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| RESEARCH ARTICLE

Awareness of Parents about the Side Effects of Phenobarbital and the Management of Epileptic Children, Taif City, Saudi Arabia: A Cross-Sectional Study

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| ABSTRACT

Many children were suffering from neurological problems. One of these neurological problems is epilepsy, which causes seizures. Children with seizures were managed with different drugs. A drug like phenobarbital is used mainly for epilepsy**.** This study aimed to assess the awareness of parents about the side effects of phenobarbital and the management of epileptic children, describe the clinical presentation of children with epilepsy and assess the knowledge of parents about the management of epileptic children. A descriptive cross-sectional study was conducted among parents of children diagnosed with epilepsy. Online questionnaire survey distributed to parents of children with epilepsy. A total of 200 parents were included. The age group is 31-40 years old, 72(36%). Parents' knowledge about epilepsy was 98(49%). There were 104(52%) parents who reported seizures caused by low doses of Phenobarbital led to a loss of consciousness. Non-compliance with the required dose occurred majorly due to forgetting the dose 102(51%). The number of children with epilepsy was significantly associated with the awareness level of parents (P=0.0001). In addition, the awareness of parents was significant at the time of epilepsy diagnosis of children (P=0.01). An inadequate awareness among parents regarding the side effects of Phenobarbital, and there were gaps in their knowledge regarding other aspects of the condition and its management.

| KEYWORDS

Children; Epilepsy; Phenobarbital; Parents; Knowledge and awareness

| ARTICLE INFORMATION

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1. Introduction

Epilepsy is one of the most frequent brain disorders that people suffer from. According to the definition, "two unprovoked seizures occurring more than 24 hours apart; a single unprovoked seizure with a significant recurrence risk (i.e., > 60% over the following 10 years); or a diagnosis of an epilepsy syndrome,". [Fisher, 2014].

Many children were suffering from neurological problems. One of these neurological problems is epilepsy, which causes seizures in the affected children, and it is considered one of the common problems in children. During the first 16 years of life, about 4-10% of children had one seizure at minimum [McAbee, 2000]. Children with seizures were managed with different drugs. One of these drugs, phenobarbital, is an anti-seizure drug and is used mainly for neonatal seizures [Ahmad, 2017].

Seizures are considered a big problem facing neonates and children. Generally, the number of incidences of neonatal seizures is difficult to know, but the study reported by Holden et al. among pregnant women showed that 5 per 1,000 live births have neonatal seizures, and the diagnosis was done clinically [Holden et al., 1982]. In Kentucky, Lanska et al. did a study about the incidence of seizures, and they found the incidence of seizures was 3.5 per 1000 live births [Lanska et al., 1995]. A previous study from the National Hospital Discharge Survey for 11 years found that the incidence of seizures in very low birth weight was between 2.4 and 9.4 per 1000 births [Lanska et al., 1996]. Also, in Texas, Ronen et al. found that seizure incidence was 2.6 per 1000 live births, and it increased in low-weight birth babies until it reached 13.5 per 1000 [Ronen et al., 1999].

Phenobarbital is also called phenobarbitone, an old anticonvulsant used to treat neonatal seizures. Doctors have used this anticonvulsant since the last century in 1904. This drug exerts its effect by stimulating the receptors of gamma-aminobutyric acid in the central nervous system leading to a postsynaptic increase in chloride ions and, as a result, reducing neuronal excitability [El-Dib et al., 2017].

A previous study showed that phenobarbital was effective in managing seizures in up to 85% of neonates [Young, 2010]. And sometimes, we need to add another anticonvulsant to treat the seizure. By measuring the concentration of the drug, they found that 15 to 40 ug/ml is the therapeutic concentration dose.

Several side effects may be manifested via the administration of phenobarbital. In a previous study, when the concentration of phenobarbital exceeded 40 ug/ml, some side effects, such as sedation and respiratory depression, appeared among participants [Ouvrier et al., 1982].

To our knowledge, there is no information about parents' awareness of the side effects of phenobarbital in Saudi Arabia. Also, the awareness of parents with epileptic children should be known to find the level of knowledge among them. Therefore, we conducted this study to assess parents' awareness of the side effects of Phenobarbital and the management of epileptic children in Taif, Saudi Arabia.

2. Materials and Methods

2.1. Study design, population, and duration

In this observational study, a descriptive cross-sectional study was conducted among parents of children diagnosed with seizures or epilepsy using phenobarbital. We conducted this study via an online questionnaire survey distributed to parents of children with epilepsy between December 2021 to February 2022 in two centers (hospitals) in Taif city, the Kingdom of Saudi Arabia.

2.2. Inclusion criteria and exclusion criteria

All parents above 18 years old in Taif city, Kingdom of Saudi Arabia. Having at least one child who was diagnosed with epilepsy or seizure and using phenobarbital. The child's age is less than 15 years, and admitted to the hospital for the management of epilepsy. In this study, all parents with children who were diagnosed with epilepsy or seizure and who refused to participate in the study were excluded from participation.

2.3. Sample size and selection

The total sample size in this study was 200 parents of children with epilepsy to measure their awareness of epilepsy. In the Kingdom of Saudi Arabia, all children diagnosed with seizures or epilepsy and using phenobarbital who were admitted to Taif hospitals in Taif city, Kingdom of Saudi Arabia, for a specific period were included. The number of children diagnosed with epilepsy or seizures was identified from Taif hospitals from the electronic record system. The parents of the children were contacted via phone call to take consent for participation after taking their contact phone numbers from the hospital system. An online google form was created from our questionnaire to measure awareness of epilepsy among parents of children who were diagnosed with seizure or epilepsy. After that, an online google form link containing the questionnaire was distributed to all parents who fulfilled the inclusion criteria via social media contact numbers.

2.4. Data Collection

An online google form link containing the questionnaire was sent to all parents of children diagnosed with seizure or epilepsy and fulfilling inclusion criteria. The questionnaire was created in English language, and after that, it was translated into the Arabic language because the Arabic language is the official language of the Kingdom of Saudi Arabia and most of the participants know only the Arabic language. An online google form will be sent to all parents with children having seizures or epilepsy containing a brief description of the study and questions which measures sociodemographic information and awareness of parents about epilepsy. Informed consent was taken from each participant.

2.5. Data management and analysis plan

Data about children and parents' contacts were collected from Taif electronic hospital records. Then, parents of children were contacted via phone call to take consent for participation in the study. The information collected via the online survey was entered into excel, then cleaned and prepared for analysis.

Data analysis for this study was done by using SPSS version 25. Descriptive statistics as numbers (percentage) or mean (standard deviation) was applied to all data. All data was prepared and cleaned before entering excel and SPSS. After that, data were coded, cleaned, and analyzed according to our plan.

2.6. Ethical Consideration

Ethical approval number 628 for this study was obtained from the research and studies department, Directorate of Health Affairs, Al Taif, Kingdom of Saudi Arabia.

3. Results

3.1. Characteristics of parents

A total of **200** parents were included in this study; the most common age group was that included participants aged 31-40 years old 72 (36%), followed by the age group 20-30 years old 58 (29%). Males were more dominant compared to females, and they represented more than one-half of the participants, 112 (56%), while the females, 88 (44%). The largest proportion of parents, 86(43%), had secondary degrees or less, followed by those parents having bachelor's degrees 57 (28.5%). And more than one-half were working, 112 (56%), while 88 (44%) were not working. The largest proportion of participants, 72 (36%), reported an income of 5-10K Saudi Riyal, followed by participants who reported an income of less than 5K Riyal 71(35.5%). The characteristics of parents are shown in table 1.

Table 4. 1 Characteristic of parents.

Characteristics	**Count (%) (n=200)**
Age	
20-30	58 (29)
31-40	72 (36)
41-50	38 (19)
51-60	32 (16)
Gender	
Male	112 (56)
Female	88 (44)
Education	
2ry or less	86 (43)
Diploma	41 (20.5)
Bachelor	57 (28.5)
Postgraduate	16 (8)
Occupation	
Working	112 (56)
Not working	88 (44)
Income	
< 5 K	71 (35.5)
5-10 K	72 (36)
10-20 K	46 (23)
> 20 K	11 (5.5)

3.2. Information about the children of the parents

Information about the children of the parents in this study is shown in table 2. 134 (67%) parents reported having only one child, whereas 47 (23.5%) reported having two children, and the least proportion, 19(9.5%) reported having three or more children. 134 (67%) parents reported having one child with epilepsy, and 66 (33%) reported having two or more children with epilepsy.

Table 4.2 Information about the children of the parents

Children of the parents	Count (%) (n=200)
Children with epilepsy	
One	134 (67)
Two or more	66 (33)

3.3. The clinical information of children

Regarding the clinical information of children, more than one-half of parents, 110(55%), reported that their children were diagnosed with epilepsy at less than one-year-old, whereas 62(31%) reported the diagnosis at the age of 1-5 years and the least proportion 28(14%) reported the diagnosis was made after five years of age.

The major associated comorbidities were paralysis 54(27%), followed by defective cognitive function 48(24%), whereas the largest proportion, 66(33%), reported no associated co-morbidities.

Table 4. 3 The clinical information of children.

Clinical information	Description (n=200)
When was your child diagnosed with epilepsy?	
< 1 year	110 (55)
1-5 years	62 (31)
> 5 years	28 (14)
Associated comorbidities	
Paralysis	54 (27)
Defective cognitive function	48 (24)
Autism	21 (10.5)
ADHD	11 (5.5)
Nothing	66 (33)

3.4. The state of parents 'knowledge about epilepsy

The state of parents' knowledge of epilepsy is shown in table 4. Around one-half of parents, 98 (49%), stated that they had enough information about epilepsy after their child's injury. The main source of information was medical papers 71(35.5%)

Table 4. 4 The state of parents 'knowledge about epilepsy.

Questions and answers	Description (n=200)
Do you have enough information about epilepsy after your child's injury?	98 (49)
What do you think is the main source of information about epilepsy? (You can choose more than one answer)	
Social media (internet)	60 (30)
TV or Radio	24 (12)
Medical papers	71 (35.5)
Friends or relatives	57 (28.5)

3.5. Knowledge of parents regarding seizure medication

The knowledge of parents about seizure medication is shown in table 5. 104(52%) parents reported seizures caused by low doses of Phenobarbital, which led to a loss of consciousness, whereas 63 (31.5%) reported involuntary movement and 40 (20%) reported a sense of fear. Non-compliance with the required dose occurred majorly due to forgetting 102(51%), followed by being busy 40 (20%), then no hope of cure 31(15.5%), and other medications 27 (13.5%).

Table 4. 5 Knowledge of parents regarding seizure medication.

Questions and answers	Description (n=200)
Seizures caused by low doses of phenobarbital lead to (You can choose more than one answer)	
Involuntary movements	63 (31.5)
Loss of consciousness	104 (52)
Sense of fear	40 (20)
The possibility of seizures or convulsions due to non-compliance with the required doses occurs because of the following:	
No hope of a cure	31 (15.5)
Forgetting	102 (51)
Being busy	40 (20)
Other medications	27 (13.5)

3.6. Knowledge about the epileptic seizure

The knowledge of parents about epileptic seizures is shown in table 6. More than one-half of parents, 117 (58.5%), reported that they thought that epilepsy was due to genetics, whereas 48(24%) thought it was an infectious disease, and 35 (17.5%) thought it was a psychiatric problem.

Very few percent reported that they knew about performing first aid for seizures 78 (39%). The most commonly reported first step for a child with epileptic seizure was going to the hospital or asking a doctor 84 (42%), followed by putting a piece of cloth in the mouth 59(29.5%), whereas the least reported step was tying the child 14 (7%).

Table 4. 6 Knowledge about epileptic seizures.

Questions and answers	Description (n=200)
Did you or still see that epilepsy:	
Psychiatric problems	35 (17.5)
Genetics	117 (58.5)
Infectious diseases	48 (24)
Do you have the knowledge of how to perform first aid for seizures?	78 (39)
The first steps used when a child has an epileptic seizure:	
Go to the hospital or ask a doctor	84 (42)
Put a piece of cloth in the mouth	59 (29.5)
Tie the child	14 (7)
Give double dose	43 (21.5)

3.7. The attitude of parents

The attitude of parents is shown in table 7; 66 (33%) reported that removing and untying the ties or anything around the neck was one way to protect a child from any damage that may happen to him during the epileptic seizure. More than one-half of parents, 109 (54.5%), reported that they were worried about medication side effects, and 126 (63%) worried about future risks and potential consequences of seizures.

There were 103 (51.5%) parents who reported that the seizure was treatable and curable.

Table 4. 7 The attitude of parents.

Questions and answers	Description (n=200)
One of the ways to protect a child from any damage that may happen to him when he has an epileptic seizure: (You can choose more than one answer)	
Remove and untie the ties or anything around the neck	66 (33)

Keep it away from any solid object that may cause him harm	95 (47.5)
Lift the person off the ground and place him on one side	105 (52.5)
Do you worry about medication side effects?	109 (54.5)
Do you worry about future risks and potential consequences of seizures?	126 (63)
Are seizures treatable and curable?	103 (51.5)

3.8. The knowledge of parents about Phenobarbital

The knowledge of parents about Phenobarbital is shown in table 8. The largest proportion of participants, 80(40%), reported their knowledge was good about Phenobarbital. The main source of information about the medication was physicians 82(41%), followed by pharmacists 47(23.5%); more than one-half of parents, 113 (56.5%), reported that the best source of information on phenobarbital was physicians, followed by pharmacist 42(21%).

Table 4. 8 The knowledge of parents about Phenobarbital.

Questions and answers	Description (n=200)
In general, how would you describe your knowledge of Phenobarbital?	
Excellent	56 (28)
Good	80 (40)
I don't know	64 (32)
What is the source of your information about the drug phenobarbital?	
Physician	82 (41)
Pharmacist	47 (23.5)
Medical pamphlet	23 (11.5)
Internet	48 (24)
What do you think is the best source for information on Phenobarbital?	
Physician	113 (56.5)
Pharmacist	42 (21)
Medical pamphlet	21 (10.5)
Internet	24 (12)

3.9. The knowledge of parents about Phenobarbital dosage

The questions about the knowledge of Phenobarbital dosage and the answers of parents are shown in table 9. More than one-half of parents, 116 (58%), stated that the dose of Phenobarbital was given at the same time daily. 75 (37.5%) reported that sometimes they stopped giving the children the medication when the child was doing well, whereas 68 (34%) reported that they rarely did that, and the least proportion, 57 (28.5%), reported that they always stopped the medication when the child was doing well. The largest proportion of parents, which exceeded one-half of the participants, 106 (53%), reported that they always measured Phenobarbital doses with a spoon, dropper, or syringe of the medication, whereas the least percentage, 20 (10%) reported that they rarely did that. In case of being too late for the dose, there were equal proportions of parents who reported that they sometimes and always gave the dose to the child when they remembered it 80 (40%). 108 (54%) participants stated that they gave the next dose when they missed a dose as it was upcoming. Only 111 (55.5%) reported that they always told the responsible doctor that their children were treated with Phenobarbital before the child underwent any medical test or operation, whereas 29 (14.5%) reported that they rarely did that.

Table 4. 9 The knowledge of parents about Phenobarbital dosage.

Questions and answers	Description (n=200)
Is the phenobarbital dose given at the same time every day?	
Rare	13 (6.5)
Sometimes	71 (35.5)
Always	116 (58)

When you see that your child is doing well, do you stop giving him Phenobarbital?	
Rare	68 (34)
Sometimes	75 (37.5)
Always	57 (28.5)
Do you measure phenobarbital doses with their spoon, dropper, or syringe?	
Rare	20 (10)
Sometimes	74 (37)
Always	106 (53)
If it's too late for a dose, do you give it to your child when she remembers it?	
Rare	40 (20)
Sometimes	80 (40)
Always	80 (40)
How do you act when you miss a dose?	
Give two doses	43 (21.5)
Give the next dose because it is really upcoming	108 (54)
Wait for the next dose, even if it is still too early	49 (24.5)
Before your child undergoes any medical tests or operations, will you tell the responsible doctor that your child is being treated with Phenobarbital?	
Rare	29 (14.5)
Sometimes	60 (30)
Always	111 (55.5)

3.10. The action of parents regarding Phenobarbital dose

The action of parents toward the Phenobarbital dose is shown in table 10. There were 63 (31.5%) participants who didn't know when they should stop using Phenobarbital and get medical help, whereas 86 (43%) reported that they would stop using the medication and get medical help when there was sudden shortness of breath, 52 (26%) reported when the child felt dizzy, and 27 (13.5%) reported that when the child felt anxious and uncomfortable. A few percent 62 (31%) reported that their children had taken an overdose of Phenobarbital, and the reasons for that were giving a replacement dose 49 (24.5%), insufficient information 98 (49%), and child was taking medication by himself 53 (26.5%).

Table 4. 10 The action of parents about Phenobarbital dose.

Questions and answers	**Description (n=200)**
When should I stop using Phenobarbital and get medical help? When my child has one of the following symptoms: (You can choose more than one answer)	
When your child feels dizzy	52 (26)
When your child feels anxious and uncomfortable	27 (13.5)
When there is sudden shortness of breath	86 (43)
I don't know	63 (31.5)
Has your child ever taken an overdose of Phenobarbital?	62 (31)
The reason for the child to get an overdose of Phenobarbital!	
Giving a replacement dose	49 (24.5)
Insufficient information	98 (49)
The child takes medicine by himself	53 (26.5)

4.11. Side effects of Phenobarbital reported by parents

The side effects reported by parents are shown in table 11; the side effects of Phenobarbital as reported by the parents, included bad mood 19 (9.5%), dizziness 31 (15.5%), anxiety 13 (6.5%), and sleepy 88 (44%), whereas 49 (24.5%) reported no side effects.

Table 4. 11 Side effects of Phenobarbital reported by parents.

Questions and answers	Description (n=200)
Did your child have any of the following side effects while using Phenobarbital?	
Bad mood	19 (9.5)
Dizziness	31 (15.5)
Anxiety	13 (6.5)
Sleepy	88 (44)
Nothing	49 (24.5)

The overall knowledge of parents was high among 85(42.5%) parents, whereas 115 (57.5%) had low knowledge (figure1).

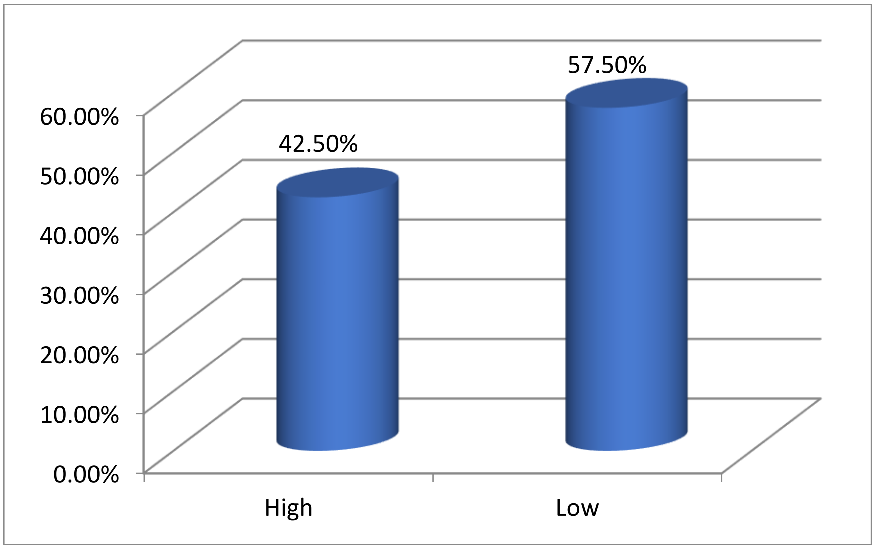

Figure 1. The level of knowledge of parents.

4.12. The correlations between the demographics of parents and their awareness levels

The correlations between the demographics of parents and their awareness levels are shown in Table 12. The factors that had a significant correlation with the awareness levels were age groups (P=0.029), gender (P=0.003), and education level (P=0.028), whereas occupation and income (P=0.2, P=0.7, respectively) had no significant association with the awareness levels.

Table 4. 12 The correlations between the demographics of parents and their awareness levels.

Variables	Awareness level High (n=85)	Awareness level Low (n=115)	P value
Age			
20-30	21 (24.7)	37 (32.2)	0.029
31-40	39 (45.9)	33 (28.7)	
41-50	17 (20)	21 (18.3)	
51-60	8 (9.4)	24 (20.9)	
Gender			
Male	58 (68.2)	54 (47)	0.003
Female	27 (31.8)	61 (53)	
Education			
2ry or less	40 (47.1)	46 (40)	0.028
Diploma	11 (12.9)	30 (26.1)	

Bachelor	30 (35.3)	27 (23.5)	
Postgraduate	4 (4.7)	12 (10.4)	
Occupation			
Working	52 (61.2)	60 (52.2)	0.205
Not working	33 (38.8)	55 (47.8)	
Income			
< 5 K	32 (37.6)	39 (33.9)	0.764
5-10 K	27 (31.8)	45 (39.1)	
10-20 K	21 (24.7)	25 (21.7)	
> 20 K	5 (5.9)	6 (5.2)	

3.13. The correlations between the number of children with epilepsy and the awareness levels of parents

Regarding the number of children with epilepsy of the parents in this study, the number of children with epilepsy was significantly associated with the awareness level of parents (P=0.0001), table 13.

Table 4. 13 The correlations between the number of children with epilepsy and the awareness levels of parents.

Variables	Awareness level		
	High (n=85)	Low (n=115)	P-value
Children with epilepsy			
One	73 (85.9)	61 (53)	0.0001
Two or more	12 (14.1)	54 (47)	

3.14. The correlations between characteristics of children with epilepsy and the awareness levels of parents

The awareness of parents was found to be significantly associated with the time of epilepsy diagnosis of children (P=0.01) and associated co-morbidities of children (P=0.0001), whereas having enough information about epilepsy after the child's injury had no association with the awareness level of parents (P=0.6), table 14.

Table 4. 14: The correlations between characteristics of children with epilepsy and the awareness levels of parents.

Variables	Awareness level		
	High (n=85)	Low (n=115)	P-value
When was your child diagnosed with epilepsy?			
< 1 year	57 (67.1)	53 (46.1)	0.011
1-5 years	18 (21.2)	44 (38.3)	
> 5 years	10 (11.8)	18 (15.7)	
Associated comorbidities			
Paralysis	26 (30.6)	28 (24.3)	0.0001
Defective cognitive function	12 (14.1)	36 (31.3)	
Autism	3 (3.5)	18 (15.7)	
ADHD	6 (7.1)	5 (4.3)	
Nothing	38 (44.7)	28 (24.3)	
Do you have enough information about epilepsy after your child's injury?	40 (47.1)	58 (50.4)	0.637

4. Discussion

Epilepsy is one of the most common neurologic diseases in the pediatric population [Jan, 2004]. Phenobarbital is the first-line antiepileptic drug (AED); it exerts its effect by stimulating the receptors of gamma-aminobutyric acid in the central nervous system, leading to a postsynaptic increase in chloride ions and, as a result, reducing neuronal excitability [El-Dib et al., 2017]. The concerns about the neurobehavioral adverse effects of Phenobarbital led to a decline in its usage for all seizure disorders [Pal, 2006]. However, Phenobarbital showed no difference from other AEDs regarding excess behavioral adverse effects; there were no significant differences between Phenobarbital and other AED in behavioral or cognitive adverse effects shown in a systematic analysis[Pal, 2006].

A systematic review from China involved 20 studies that revealed no evidence of the correlation between Phenobarbital and a higher risk of adverse events. However, it was correlated with a higher adverse drug reaction rate related to withdrawal than other AED [Zhang et al., 2011]. However, according to some studies, 30-50% of children receiving phenobarbital experience behavioral side effects [de Silva, 1996], [16]. Parents' awareness of children with epilepsy was associated with lowered parental anxiety [Zainy, 2013]. Also, knowledge about epilepsy leads to less social isolation, depressive symptoms, and stigmatization [Hirfanoglu et al., 2009]. Parents' awareness of the care of children potentially affects the health status of children by reducing morbidity and mortality rates [Saramma et al., 2010]. Parents' knowledge about the disease and medications could affect compliance with anti-epileptic drugs [Shaju, 2014]. Parents' awareness of epilepsy management and the adverse effects of medication and dosage was an important factor in their knowledge about epilepsy. Therefore, we conducted this study to investigate parents' awareness of the side effects of phenobarbital in the management of childhood epilepsy.

However, the knowledge of parents about childhood epilepsy, in general, was inadequate and needed improvement, as reported in a previous Saudi study. Among 117 parents from Saudi Arabia, it was found that parents' knowledge about epileptic children needs improvement, which led to poor parental practice [Shore, 1998]. Moreover, the poor practice of parents toward epilepsy involved poor practice toward medication and management.

Previous studies showed that parents had inadequate knowledge about the disease and pharmacotherapy of their epileptic children [McNelis, 2007]. Lack of awareness was the major barrier to the successful management of epilepsy [Shaju, 2014].

In the present study, parents' knowledge about the side effects of Phenobarbital was generally inadequate, as only (42.5%) had high awareness, whereas (57.5%) had low awareness. Parents' awareness was significantly affected by various factors, such as age, gender, education level, number of children with epilepsy, the time of diagnosis of epilepsy, and associated co-morbidities. High awareness of parents was associated with those with an age range of 31-40 years, whereas those with a younger age of 20-30 years significantly reported low awareness. Surprisingly, male parents showed significantly high awareness, whereas a significant proportion of female parents showed low awareness, although it was well known that mothers were the people responsible for the care of children. In a previous study on mothers, it was demonstrated that one-half of mothers had total management scores in managing their epileptic children, and these were either good or satisfactory [Badawy, 2015].

In addition, in this study, the education level was a significant determinant of the level of awareness of parents; however, unexpected findings were obtained. Those with secondary or less education represented the largest proportion of those who showed a high level of awareness, followed by parents having a bachelor's degree. Having one child was associated with having a high level of awareness, and this may return to the focus of parents on how to increase their knowledge rather than focusing on more than one child for caring. Parents who reported no co-morbidities of children were represented by the highest proportion of those who reported a high level of awareness.

A previous study conducted on parents of children with epilepsy who were on either polytherapy or monotherapy showed that (41.6%) of parents with children on polytherapy were more aware of the side effects of drugs compared to those with children on monotherapy (10.35%) [Varghese, 2019]. There was a gap in the knowledge of parents regarding the side effects of the drug used for the management of epilepsy.

The awareness in our study covered a wide range of aspects, as we assessed parents' awareness regarding their source of information, their knowledge about the nature of epilepsy, the management of epileptic seizures, and their compliance toward management using phenobarbital and phenobarbital side effects.

A few proportions of our participants reported that they had enough information about epilepsy after their children's injury, and the major source of knowledge was medical papers. This indicates that parents were searching for more knowledge, and they should be encouraged as they relied mainly on medical papers to obtain the correct information.

More than one-half of our participants reported that genetics is the major cause of epilepsy, whereas the least proportion reported it is a psychiatric problem. In a previous Saudi study, it was found that less than one-half of parents (48%) believed that epilepsy is a mental disorder [Zainy, 2013].

A previous study from Serbia conducted on parents of children with epilepsy showed that almost all parents knew that epilepsy isn't an infectious disease (99.5%) [Gazibara, 2014], which was better compared to our findings, where (24%) reported that epilepsy is an infectious disease. A study from Jordan revealed that the large majority of parents (90.3%) knew that epilepsy isn't related to psychiatric disease, and almost one-half of parents reported that the internet was the main source of their knowledge [Masri, 2017]. A study from India showed that parents had average knowledge about seizures [Jyoti, 2013]. Another study showed that (52.5%) of parents attributed seizures to mental illness, and (37.7%) attributed seizures to supernatural powers and evil spirits [Rani, 2019].

A very low proportion of parents in this study reported that they knew how to perform first aid for seizures, and the first step chosen by the largest proportion of parents was going to the hospital or asking a doctor. The major strategy reported to protect a child from any damage that may happen to him during an epileptic seizure is lifting the child off the ground and placing him on one side.

Varghese and Sharma demonstrated that only (10.16%) of parents knew some first aid for acute seizures, and more than one-half of parents (55.93%) brought their children to the hospital for emergency care [Varghese, 2019].

This reflected the gap in the knowledge of parents about first aid for the management of seizures, which was similar to our study.

In our study, more than one-half of parents stated that they were worried about future risks of seizure consequences and medication side effects. Almost one-half of parents stated that seizures were treatable.

Regarding the treatment of Phenobarbital, a few proportions (28%) believed that their knowledge of Phenobarbital was excellent, whereas (40%) reported that it was good. Although the main source of information about Phenobarbital was physicians, more than one-half of parents also reported that physicians were the best source of information about the drug. These findings reflected parents' trust in the physicians, so physicians should increase the awareness of parents about the dose, side effects, and benefits of the drugs.

There were poor knowledge and practice of parents regarding the dosage of Phenobarbital; only (58%) reported giving the dose of the drug at the same time daily, and there were (28.5%) and (37.5%) reported that they always and sometimes, respectively, stopped giving the medication when the child was doing well. Moreover, only (55.5%) reported that they informed the responsible personnel about the child's medication before performing the medical test operations.

More than one-half of parents reported that low doses of Phenobarbital resulted in loss of consciousness, and (43%) stated that they should stop Phenobarbital and get medical help when there was sudden shortness of breath. Taking overdose was reported by only a few proportions of parents. The major reason for the overdose was insufficient information; this ensured the lack of parents' knowledge regarding Phenobarbital, although various side effects of Phenobarbital were reported by parents, including sleep, anxiety, dizziness, and bad mood.

The knowledge about the nature, duration, and side effects of epilepsy treatment and adherence to drug regimens among parents of epileptic children was considerably low, as reported in an Indian study [Shaju, 2014]. Compliance with treatment was the key factor for a successful outcome of treatment.

The advancement and effectiveness of the treatment of disease were found to be positively associated with the compliance of the patient with the treatment. Non-compliance with treatment could be noted in many forms, such as using medications that weren't prescribed, missing appointments, failure to use, and irregular use of prescribed medications [Çakır, 2010].

Non-compliance with epileptic treatment is a problem that may lead to re-hospitalization of patients, continuing seizures, morbidity, and mortality [Tan, 2015]. Indeed, compliance with AED is a crucial step for the prevention of the risk of recurrent seizures [Shaju, 2014].

In our study, the non-compliance of parents to the required dose of Phenobarbital led to seizures commonly caused due to forgetting. This means that they may require a reminder that reminds them of the time of each dose to avoid forgetting the dose. Also, (20%) reported that they might be busy, and this required the availability of another person to give the dose to the children.

Good drug adherence could be achieved by imparting health education to patients and their families [Sureka, 2007]. The communication between parents of children with epilepsy and health professionals regarding the nature of the disease, its characteristics, treatments used, benefits and adverse effects of the used medications, dosage adjustments, and potential drug interactions is crucial [Walker, 2012].

A key factor for managing epileptic children is adequate education [Jan, 2005]. It is recommended that education and support for parents and children with epilepsy should be the principal goal of healthcare services [Gazibara, 2014]. Special awareness programs for parents of epileptic children are recommended to reduce the knowledge gaps of parents regarding the treatment of epilepsy and ensure optimal compliance with the treatment [Shaju, 2014].

5. Conclusion

To sum up, this study aimed to assess the awareness of parents about the side effects of phenobarbital and the management of epileptic children. The results of the study showed that the majority of the parents had good knowledge about epilepsy, but a significant number of parents reported seizures caused by low doses of Phenobarbital, leading to loss of consciousness. Non-compliance with the required dose occurred mainly due to forgetting the dose. The number of children with epilepsy was significantly associated with the awareness level of parents, and the awareness of parents was significant at the time of epilepsy diagnosis of children. This study highlights the need for improved education and support for parents of children with epilepsy to ensure proper management and treatment of the condition.

6. Limitation and Future suggestion

1. It was conducted using an online survey which may not have reached all parents of children with epilepsy, thus leading to a potential selection bias.
2. The sample size of 200 parents is relatively small and may not be generalizable to a larger population.
3. The study was conducted in one location and may not be applicable to other regions or cultures.

Future research suggestions include:

1. Conducting a larger study that includes a diverse population of parents from different regions and cultures.
2. Using a mixed-methods approach, including both qualitative and quantitative methods, to gain a more complete understanding of the experiences and perspectives of parents of children with epilepsy.
3. Assessing the effectiveness of educational interventions in improving the knowledge and management of epilepsy in children by parents.
4. Examining the long-term effects of treatment on children with epilepsy and their families to evaluate the overall outcome.

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