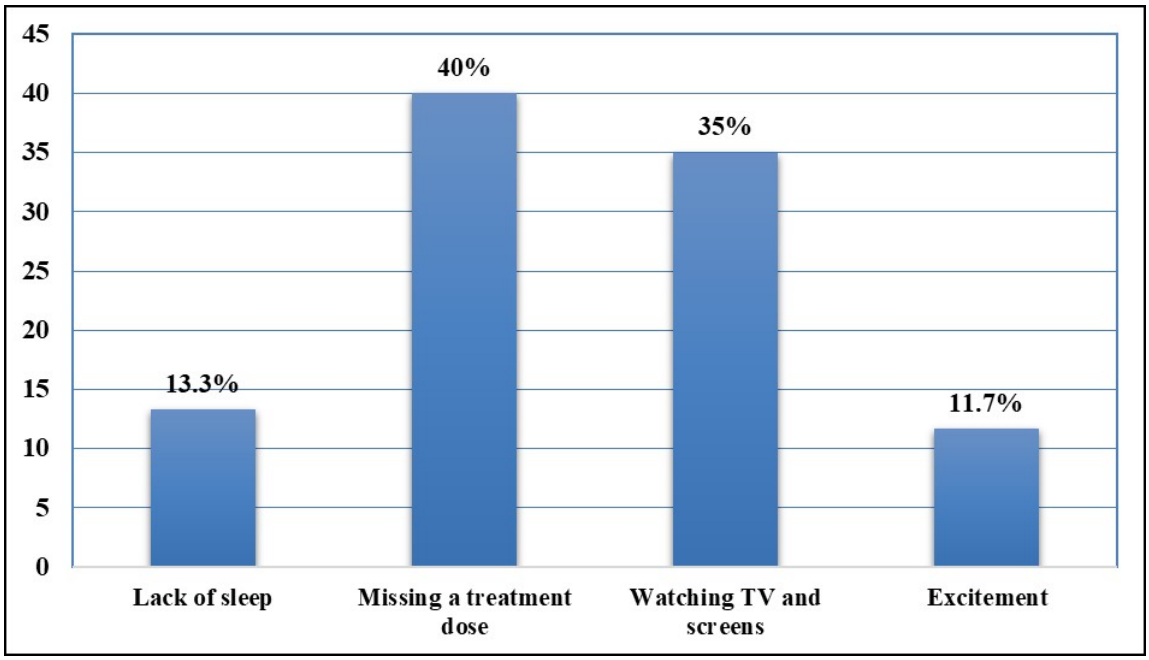

Figure (3) Mothers' Knowledge regarding Seizures Triggering Factors

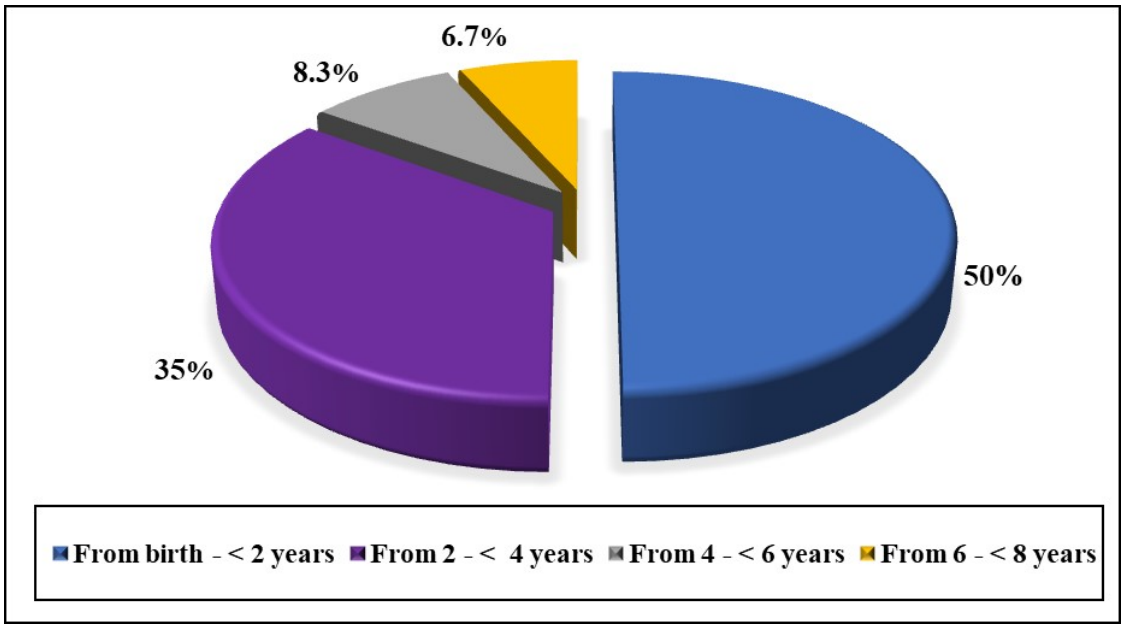

Figure (4) Mothers' Knowledge regarding Age of First Seizures Attack/Years

Table (3): Mothers Total Knowledge Regarding Epilepsy and Epileptic Seizures. (n=120)

Mothers' total level of knowledge.	No.	%
Low level	**10**	**8.3**
Moderate level	**66**	**55.0**
High level	**44**	**36.7**
Mean ± SD	**13.033 ± 2.79**	

Table (4): Mothers' Perception of Epilepsy Threats (n=120).

Mothers' perception of epilepsy threats.	Agree		Neutral		Disagree	
	No	%	No	%	No	%
Physical Threats						
Suffering from severe exhaustion.	102	85.0	5	4.1	13	10.9
Experiencing sleep problems.	109	90.8	3	2.6	8	6.6
Stress and anxiety affected physical health.	115	95.9	5	4.1	0	0.0
Suffering from injuries.	76	63.3	0	0.0	44	36.7
Difficulties meeting their own health needs.	115	95.9	0	0.0	5	4.1
Psychological Threats						
Feeling worried.	117	97.5	3	2.5	0	0.0
Feelings of sadness or depression.	120	100	0	0.0	0	0.0
Feeling lonely or isolated.	90	75.0	0	0.0	30	25.0
Feeling guilty.	77	64.2	0	0.0	43	35.8
Seeking psychological counseling or therapy.	15	12.5	0	0.0	105	87.5
Social Threats						
Facing stigma or negative reactions.	98	81.7	0	0.0	22	18.3
Epilepsy affected family relationships.	70	58.3	0	0.0	50	41.7
Epilepsy affected ability to achieve career goals.	89	74.2	0	0.0	31	25.8
Difficulties to access community services.	103	85.8	0	0.0	17	14.2

Table (5): Mothers' Total Perception Regarding Epilepsy Threats. (n=120)

Mothers' total level of perception	Negative		Positive	
	No	%	No	%
Physical threats	106	88.3	14	11.7
Psychological threats	84	70.0	36	30.0
Social threats	90	75.0	30	25.0
Mean ± SD	26.67±11.37			

Discussion

Epilepsy is a chronic neurological disorder, characterized by recurrent unprovoked seizures **(Beghi, 2020)**. It starts in childhood in 60% of cases and most of the clinically significant aspects of the disease occur during childhood **(Truls, et al., 2025)**.

Epilepsy can significantly disrupt children and family life owing to its chronic course, need for regular medications use, adverse effects, and its associated stigma with social constraints. **(Hansen, Szaflarski, Bebin, & Szaflarski, 2018)**.

Mothers' role is crucial in the management of children with epilepsy before, during, and after the seizures. Mothers of epileptic children may perceive many threats, and fears about their children. So, it is important for pediatric nurses to assess these threats in order to alleviate it **(Tavares et al, 2021)**.

In relation to the studied mothers' knowledge about causes epilepsy, half of the studied mothers mentioned genetic predisposition as a cause of epilepsy in children, while more than one-quarter of them mentioned infections of the nervous system. From researcher point of view, this results may be due to about two-thirds of the studied mothers were from rural areas where consanguineous marriage was common.

A study done by **Farghaly et al., (2021)** about "Prevalence of childhood and adolescence epilepsy in Upper Egypt" weren't in harmony with the current results as they found epilepsy was idiopathic in two-thirds of children in their study.

Regarding type of seizure, the current study ruled out that, most of the mothers mentioned that their children had generalized seizure. This was in agreement with **Farghaly et al., (2021)** who stated that, generalized seizures were more frequent in childhood. On contrary, **Pokharel,**

Poude,& Sami Lama, et al., (2020) who carried out a study to "assess burden and its predictors among caregivers of patients with epilepsy" weren't congruent with this finding and found that, more than half of the children had focal onset of seizures.

Concerning presence of aura before seizure attack, the present study showed that, more than half of the studied children didn't experience aura before seizure attack. This may be justified by the majority of the studied children had generalized seizures, and auras are more common in focal seizures. **Shahin,& Hussien (2021)** in their study about "knowledge, attitude, practice, and self-efficacy of caregivers of children with epilepsy" were in the same line, and ruled out that, most of their studied children didn't have aura before seizures.

It was clear that, half of the studied children their first seizure attack occurred before the first two years of life. This may be attributed to decreased seizure threshold of the immature brain among young children. This finding was consistent with **Farghaly et al., (2021)** who found that, most of seizures occurred during infancy and early childhood.

In relation to the studied mothers' knowledge about epilepsy and epileptic seizures, it was clear that, more than half of the studied mothers gave correct and complete answers related to meaning of epilepsy. This could be justified by; many of the studied children had epilepsy at a younger age which made mothers familiar with its meaning.

In congruence with the current results, **Nagan, Caffarelli & Donatelli, et al., (2017)** conducted a study to assess "parental knowledge and misconceptions about epilepsy" and reported that, about two-thirds of the parents of children with epilepsy had sufficient knowledge about definition and nature of epilepsy and its seizures.

Regarding causes and treatment of epilepsy, about one-quarter of the studied mothers gave correct and complete answers about causes and few percentages knew treatment of epilepsy. This may be attributed to low educational level of the studied mothers. A study performed by **Hamaad & Alseraty (2019)** about "Impacts of seizure care simulation intervention on mothers' of epileptic children efficiency, believes, anxiety and seizure care" was in the same line with the current results. They ruled out that, only few percentages of the studied mothers gave correct answers about causes of epilepsy in their study. Also, a study conducted by **Shahin et al., (2021)** were in harmony with the current findings as they found marked decrease in

mothers' knowledge of epilepsy especially regarding medical treatment.

Regarding mothers' total knowledge about epilepsy and epileptic seizures; it was observed that, about one-third of the studied mothers had high level of knowledge related to epilepsy and epileptic seizures. This could be attributed to mothers' low educational level, whereas more than one quarter of them had primary education. Also, about two-thirds of the studied mothers lived in rural areas that make access to health services is not easy. All these factors may precipitate to low knowledge level.

This finding was consistent with **Turan, Sefika,& Yangoz (2022**) in their study entitled ″effect of educational interventions on level of epilepsy knowledge in children with epilepsy and their parent″, and a study conducted by **Akbas,& Kartal(2022**) addressed ″knowledge, attitudes, and behaviors of parents regarding epilepsy″ who proved that, the parents in their studies had poor knowledge.

The current results were in harmony with **El-Amin, El-Sadig & Mohamed (2021**) who carried out a study about ″knowledge, attitudes, and practices of caregivers of children with epilepsy in Sudan″ and revealed that, caregivers had deficiency in knowledge level and required periodic educational programs about epilepsy.

Regarding mothers' perception of epilepsy threats, It was clear that, the majority of mothers feared from epilepsy stigma, complications, leaving children alone after mothers' death, and fear of the unknown. From researcher point of view, this may be due to chronic nature of epilepsy, and its associated stigma.

In the same line a study of **Verna & Minu (2021)** entitled "A study to assess the effectiveness of video assisted teaching program on knowledge regarding seizure among mothers of under five children" reported that, majority of the studied mothers had many epilepsy threats.

This result also, was in agreement with the study carried out by **Sheijani, Chehrzad, & Reza, et al., (2020)** whose study was "evaluate effect of creating opportunities for empowerment program on parents of children with epilepsy", and their findings indicated that, the majority of the studied mothers had many epilepsy threats.

Conclusion and Recommendations:

Conclusion

Based on the results of the present study, it can be concluded that, the majority of the studied mothers had negative perception towards physical, social and psychological threats facing their children with epilepsy.

Recommendations

The following recommendations are suggested:

1. Regular & continuous educational programs should be conducted to enhance mothers' knowledge and practice regarding care of their children with seizure.
2. Manual booklet and brochures about epilepsy and seizure management in a simple Arabic language must be available at Neurological Outpatient Clinic.
3. Psycho-social support and counseling services for mothers to address emotional stress, fears, and misconceptions related to epilepsy.
4. Community awareness programs should be tailored to suit cultural beliefs and values of the mothers, especially in communities where epilepsy is stigmatized.
5. Further researches should be conducted on a larger sample of children from different ages to achieve generalizability.

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