

Assess of Maternal Practices on Quality of Life for Their Epileptic Children

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ABSTRACT

Background: Pediatric epilepsy is one of the most common neurological disease worldwide. In Egypt the epilepsy prevalence in children was reported as (9/1000). Parents, especially mothers, have essential roles in assisting their epileptic children in manage their condition and deal with psychological issues. **Aim:** The present study aims to; assess of maternal practices on quality of life for their epileptic children. **Subjects and Methods: Design,** A descriptive cross sectional research design was used to conduct the study at El-Arab health unit in Port Said city. **Subjects:** A purposive sample of 80 mothers and their epileptic children was included in the study. Children's age ranged from 6-12 years. **Tools** Three tools used for collecting data consisted of; (1) A structured interviewing sheet include personal characteristics of epileptic children and their mothers, and medical history, (2) Mothers practices questionnaire sheet, (3) Quality of life (QOL) sheet. **Results:** the current study revealed that about three quarters of the studied mothers (73.8%) had inadequate practice score, about two thirds of the studied children (62.5%) had inadequate QOL scores. **Conclusion:** the most of the studied mothers had poor practices which negatively effects on their children quality of life. **Recommendations:** provide supportive educational interventions to support epileptic child and his/her family in all quality life domains and disease management process, increase awareness of epileptic children's mothers and care givers about care practices regarding epilepsy and existing resources in Egypt, and develop patient education sessions through mass media to reduce exposure to seizure triggers.

Key words: Epileptic children, Maternal practice, Quality of life.

INTRODUCTION

Pediatric epilepsy is one of the most common neurological disease worldwide. In Egypt the epilepsy prevalence in children was reported as (9/1000). Parents, especially mothers, have essential roles in assisting their epileptic children in manage their condition and deal with psychological issues (Ayar et al., 2021). A number of characteristics, such as the strength of the parent-child bond, parenting assurance, family ties, functioning and stress, and parental psychopathology, are worse for families with children who have epilepsy. In contrast to epilepsy-related issues, these factors frequently have a stronger detrimental impact on the child's quality of life and psychopathology (Puka et al., 2018).

As maintained by El Nabawy and Abdelgawad (2022), common misunderstandings in epilepsy include overprotection of children with epilepsy from their family, which prevents them from participating in sports or social activities or attending school, resulting in high levels of fear and lack of confidence. Furthermore, Hamaad and Alseraty (2019) asserted that, low levels of self-efficacy in managing seizure are associated with negative attitudes toward epilepsy as an illness, fears about seizures and greater severe episodes, less family support and management, and more depressive symptoms.

The major part of care duty for the epileptic children is often taken by their mothers. They are particularly crucial in assisting their epileptic children in adjusting to their condition. Practically speaking, they must seek treatment, ensure their kids follow treatment regimens, provide care before, during, and after the attack, help the kids operate both within and outside the home, and control how other people's attitudes affect the kids (Gamal et al., 2021). The support and understanding of mothers of children with epilepsy are invaluable in helping develop ordinary living skills (Akbas and Kartal, 2022).

Conde-Guzón et al. (2020) argues that epilepsy is a chronic neurological illness has effects on the quality of life of the epileptic children and their families. It considered critical to evaluate the well-being and quality of life of epileptic children. On another hand, parents are considered the core of the epilepsy management as supervisors of their children. Ayar et al. (2021) suggested that the management of the epilepsy for epileptic children, their parents should assess the QoL of the child life.

Moreover, epileptic children are at risk of cognitive, psychological, behavioral, and social negative outcomes that can ultimately lead to poor quality of life. Hence, it is important to identifying potential risk factors associated with poor outcomes when deciding the treatment for epileptic children (Phillips, Widjaja, and Smith, 2020) The need to raise awareness about epilepsy among caregivers, particularly mothers who assist their epileptic children physically and emotionally is critical (Saraswathi, 2019).

Epilepsy management necessitates a grasp of how epilepsy affects all parts of a child's life. Traditionally, epilepsy care has focused on seizure control, with little attention made to QOL (Pachange et al., 2021). In this context, pediatric nurses are a crucial part of this service and comprise care planning, encouraging proper involvement, risk assessment, liaison with schools and respite care, training in rescue medicine, and telephone counseling (Mammas and Spandidos, 2020). Pediatric nurses also, in an ideal position to establish a link between the physicians and the affected families and offering valuable advice and support (El-Marzaky et al., 2019).

Significance of the study

Parents especially mothers, play a significant role in management of epilepsy especially the management of epileptic fits in terms of home management. So that, raising awareness about epilepsy and its etiology will increase the knowledge and practices toward epileptic children. Therefore, this study aimed to assess the effect of epileptic children's mothers practice on the quality of life for their children.

AIM OF THE STUDY

The study aim was to study the effect of maternal practices on quality of life for their epileptic children.

SUBJECT AND METHOD

A. Technical design

This design includes a description of the research design, setting, subjects, and tools of data collection.

Research design

A descriptive cross sectional research design was utilized to meet the aim of this study.

Study setting

The current study was conducted at El-Arab health unit in port said.

Subjects

A purposive sample of 80 mothers and their epileptic children was included in the study. Children's age ranged from 6-12 years.

Tools for data collection:

Three data collection instruments were used:

1- A structured interviewing tool:

The scale was developed by the researcher in Arabic language. This tool includes three parts:

- **Part I: Personal characteristics of the mothers:** It includes data related to epileptic children's mothers as: age, marital status, residence, level of education, occupation, income, number of children, did you attend training about Epilepsy? did you have experience in care of child with epilepsy?
- **Part II: Personal characteristics of children:** It includes data related to epileptic children as: age, gender, number of siblings, birth order of the child, academic year, academic level, School problems due to illness and the special services received from the school.
- **Part III: Child's medical history:** It includes data related to epileptic children medical history as: onset of epilepsy, duration, frequency of seizures, specific events or circumstances, receiving treatment, the effect of taking medication, other chronic illnesses, hospitalization due to illness, and family history of the disease.

2- Mothers' practices questionnaire:

This tool was adapted by the researcher from **Hamaad & Alseraty (2019)** to assess mother's practices in caring for their epileptic children before, during and after the attack and mothers' practices in the management of side effects of antiepileptic drugs.

Scoring: every mother was answered on a 3-point Likert scale ranging from 1 to 3; a score of 1= never, 2= sometimes, 3=always.

3- Quality of life (QOL):

This tool adapted by the researcher from Sidhu et al. (2019) and will be used to evaluate the QOL of the children. The QOL is a parental, multifaceted epilepsy-specific scale for evaluating the QOL of children aged 4-18 years. It contains 60 items covering five domains of life function: Physical activities (1:12), well-being (13:31), social activities (32:40), child's behavior (41:58), general health (59,60).

Scoring: The scoring was based on a scale of 0 = worst outcome to 5 = best outcome. Several items have reverse anchors and therefore when it coded the items were need to reverse the scores of those items. The items were reversed are: 1-7, 9, 16-27, & 29-34 and 38.

The score for each domain was obtained by calculating the average of the items (except items 6 and 16) completed by the patient and then applying a linear transformation to obtain an average score ranging from 0 to 100.

B- Operational design

The study field of work was carried out through the following phases:

Preparation phase

It included reviewing of relevant literature, different studies and theoretical knowledge of various aspects of the problems using books, research articles, internet, periodicals and magazines.

Content validity

Tools were tested by seven experts from the faculty of nursing in field of pediatric nursing to test its content validity and modifications according to the experts' comments and recommendations were done.

Reliability

The reliability of the developed tools was estimated it show a positive significance with ($r=0.84\%$).

Pilot study

After the tools have been developed, they were tested through a pilot study, which was carried out on 10% of the total sample of the epileptic children's mothers. It was done on 8 mothers attended to El-Arab health unit in Port-Said city and these were excluded from the total sample.

Field work

- The director El-Arab health unit was provided official written approval for the study's conduct, and each participant (mother) provided verbal agreement after being made aware of the study's nature and objectives.
- Oral agreement for participation was obtained after illustrating the purpose of the study. Then, the researcher started the interviewing process, which lasted for about 15-30 minutes. The three tools were completed by the researcher during the interview with each mother.
- After completing the filling of the tool, the researcher reviewed every point within the tool ahead of the patient to make certain that no points are missed. The actual fieldwork took place over the course of ten months, within the period from the start of February, 2020 and completed by November, 2020.

C- Administrative design

Official letters were directed from the Dean of the faculty of Nursing to the meager of El-Arab health unit in port said requesting their cooperation and permission to conduct the study, after explaining the aim of the study.

Ethical considerations

The research ethics committee at the Faculty of Nursing, Port Said University, approved the study protocol. All research ethics principles were complied with according to Helsinki Declaration. Oral consent was obtained from mothers after explaining the aim of the study and its procedures to them to assured that the information obtained were confidential and used only for the purpose of the study and maintain their privacy. Mothers were informed that they were allowed to choose to participate or not in the study and they have the right to withdraw from the study at any time with no consequences. The study maneuvers could not have any actual or potential harms to participants.

D. Statistical design

After completion of data collection, data was organized, tabulated and computerized in Microsoft Excel 2019, and statically analyzed. The statistical package for social science (SPSS) version 28 was used to analyze the data on a PC. Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables, means and standard deviations for quantitative variables. Cronbach alpha coefficient was calculated to assess the reliability of the adequacy scale through its internal consistency. Qualitative categorical variables were compared using the chi-square and p-value test.

RESULTS

Table (1) shows socio-demographic characteristics of the studied epileptic children's mothers indicated that, the most of the studied epileptic children's mothers (82.5%) their age group was ranged from 26 to 36 with mean 30.6 ± 4.7 years. While less than three quarters of them (71.3%) of them were married and less than three quarters (73.8%) of them are living in urban areas. Moreover, more than a half of them (52.5%) had secondary school level of education. While more than three quarters (75.5%) were working and less than two thirds (65%) of them their income not enough. In the other way, more than three quarters of them (76.3%) were have less than three children, and all of them (100%) weren't have training about epilepsy and weren't have experience in caring child with epilepsy.

Table (2) reveals socio-demographic characteristics of the studied epileptic children, which more than a half of studied epileptic children (56.3%) were males and a half of them (50%) their age group was ranged from 8 to 10 years with mean 9.0 ± 1.8 years, less than two thirds (62.5%) of them were have one brother and less than three quarters (73.8%) of them ranked second among their brothers. In the other way, all of the studied children (100%) were entering custody, the most of them (82.5%) weren't have nursery problems due to their illness, and all of them (100%) weren't leave custody because of their illness, as well as the table indicates that, near to one quarter (26.3%) of the total children were in the 4th grade academic year and less than three quarters (73.8%) of them were indicate moderate level and all of them (100%) weren't have problems at school due to their illness.

Table (3) clears distribution of the children according to their medical history and clarified that, more than a half of the studied children (51.2%) were suffered from the epilepsy from 2 – 3 years, and less than three quarters (71.3%) of them have seizures less than 3 times a month and more than a half of them (52.5%) mentioned the duration of seizure one minute. As well as, all of the studied children (100%) reported that seizures begin due to specific events or circumstances and they experience the same sensations before starting each shift. More than a half (53.8%) of them start receiving treatment from more than 24 months, and all of them their condition improved by medication. While all of studied epileptic children (100%) didn't suffer from any other chronic illnesses and didn't taking medication for these diseases, and the most of them (82.5%) didn't hospitalize due to illness. Whereas, all of them (100%) their brothers haven't been exposed to this disease and didn't have another family history of the disease.

Figure (1) states distribution total maternal practice levels, which less than three quarters (73.8%) of mothers had inadequate practice. while, more than one quarter (26.3%) of them had adequate practice scores.

Figure (2) shows distribution of total Quality of Life levels indicated that, less than two thirds of the studied epileptic children have poor QoL level, while less than one tenth of them have good QoL level.

Table (4) presents the correlation between the epileptic children quality of life and the maternal practice score. There was statistically significant correlation between

maternal practices scores and children's QoL of epileptic children, were $X^2 = 5.304$, $P=0.002$ respectively.

Table (1): Socio-demographic characteristics of the studied epileptic children's mothers (n=80).

Personal characteristics		N	%
Age/ years	< 26	15	18.8
	26 < 37	51	82.5
	37 or More	14	17.5
	Mean \pm SD	30.6 \pm 4.7	
Marital Status	Married	57	71.3
	Divorced / Single	14	17.5
	Widow	9	11.3
Residence	Rural	21	26.3
	Urban	59	73.7
Educational Level	Secondary Education	42	52.5
	University Education	38	47.5
Occupation	Not Working	34	42.5
	Working	46	57.5
Income	Enough	28	35.0
	Not Enough	52	65.0
Number of Children	< 3	61	76.3
	3 or More	19	23.8
Academic Level	High	7	8.8
	Moderate	59	73.8
	Low	14	17.5
Did you attend epilepsy training?	No	80	100.0
	Yes	0	0.0
Do you have an experience in care of child with epilepsy?	No	80	100.0
	Yes	0	0.0

Table (2): Socio-demographic characteristics of the studied epileptic children (n=80).

Personal characteristics		N	%
Gender	Male	45	56.3
	Female	35	43.8
Age	< 8	20	25.0
	8 – 10	40	50.0
	More than 10	20	25.0
	Mean ± SD	9.0 ±1.8	
Number of child siblings	None	11	13.8
	One	50	62.5
	2 or More	19	23.8
Birth order	First Child	59	73.8
	Second Child	21	26.3
Did the child enter custody?	Yes	80	100.0
	No	0	0.0
Do you have nursery problems due to his illness?	Yes	14	17.5
	No	66	82.5
Did he have to leave custody because of his illness?	No	80	100.0
	Yes	0	0.0
Academic year	1st Grade	5	6.3
	2nd Grade	15	18.8
	Third Grade	15	18.8
	4th Grade	21	26.3
	5th Grade	14	17.5
	6th Grade	10	12.5
Academic Level	High	7	8.8
	Moderate	59	73.8
	Low	14	17.5
Do you have problems at school due to his illness?	No	80	100.0
	Yes	0	0.0
Do your child receive special health services from school?	No	80	100.0
	Yes	0	0.0

Table (3): Distribution of the children according to their medical history (n=80).

Items	N	%	
Duration of illness	< 2	10	12.5
	2 – 3	41	51.2
	More than 3	29	36.3
Number of shifts per month	< 3	57	71.3
	3 or More	23	28.7
Duration of a seizure (Minutes)	1 Minute	42	52.5
	1.5 Minutes	10	12.5
	2 Minutes	28	35.0
Do seizures begin due to specific events or circumstances?	Yes	80	100.0
	No	0	0.0
Does the child experience the same sensations before starting each shift?	Yes	80	100.0
	No	0	0.0
Since when did he start receiving treatment?	12 months or less	9	11.3
	12 < 24 months	28	35.0
	More than 24 months	43	53.8
What's the effect of taking medication on time?	Improve	80	100.0
	No changes	0	0.0
	Getting worse	0	0.0
Do your child suffer from any other chronic illnesses?	No	80	100.0
	Yes	0	0.0
Is your child constantly taking medication for these diseases?	No	80	100.0
	Yes	0	0.0
Has the child ever been hospitalized due to illness?	Yes	14	17.5
	No	66	82.5
Has one of the child's brothers been exposed to this disease?	No	80	100.0
	Yes	0	0.0
Is there another family history of the disease?	No	80	100.0
	Yes	0	0.0

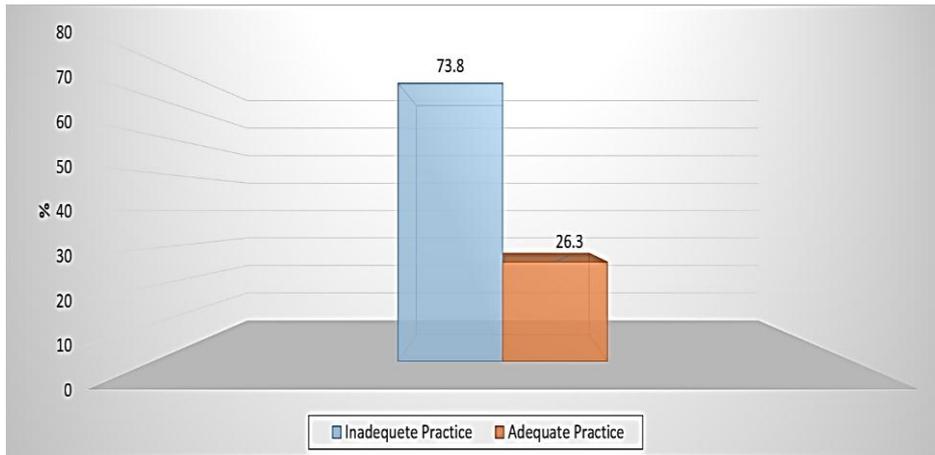


Figure (1). Distribution of Mothers' levels of practice

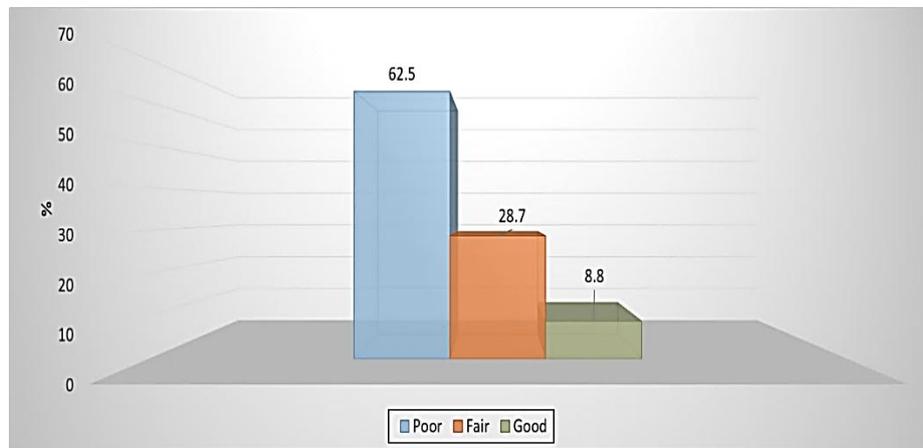


Figure (2). Distribution of Quality-of-Life levels

Table (4). Association between the maternal practices and Quality-of-Life level among their children N=80

Quality of Life levels	Maternal practice				Chi – Square	
	Inadequate n= 59		Adequate n=21		X ²	P
	n	%	n	%		
Poor	41	69.5	9	42.9	5.30 4	0.02 *
Fair	13	22.0	10	47.6		
Good	5	8.5	2	9.5		

X²: Chi-Square test

*significant at P≤0.05

DISCUSSION

Epilepsy is a chronic disease that is most prevalent among neurological system diseases and affects individuals of all age groups Leal et al., (2020). Parents, especially women, are the main caregivers who are responsible for managing the care because many children are too young to assume partial or whole responsibility for their care. Accurate knowledge about the epilepsy impacts on children and their families, especially mothers, and the development of skills are essential elements for assisting them in becoming stronger partners in children-centered care. The challenges that epilepsy presents to a child and family include challenging treatment regimens and psychosocial comorbidities that affect day-to-day functioning, inflict a heavy financial and social load on families, and are associated with low quality of life Nashaat et al., (2022). So that the present study aimed to study effect of maternal practices on quality of life for their epileptic children.

As regard to socio-demographic characteristics of the studied epileptic children's mothers, the current results showed that the most of the studied mothers their age group was ranged from 26 to 36 years, and about three quarters of them were married and living in urban areas. While, more of than three quarters of them were working and nearly two thirds of them reported that their income not enough. This finding might be due to the study conducted in port said governorate which considered as urban area, Likewise, most of the women in the city of Port Said are workers, whether in the public or private sectors, to face financial pressures. Moreover, these mothers' characteristics may reflect positively on their knowledge and practice about care for their children. These findings in line with the study conducted by Nashaat et al. (2022) who reported that the highest age in the studied mothers were less than forty years and insufficient income. Also, Shahin and Hussien (2021) found that most of the studied mothers were with insufficient income and low level of education.

Regarding socio-demographic characteristics of the studied epileptic children, the present results revealed that more than a half of the studied children were males and their age group were from 8 to 10 years old, and nearly three quarters of them were first in birth order. Also, all of them were entered to custody, and the most of them didn't have nursery problems or academic problems. This finding in agreement with Nashaat et al., (2022) who observed epilepsy occur more in boys than girls and their age group under 10 years old. Also, the results by Saleh et al. (2021) found that two thirds of the children

were males. While the current result was incongruent with Badawy et al. (2018) who reported that the prevalence of epilepsy among studied children were higher in females than males. Also, EL Nabawy & Abdelgawad, (2022); Shahin & Hussien, (2021); (AbdAllah, Sharafeddin, and Ghonemi, (2019) were reported that the highest percent of the studied children were girls, there order in birth was the second.

The current study showed that all of the studied children didn't have academic problems due to their illness and didn't need to receive special health services from their school. This finding may due to awareness of Port Said city society by epilepsy illness which reflect on acceptable educational level of epileptic children. This result in agreement with Horaib, et al. (2021) who found that three quarters of the studied epileptic children went to school regularly, the majority of them had no previous academic failure. While disagreed with Pachange et al. (2021); Subki et al., (2018) who found that the academic level of the children was affected negatively by their illness.

Concerning the medical history of the studied epileptic children, the present findings revealed that more than a half of the studied children were suffered from the epilepsy from 2 to 3 years, and more than nearly three quarters of them have seizures less than 3 times a month. As well as, all of the studied children reported that seizures begin due to specific events or circumstances and they experience the same sensations before starting each shift. The current results supported by Shahin and Hussien (2021) who illustrated that two thirds of studied epileptic children were mentioned that the seizures preceded by precipitating factors. AbdAllah et al., (2019) also reported that a half of the studied children had one or two attacks per month. While the present findings not match with the results conducted by El Nabawy and Abdelgawad (2022) who discovered that more than a half of the studied students were with the duration of epilepsy was less than 4 years; the seizures mostly occurred 3 to 5 times per month, lasted for 3 to 5 minutes. Also AbdAllah et al., (2019) found that the mean disease duration was 6.62 years.

Regard to the maternal practices in dealing with seizures, the current results illustrated that there was a marked inadequate maternal practices of the studied epileptic children's mothers. This result reflects the significant needs to provide educational intervention to epileptic children mothers and caregivers to improve their practice. This finding was in line with Elshiekh, El-Dakhakhny, and Moustafa (2016) who found that the highest percent of the studied mothers were had poor practices of epileptic care for

their children. And consist with El-Amin, et al. (2021) who reported that the studied mothers were have significance poor practice and low attitudes level regarding the disease care. The same study concluded that, epileptic children caregivers need continuing education about the illness care process. Similarly, Wasilewski, et al. (2020) who showed that the effectiveness of caregivers' training intervention in improving their practices in caring for their children.

Concerning the quality-of-life domains score, the present results clarify that, more than two thirds of the studied epileptic children have poor quality of life level, and there was a statically significance relation between the maternal practices and quality of life of their children. This reflects the strong effect of the mothers practice on their children mental, physical and social ways of coping with illness. This findings in agreement with Hamaad and Elseraty (2019) who reported that the majority of the studied mothers their children cannot live with others can't do physical activities, has low intellectual abilities and believes that epilepsy is an obstacle of their children to live a good life, and this believes were changed post implantation of intervention. And consist with EL Nabawy and Abdelgawad (2022) who stated that most of the epileptic children parents reported that epilepsy affected the child's daily activities and considered epilepsy a barrier to the child exercising. Similarly, Badawy, et al. (2018) stated that the highest percent of the studied children had poor level of total quality of life.

CONCLUSION

Based on the findings of the present study, it can be concluded that:

The most of the studied mothers had inadequate practices which negatively effects on their children quality of life.

RECOMMENDATIONS

Based on the results of the present study, the following recommendations were suggested:

Provide supportive educational interventions to support epileptic child and his/her family in all quality life domains and disease management process, increase awareness of epileptic children's mothers and care givers about care practices regarding epilepsy and

existing resources in Egypt, and develop patient education sessions through mass media to reduce exposure to seizure triggers.

LIMITATION OF THE STUDY

The study was affected by the Covid-19 period, as this led to a decrease in the number of visits to treatment centers, which resulted in reducing the number of the sample to 80 children instead of 100.

References

- AbdAllah, A. M., Sharafeddin, M. A., & Ghonemi, N. A. (2019). Burden of epilepsy on adolescents and their families in Zagazig University hospital. "A cross sectional study". *Kasr Al Ainy Medical Journal*, 25(3), 104.
- Akbas, Y., & Kartal, S. (2022). An evaluation of the knowledge, attitudes, and behaviors of parents regarding epilepsy. *Epilepsy & Behavior*, 129, 108621.
- Ayar, D., Ünalp, A., Bektaş, M., Yılmaz, Ü., Karaoğlu, P., & Yalçıntuğ, F. M. (2021). Psychometric properties of a Turkish version of the quality of life in childhood epilepsy questionnaire. *Journal of Pediatric Nursing*, 62, 91-97.
- Badawy, G., Abusaad, F., & Hashem, S. (2018). Effect of an educational program for adolescents with epilepsy on their quality of life and self-management skills. *Mansoura Nursing Journal*, 5(1), 41-53.
- Conde-Guzón, P. A., Soria-Martín, C., Cancho-Candela, R., Quirós-Expósito, P., Conde-Bartolomé, P., & Bulteau, C. (2020). Parental report of quality of life in children with epilepsy: A Spanish/French comparison. *Epilepsy & Behavior*, 105, 106968.
- EL Nabawy Ahmed, G., & Abdelgawad Said, D. (2022). Quality of life of children with epilepsy: Parent prospective. *International Egyptian Journal of Nursing Sciences and Research*, 3(1), 318-336.
- El-Amin, R. O., El-Sadig, S. M., & Mohamed, I. N. (2021). Knowledge, attitudes, and practices of caregivers of children with epilepsy in Sudan. *Epilepsy & Behavior*, 123, 108283.
- El-Marzky, N. M., El-Sharkawy, S. S., & AdlyRM, H. (2019). Stressors and Coping Patterns of Mothers Having Children with Epilepsy. *Egyptian Journal of Health Care*, 10(1) 208-222.
- Elshiekh, D. E., El-Dakhkhny, A. M., & Moustafa, K. Z. E. A. (2016). Assessment of Maternal Care Provided To Their Epileptic Children At Zagazig University Hospitals. *Zagazig Nursing Journal*, 12(1), 177-194.

- Gamal Mohamed El Maghraby, M., Mohamed Mourad, G., Abdel-Hamid Zaki, R. (2021). Psychosocial Stressors among Epileptic Children. *Egyptian Journal of Health Care*, 12(4), 983-996.
- Hamaad, W. A., & Alseraty, W. H. H. (2019). Impacts of seizure care simulation intervention on mothers' of epileptic children efficiency, believes, anxiety and seizure care. *American Journal of Nursing Research*, 7(3), 293-300.
- Horaib, W., Alshamsi, R., Zabeeri, N., Al-Baradie, R. S., & Wahab, M. M. A. (2021). Quality of Life and the Perceived Impact of Epilepsy in Children and Adolescents in the Eastern Province of the Kingdom of Saudi Arabia. *Cureus*, 13(12), e20305.
- Leal, S. T. F., Santos, M. V., Thomé, U., Machado, H. R., Escorsi-Rosset, S., Dos Santos, A. C., ... & Hamad, A. P. A. (2020). Impact of epilepsy surgery on quality of life and burden of caregivers in children and adolescents. *Epilepsy & Behavior*, 106, 106961.
- Mammas, I. N., & Spandidos, D. A. (2020). [Opinion] The challenge of paediatric epilepsy nursing: An interview with Mrs. Jenny O'Brien, paediatric epilepsy nursing specialist at the Wirral University Teaching Hospital, UK. *Experimental and Therapeutic Medicine*, 20(6), 1-1.
- Nashaat, N. A. M., El-Ghany, A., Mustafa, G., Mahmoud, S. F., El Sebaie, S. R., AbdelrhmanAlhanafy, S., & Mohamed, E. S. H. (2022). Effect of Nursing Intervention program on Mothers' Knowledge, Practice and Attitudes toward Management of their Children with Epilepsy and Intellectual disability. *Tanta Scientific Nursing Journal*, 25(2), 198-216.
- Pachange, P. N., Dixit, J. V., Arjun, M. C., & Goel, A. D. (2021). Quality of life among middle and secondary school children with epilepsy. *Journal of Neurosciences in Rural Practice*, 12(03), 490-494.
- Phillips, N. L., Widjaja, E., & Smith, M. L. (2020). Family resources moderate the relationship between seizure control and health-related quality of life in children with drug-resistant epilepsy. *Epilepsia*, 61(8), 1638-1648.

- Puka, K., Ferro, M. A., Anderson, K. K., & Speechley, K. N. (2018). Health-related quality of life in mothers of children with epilepsy: 10 years after diagnosis. *Quality of Life Research, 27*(4), 969-977.
- Saleh, S. H. A., Mohammed, M. E. H., & Abounaji, O. A. (2021). Health related quality of life in Egyptian children and adolescents with epilepsy. *The Egyptian Journal of Hospital Medicine, 85*(2), 3772-3777.
- Saraswathi, P. (2019). A study to Assess the Effectiveness of Structured Teaching Programme on Knowledge regarding Home Care Management of Epilepsy among the Mothers of Children with Epilepsy in Neurology Outpatient Department at Institute of Child Health and Hospital For Children, Egmore, Chennai-08 (unpublished doctoral dissertation, College of Nursing, Madras Medical College, Chennai).
- Shahin, M. A. H., & Hussien, R. M. (2021). Knowledge, attitude, practice, and self-efficacy of caregivers of children with epilepsy: impact of a structured educational intervention program. *Epilepsy & Seizure, 13*(1), 1-16.
- Sidhu, M., Streiner, D., & Ronen, G. (2019). P. 049 Quality of life in children with absence epilepsy. *Canadian Journal of Neurological Sciences, 46*(s1), S27-S27.
- Subki, A. H., Mukhtar, A. M., Al-Harbi, R. S., Alotaibi, A. K., Mosaad, F. G., Alsallum, M. S., & Jan, M. M. (2018). The impact of pediatric epilepsy on children and families: a multicenter cross-sectional study. *Clinical Practice and Epidemiology in Mental Health: CP & EMH, 14*, 323.
- Wasilewski, A., Serventi, J., Ibegbu, C., Wychowski, T., Burke, J., & Mohile, N. (2020). Epilepsy education in gliomas: engaging patients and caregivers to improve care. *Supportive Care in Cancer, 28*(3), 1405-1409.
- World Health Organization (2022). Epilepsy: a public health imperative (fact sheets). Geneva.

تقييم ممارسات الأمهات على جودة الحياة لأطفالهم المصابين بالصرع

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الخلاصة

الصرع من الأمراض العصبية المزمنة الأكثر شيوعا ويصيب جميع الفئات العمرية على الصعيد العالمي. ويتعرض الأطفال المصابون بالصرع للمفاهيم الخاطئة والمواقف السلبية المحيطة بهم وبمرضهم والتي تؤثر على جودة الحياة. لهذا تهدف الدراسة الحالية إلى تقييم ممارسات الأمهات على جودة حياة أطفالهم المصابين بالصرع. تم استخدام تصميم بحثي وصفي لإجراء الدراسة في مركز صحة حي العرب بمدينة بورسعيد. وتكونت عينة الدراسة من ٨٠ طفلا مصابا بالصرع وأمهاتهم من المترددين على المركز لتلقى الخدمات الصحية. وقد أظهرت نتائج الدراسة أن حوالي ثلاثة ارباع الأمهات الخاضعات للدراسة (٧٣.٨%) لديهن مستوى ممارسة الرعاية غير مرضي لديهن كما أظهرت أيضا ان ثلثي الأطفال تقريبا لديهم مستوى منخفض لجودة الحياة بمتوسط (١٠٢.٦ ± ٤٦.٣). الخلاصة: وقد تخلصت الدراسة بوجود علاقة طردية لممارسة الرعاية لدى أمهات الأطفال المصابين بالصرع على جودة حياة أطفالهن. وأوصت الدراسة بتقديم تدخلات تعليمية داعمة لدعم الأطفال المصابين بالصرع وعائلاتهم في جميع مجالات جودة الحياة وعملية إدارة المرض، وزيادة وعي أمهات الأطفال المصابين بالصرع ومقدمي الرعاية حول ممارسات الرعاية فيما يتعلق بالصرع والموارد الموجودة في مصر، وتطوير جلسات تثقيف المريض من خلال وسائل الإعلام لتقليل التعرض لمسببات النوبات.

الكلمات المرشدة : ممارسات الامهات، جودة الحياة، الأطفال المصابين بالصرع.