
Discussion

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Epilepsy is a common neurological disorder in children and can have a major impact on children's development. Epilepsy starts in childhood in 60% of cases and most of the clinically significant aspects of the disease occur during childhood (**Jan, 2005 and Zainy et al., 2013**).

Parents of children with epilepsy are at high risk of having anxiety, which correlates significantly with their children's quality of life (**Li et al., 2008**). Parents' knowledge of epilepsy is associated with lowered parental anxiety. Also, family activities are less restricted if they are more knowledgeable, and they reported less worries regarding their children. Knowledge of epilepsy also leads to less stigmatization, social isolation, and depressive symptoms (**Hirfanoglu et al., 2009**). Overall, parents' attitudes toward children with epilepsy are significantly influenced by the depth of their knowledge of the disease (**Salazar, 2009**).

Misconceptions and misinformation should be identified and corrected for optimal care and management. Many families in Egypt are not properly informed about epilepsy, and some are misinformed from unreliable sources leading to poor management of their epileptic children (**Monir et al., 2013**). Therefore, the aim of this study was to assess mothers' level of knowledge and management of their children with epilepsy.

The finding of the current study revealed that more than half of the studied children were in the age 6 to less than 12 years, while slightly less than one third of them were in age less than 6 years of age (**Table V and Figure II**). This finding is supported by **Mansy et al., (2012)** who reported that epilepsy was more prevalent in children younger than 12 years of age. The finding of the current study may be explained in the fact that it is the age characterized by increase in activities which may increase the risk of exposure to infections and accidents affecting integrity of nervous system that may lead to epilepsy.

The present study showed that most of the epileptic children are living in rural areas (**Table IV**). This finding may be attributed to the limited access to health services and poor health literacy of families resident in rural areas beside the higher rates of

consanguineous marriage and home delivery that may increase the risk of developing epilepsy in rural areas than urban. This finding is congruent with *El-Senousey et al., (2009) & Mahmoud, (2009)*, who reported higher incidence of children with epilepsy among rural residents.

One of the major developmental task for all children is to achieve success in school. The finding of the present study revealed that academic achievement of more than two third of the epileptic children in their past year was successful, while the minority of them have a previous academic failure (**Table VI**). This result is congruent with *Lagunju et al., (2009)* who reported that more than half of the children did not experience any form of limitation in school work. On the contrary, many studies as *Mansy et al., (2012); Munyoki et al., (2010) & Babikir, (2009)* reported that, epilepsy greatly affect the academic achievement of epileptic children. The finding of the current study may be attributed to the fact that epilepsy doesn't affect intellectual functions and intelligence if the affected children adhere to their medication regimen and follow-up where the majority of the children in the present study had a regular follow-up (**Table VI**).

Regarding school absenteeism, the present study revealed that two fifth of the epileptic children were absent for either one or two days /week (**Table VI**). This result could be due to the frequent hospitalization where the majority of the children were hospitalized in the year before the study. School absenteeism in the present study could be due to the frequent follow up visits (**Table VIII**). In addition, the great risk of the epileptic children having seizures might get mothers often prefer to keep their children at home. Other mothers might keep their children out of school because of frequent symptoms of the disease, such as migraines. Also, peer rejection of epileptic children may lead to school rejection from the epileptic children, which may creates a situation where children are frequently absent from school. These findings were in agreement with *Ali et al., (2014)* who reported that half of the children in their study were absent from school for > 5 days per month.

Regarding the age at first epileptic seizure, the finding of the present study revealed that more than two third of the epileptic children had their first epileptic seizure below the age of 5 years (**Table VII**). This finding is congruent with the study of *Kandil et al., (2007)* who reported that the highest frequency rate of epilepsy onset

occurs during early and middle childhood period. *Farahat et al., (2010)* reported that about two third of children, had their first seizure in the first 5 years of age then the percentage decreases gradually with increasing age. Also, *Velez & Eslava-Cobos, (2006)* found in their study that one third of epileptic children had their onset in infancy period. The finding of the present study may be attributed to the fact that the developing brain of infants and children is much more sensitive to react with convulsive seizures when it is injured by trauma, infection, or by simple febrile illness when compared to adults (*Soderfeldt et al., 2006*).

Concerning the first time of medical consultation, the vast majority of mothers consult physician immediately after the occurrence of first seizures (**Table VII**). This finding may be due to mothers' experience of their children's first seizure frightening them and may make them believe that their children's condition is life-threatening. This finding is supported by *Jantzen et al., (2009)*.

Most seizures last from fractions of a second to less than a five minutes and end on their own without intervention (*Friedman et al., 2014*). In the present study, mothers stated that their children's seizures continued for less than 5 minutes in near the half of the children (**Table VII**). This result may be attributed to the adherence of more than two thirds of the studied children to their medications time (**Table XVII**). On the other hand, nearly half of mothers didn't count the seizure duration at all. This finding may be related to mothers' fear and anxiety that may accompany the unpredictable nature of the seizures which may cause mothers miss to count the duration of seizure or may be due to the unpredictable nature of the seizures where no witness at the time when seizures occurred. In addition, missing the count of seizure duration may be also due to nocturnal seizures that may be missed by mothers. This finding is consistent with *Akman et al., (2009) & Monir et al., (2013)* who found less accurateness of seizures reporting by parents in their studies.

Regarding the frequency of seizures, the study finding showed that the minority of children had fits once or more / day and the higher percentage fits were once or more / month (**Table VII**). This low percentage of daily fits might be due to regular follow-up by the vast majority of the children (**Table VIII**). Mothers' effort to adhere to give drugs on time to their children could be another cause for this finding (**Table XVII**). Nearly similar findings were obtained from the study of *Vestergaard, (2011) &*

Farahat et al., (2010) who reported a low frequency of daily fits on their study sample. On the contrary **Begley et al., (2007)** found in their study that the majority of children had daily fit.

It has long been assumed that genetic factors play a role in epilepsy, familial occurrence of epilepsy ranged from 5-35 % in several studies, which considered risk factors of epilepsy (**Daoud et al., 2007**). Although the exact modes of inheritance remain unclear in most cases (**Cowan, 2008**), the result of the present study showed that the minority of children had a positive family history of epilepsy (**Table VII**). This finding is supported by other studies from Kenya and Egypt where they reported similar results (**Edwards et al., 2008 & Kheder et al., 2013**).

Regarding definition of epilepsy, the present study showed that slightly less than half of mothers did not know the definition (**Table X**). This finding may be attributed to concentration of the medical staff on medical terminology with poor clarification about the meaning of the disorder to the mothers. This finding was in same line with **Adikaibe et al., (2013)** who showed that the majority of mothers failed to correctly define epilepsy.

In relation to mothers' knowledge about causes of epilepsy, the study findings revealed that more than half of mothers didn't know the causes of the disorder (**Table X**). This finding is supported by **Frank-Briggs and Alikor, (2011)** who found that the majority of the parents didn't know the cause of the epilepsy. This finding could be attributed to the fact that epilepsy cause is unknown in the majority of children (**Farahat et al., 2010**).

Febrile convulsion is considered a fundamental marker of an individuals' seizure threshold and risk for development of further epilepsy (**Kandil, 2007 & Hovinga and Phelps, 2000**). The highest percent of mothers in the current study mentioned that febrile convulsion is the cause of epilepsy (**Table X**). This finding may be interpreted by mothers' reporting that their children complained from fever frequently followed by seizures and it was ascertained by the physician. This finding is consistent with **Mahmoud, (2009)** who found a history of febrile convulsions in about one third of their epileptic children.

In relation to mothers' knowledge about manifestations of epilepsy, it is revealed that the majority of mothers mentioned drooling or excessive saliva, rapid eye movement, body stiffness and jerking motion of the arms and legs, loss of consciousness, cyanosis and loss of bladder or bowel control as the manifestations of epilepsy (**Table XI**). These findings may be explained in the light of the fact that these manifestations are visible ones that mothers can observe while the invisible manifestations as sensory and autonomic manifestations are unobserved to mothers (**Table VII**). This result is supported by the fact that mothers' knowledge about manifestations of epilepsy in general didn't exceed their knowledge about manifestations of their epileptic children (**Table VII**); so, they restrict epilepsy to their children's unique manifestations. This finding is congruent with many studies as *Bassili et al., (2002)*; *Baker et al., (2005)*; *Berg et al., (2005)*; *Lagunju, (2009)*; *Frank-Briggs and Alikor, (2011)* & *Elmasry et al., (2013)* who found that the majority of the caregivers were not aware of the clinical features of epilepsy except the muscular jerks and they believed that only those with obvious motor activity really have a seizure, other subtle types are not known by mothers.

As regard to mothers' knowledge about triggering factors of epilepsy, it is revealed from the current study findings that two thirds of mothers stated that fever is a trigger factor of epilepsy, as well as psychological and physical stress which reported by more than half of the mothers (**Table XII**). This finding may be attributed to mothers' return the seizures to the direct visible circumstances that precede it and do not give attention to the indirect circumstances that may precipitate the occurrence of the seizures over time as watching T.V and computer games. This finding may be supported by mothers' information about the trigger factors that precipitate the attack of their epileptic children (**Table IX**). This finding is congruent with the studies of *Sidig et al., (2009)* and *Mahmoud, (2009)* who found the same trigger factors were identified by their participants and *Balamurugan et al., (2013)* who found that the majority of patients in their study had at least one or two precipitating factor.

The present study indicated that two fifth of the mothers didn't know the symptoms of aura (**Table XIII**). This may be attributed to inability of mothers to observe it on their children because it is sensory in nature and / or to the young age of the epileptic children in the study as they can't describe the symptoms of aura to their

mothers. This result is supported by *Haut, (2005)* who reported that aura is more frequent in epilepsy especially prior to generalized tonic-clonic seizures and often accompanied by retrograde amnesia for the event, so the frequency of aura is actually under-reported in these epileptic children.

Regarding mothers' knowledge about treatment of epilepsy, it is indicated that more than two thirds of the studied mothers mentioned anti-epileptic drugs as a treatment of epilepsy (**Table XIV**). This finding is consistent with a population-based survey done by *Kobau et al., (2008)* who found the same result. The finding of the current study may be interpreted as AEDs is the most treatment modality used in the general hospitals and the drugs prescribed by physicians to control seizures.

The minority of the mothers knew the other treatment alternatives as surgery, diet therapy and VNS (**Table XIV**). This finding may be related to most of this treatment modalities are recent and not used in a wide range. Also *Choi et al., (2009)*; *Cohen-Gadol et al., (2006)* & *Haneef et al., (2010-b)* mentioned that all types of epilepsy are not amenable to these treatment modalities.

Concerning mothers' knowledge related to side-effects of anti-epileptic drugs, the present study revealed that two third of the studied mothers didn't know that there are side-effects of anti-epileptic drugs (**Table XIV**). This finding may be attributed to mothers' lack of knowledge about the side-effects and may be due to the limited time they spent with the health staff as doctors and nurses on every follow-up visit so the doctors and / or nurses don't have time to explain the side-effects. Mothers' lack of knowledge about the drug side-effects is going in line with *Vingerhoets, (2006)* & *Yong et al., (2006)*, who reported that there are many children and their families have knowledge deficit about AEDs and its side-effects.

Regarding dangers of epileptic seizures, near two third of mothers mentioned tongue or lips biting as the danger of the epileptic seizures (**Table XV**). This finding is supported by *Fong and Hung, (2005)* who found that there is a risk of tongue biting in more than half of children during the epileptic seizures. This finding may be due to bad positioning of children during seizures as only less than one quarter of the mothers in the current study reported that they place their children on their side to prevent tongue biting and aspiration of secretion during the seizures.

Injuries as dangers of epileptic seizures were stated by almost half of the mothers (**Table XV**). This finding may be attributed to the unpredictable nature of epileptic seizures and sudden falling which may increase the exposure of the epileptic children to injuries. These findings are congruent with *Vibhore et al., (2014)* as they stated that the risk for injury is higher in children with epilepsy, particularly those with generalized tonic-clonic seizures.

As regard to mothers' knowledge about epileptic seizures that require their children's referral; the finding of the current study revealed that the most known cause for the children referral to the nearest emergency services by the mothers was when the children have a recurrent episode, without regaining awareness in between seizures (**Table XV**). This finding may reflect mothers' attention to the jerking motion only and not consider the duration of seizures and the circumstances in which it occurred. This finding was supported by *Connolly et al., (2014)* who reported that the cases of the epileptic children referred to the emergency setting are mainly recurrent episode without regaining awareness in between seizures.

Mothers' management of their epileptic children plays the most significant role in helping them to adapt with their condition. The mothers functions includes: providing the safety precautions for their children in and outside home, ensuring their children's compliance with treatment, providing care before, during and after the attack (*Rodenburg et al., 2011*).

Regarding safety precautions before the epileptic seizures, it is clear from the present study that, about two thirds of mothers notifying the school about their children's illness (**Table XVI**). This finding can be a result of mothers being particularly concerned about the unpredictable risk that seizures place on their children and they want to ensure their safety until they return home. Moreover, mothers may felt that informing the staff member at the school about their children epilepsy ensured the safety of the children during all aspects of the day in the event of a seizure. This finding is in agreement with *Buelow et al., (2006)* who reported in their study that most parents communicate and interact with school personnel about their children condition.

The minority of mothers mentioned the other safety precautions as, prevent child from closing bath room from inside, prevent child from using computer and

watching T.V for long periods (**Table XVI**). These findings may return to mothers' unawareness about the importance of safety precautions, as well as mothers' safety restrictions and limitations may be difficult for the children to apply, where the children need to enjoy the same activities as their peers, and maintain a sense of normalcy. The finding of the present study is supported by *Glaser et al., (2012)* who reported that safety precaution is a priority in epilepsy management. However, this finding was in contrary with *Zainy et al., (2013)* who found that many parents are restricted in their application of the safety precautions.

Regarding safety measures that should be taken by mothers if the children are experiencing an aura before the onset of a seizure, it was found that most mothers didn't lie down the children on their side on the ground to prevent their injuries (**Table XVI**), it may be returned to lack of their knowledge or the unpredictable nature of their children epileptic seizures. This finding may be attributed to the fact that more than half of mothers of the present study have knowledge about aura symptoms and can expect it's occurrence, however This finding is supported by *Dimberg and Burns, (2005)* who reported that there is a gap in mothers' knowledge in relation to prediction of aura and taking safety measures accordingly.

It is obvious from the current study that none of the children carried the medical alarm (**Table XVI**). This finding could be due to mothers' unawareness about benefits of wearing medical alarm and absence of Egyptian and medical staff culture about its importance for epilepsy. Similar observation was mentioned by *Taylor et al., (2011-b)* who found that there is only one child wearing the medical alarm.

In relation to mothers' management of drugs, it was found that more than two thirds of the studied mothers gave the AEDs on times(**Table XVII**). This finding could be returned to the instructions from health team member about the importance of adhering to AEDs regimen that create awareness in the mothers or may be due to the fact that the children get their antiepileptic drugs free and regularly from the hospitals. This finding is supported by *Faught et al., (2009)* who found a high level of drug compliance.

Regarding to mothers' management for prevention of dosing forgetfulness, most of them were following methods to remember the medication time as link drug with a

daily routine, e.g., with meal or setting the alarm clock (**Table XVII**). This finding may be explained by the stress of health team on the importance of adhering to medication regimen and may be due to mothers' observations that seizures frequency decreased when their children were take regular drugs. This finding is supported by *Davidson et al., (2007)* who stated that mothers should setting strategies to anti-epileptic medications regimen to prevent missing doses.

Regarding mothers' management when epileptic seizures decreased in frequency, the result of the present study clarified that less than half of the mothers decreased and stopped the dose without medical consultation when frequency of epileptic seizures decreased (**Table XVII**). This finding may be attributed to mothers' unawareness about the importance of consulting physician before changing the medication regimen. This finding is consistent with many studies as *Hammad, (1992); Bassili et al., (2002) and El-Sharkawy et al., (2006)* where they found lack of adherence with medications either by decreasing or stopping the AEDs.

Andermann et al., (2007) reported that differences in bioequivalence between different manufacturers may increase the risk of seizures or adverse events. In relation to mothers' use of drug alternatives, it is revealed from the finding that about half of the mothers use the alternatives drugs without medical consultation (**Table XVII**). This finding may be attributed to unavailability of the prescribed drugs in the market or to mothers' inability to buy the drug where most mothers in the current study reported that their income is insufficient (**Table IV**).

The majority of the studied mothers used the known medications without medical consultation when their children infected with an acute illness (**Table XVII**). This finding may be due to the poor knowledge of mothers about AEDs and medication interaction. *Perucca and Kwan, (2005)* noted that the interactions with other medications or even other substances can attenuated or potentiate metabolic consumption of anti-epileptic medication that may lead to an excessive drug load, leading to suboptimal outcomes, including greater incidence or severity of side-effects or even increased the frequency of seizures.

Regarding the management of side-effects of AEDs, more than half of mothers in the current study didn't give attention to these side-effects (**Table XVII**). On the

contrary, *Adikaibe et al., (2013)* reported that families are knowledgeable about side-effects of AEDs. The finding of the current study may be attributed to inability of mother's to understand that these manifestations are related to AEDs side-effects because they lack knowledge about side-effects of AEDs as the present study clarified that about two third of mothers didn't knew about side-effects of AEDs (**Table XI**).

Concerning mothers' management during the epileptic seizure, most of them knew what to do during the epileptic seizure situation where all the mothers mentioned that they stayed with their children until seizure ends and restore their consciousness, then removing the hard objects that cause injury (**Table XVIII**). This finding may be due to fears on their children so they can't leave them during the attack and try to protect them. In addition, two third of the mothers had "good" and "satisfactory" scores in the management during the epileptic seizures (**Table XXI**). This finding may be due to the frequent hospitalization of the majority of the children that made the mothers more close to the health care members and take the chance to observe what they do. This finding was supported by the study carried out in Saudi Arabia by *Zainy et al., (2013)*. On the contrary, *Sidig et al., (2009)* indicated that more than half of mothers didn't know about the initial procedures to adopt during the child's seizure.

Many mothers in the present study performed unnecessary or even harmful procedures as bribing face with water, restraining their children and putting anything solid like a spoon in mouth (**Table XVIII**). This finding could be due to mothers' adherence to old beliefs in caring for the epileptic individual that were wrongly recommended, e.g., put a spoon in mouth to prevent tongue biting. These beliefs are exclusively present especially in rural regions. This finding is supported by *Frank-Briggs and Alikor, (2011)* who found in their study that many harmful procedures in caring of the epileptic children were performed.

The current study findings revealed that the majority of the mothers practicing many forms of care after the epileptic seizures where the majority of them clean children's mouth from saliva, observe their children's level of awareness, breathing, and general condition as well as examine them for involuntary urination or defecation (**Table XIX**). It is clear that mothers provide the care for visible signs and neglected the hidden ones as, keep the children on their side or on back and head turned to one side. In addition, mothers might think that their roles finished with the end of the seizures.

This finding is supported by the current study result that more than half of the mothers had “unsatisfactory” scores regarding the management after the epileptic seizures (**Table XXI**). Also, **Price and Gwin, (2008)** described a similar finding in their study as they reported that many mothers did not perform the care after seizures.

Recording of epileptic seizures is very significant either for diagnosis or measuring the progress of the disorder since it is unusual for the health care providers to actually observe a seizure during an office visit, so self-report of seizures (or report by family members) is very important (**Vestergaard, 2011**). The current study showed that the minority of the mothers recorded the time, duration and signs of epileptic seizures (**Table XIX**). This finding may be the result of deficit in instruction given by the health team members regarding the importance of recording of the epileptic seizures or they did not ask mothers about the records. Also mothers may be busy by home activities especially in rural areas or they getting used to the illness of the chronic nature, so they did not record. This finding was supported by **Monir et al., (2013)** who found that mothers didn't record the seizure events.

The current study proved that, the total knowledge scores of mothers regarding epilepsy were “poor” scores, regardless of their age, education or duration of illness. This finding may be attributed to mothers' get used to the illness because of the chronic nature of the disorder so they do not ask or search about their children's illness. Also, this finding may reflect the insignificant role played by nurses as health educators or counselors, as the minority of mothers in the current study gained their information from nurses (**Table XX**). At the same time being a housewife preventing the exchange of information with others outside home so they get “poor” knowledge scores, where the majority of the studied mothers were housewives. This finding is congruent with many studies as **Shore et al., (2009)** and **Behrouzian & Neamatpour, (2010)** who found that mothers' information needs are not being met and indicated that their need for information remained high, so they continue to have questions about epilepsy causes, and wanting more information about how to keep their children safe during a seizure.

Although mothers had “poor” knowledge scores in the current study, their management scores were better, where slightly more than half of the mothers had “good” and “satisfactory” scores regarding their total management (**Table XXI and**

Figure V). This contradiction may be attributed to the focus of the health care team on the practical and management aspects of the disorder and missing the knowledge. It may be returned to the limited time or overcrowding in the follow-up clinic. In addition, the majority of mothers in the present study were housewives that provide them with more available time and saved effort than working mothers to give better management to their epileptic children. This finding is consistent with *Beca et al., (2010)* which revealed that most of the mothers in their study had “satisfactory” level of epilepsy management regardless of their “poor” level of knowledge.

As regards mothers’ management scores according to their education, the current study revealed that there was statistical significant relation between mothers’ total management and their education (**Table XXII**). It was found that the majority of the mothers who completed their secondary / diploma education and the university level had “good” and “satisfactory” scores in their total management (**Table XXII**). This finding could be explained in the light of the fact that education might helped in providing better care, where they gain understanding of the importance of regular therapy and management. This finding is supported by *Wada et al., (2001) and Guekht et al., (2007)* who found that children of educated mothers had an optimal management compared to the children with illiterate ones.

Regarding mothers’ management scores of their epileptic children according to their age, the current study revealed that the majority of mothers aged 30 years & more had “good” and “satisfactory” scores respectively regarding their management throughout the study (**Table XXII, XXIII, XXIV and XXV**). This finding may be explained in the light of the fact that mothers depends on their experience as a source of information (**Table XX**), where their experience increased with their age and the chronicity of the disorder over time. This finding is supported by *Shore et al., (2008)* who found that mothers’ care was better in older mothers than younger age ones.

The present study findings revealed that there was statistical significant difference between mothers’ management scores of their epileptic children and their children’s gender, where the majority of the mothers who have male children had “unsatisfactory” scores in management before the epileptic seizures (**Table XXVII**). This finding may be attributed to the fact that seizures safety precautions and medication regimen may be more difficult to implement on the male children, who is

more active and independent than female children. However, this explanation was in contrary with *Duffy et al., (2011)* who found that there is no difference between boys and girls in their maternal management.

The present study revealed that there was statistical significant relation between mothers' management of their children and the number of siblings. More than one third of mothers who have more than two and three siblings had "unsatisfactory" scores of management before the epileptic seizures (**Table XXVII**). This finding may be due to mothers' inability to care their epileptic children in the presence of many siblings as they do not have time devoted to their sick children. Moreover, the management before the seizures requires more considerable attention from the mothers to be able to set and follow safety precautions for their children's before seizures in the presence of other children and household activities. This finding go on line with *Carbone et al., (2013)* who stated that mothers require countless time to provide the safety precautions for their epileptic children and experience loss of control on children safety in many situations.