Stressors and Coping Patterns of Mothers Having Children with Epilepsy

Thesis

Submitted For Partial Fulfillment of the Requirements for Master Degree in ***Pediatric Nursing***

By

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Nora Mahmoud Ahmed El-Marazky

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List of Abbreviations

AED : Antiepileptic drug
BUN : Blood Urea Nitrogen
CBC : Complete Blood Count
CT : Computed Tomography
EEG : Electro Encephalo Gram
EF : Executive Function
FMRI : Functional Magnetic Resonance Imaging
ILAE : The International League Against Epilepsy
IOM : Institute of Medicine
IQ : Intelligence Quotient
MRI : Magnetic Resonance Imaging
NCGC : National Clinical Guideline Centre
NI HCE : National Institute for Health and Clinical Excellence
NPOC : Neurology Pediatric Out-Patient Clinic
PET : Positron Emission Tomography
RBCs : Red Blood Cells
RNS : Responsive Neurostimulation
SUDEP : Sudden Unexplained Death in Epilepsy
VNS : The Vagus Nerve Stimulator
WBCs : White Blood Cells
WHO : World Health Organization

Abstract

Epilepsy is a condition of recurrent fits resulting from paroxysmal involuntary disturbances of the brain function that are unrelated to fever or an acute cerebral insult. Mothers of children with epilepsy have significant worries and stress around the epilepsy diagnosis, co morbidities, treatments and management of disease that maintain over tim***e The aim of this study :*** To assess stressors and coping patterns of mothers having children with epilepsy. **Subjects & Methods:** A descriptive design was conducted at the outpatient clinic in the Neurological pediatric outpatient clinic affiliated to Ain Shams University Hospitals. **Study subjects:** A convenient sample of children suffering from epilepsy and their mothers (N= 100). **Tools** of the study involved 1) Structured questionnaire sheet to assess the children and their mothers' characteristics as well as knowledge of the mothers about epilepsy. 2) Parenting Stress Index (Abidin, 1995) to assess parents, stress. 3) Coping patterns scale (Jalowiec and Powers, 1991) to assess the mothers coping patterns toward their children suffering from epilepsy. **Results:** The present study revealed that, the mean age of the children was less than five years and more than two fifth of them were ranked as the third child and more in their families, more than half of the children were male. The mean age of the mothers was from twenty five to thirty years and less than one third of them had secondary education. As regards the mothers' occupation, the majority of them were housewife. More than one third of the mothers has a moderate level of psychological stressors. While, more than half of them have a moderate level of social stressors and less than two thirds of them have high levels of physical stressors. Additionally, more than half of the mothers had a moderate coping pattern. **Conclusion:** The results of this study concluded that, the mothers of children with epilepsy are facing with many stressors resulting from their children with epilepsy; these stressors included physical, psychological and social stressors and moderate coping pattern with their children with epilepsy. **Recommendation:** Emphasize the importance of availability and distribution of pamphlets and booklet containing the basic knowledge for mothers about the disease of their children.

Key words: Epilepsy, Stressors, Coping Patterns, Children, Mothers.

Introduction

Epilepsy is a neurological condition characterized by recurrent paroxysmal attacks of unconsciousness or impaired consciousness that may be followed by contraction and relaxation of muscles resulting in an alternating tonic and clonic movements of the muscles or abnormal behavior ***(Epilepsy Action, 2013).***

Every year, approximately 50, 000 new cases of epilepsy are diagnosed in children and adolescents under the age of 18 years ***(Global Campaign against Epilepsy, 2011).*** In Egypt, the prevalence of epilepsy is about 9/1000 children per year, however, male are slightly more likely to develop epilepsy 10.5/1000 than female children (7.4/1000) ***(Farghaly et al., 2012).***

Epilepsy affects every child differently depending on age, types of seizures, response to treatment and whether or not the child has the other health issues. In some children, the seizures are easily controlled with medicine and eventually outgrown. While, in other children, epilepsy can create difficult challenges throughout their lives ***(Herzer, Denson & Baldassano, 2011).***

The stress of a new epilepsy diagnosis may play a significant role in the daily activities of families having children with epilepsy. Most parents are extremely upset when their child is diagnosed with epilepsy, mainly because of the stigma associated with the condition ***(Ziegler et al., 2011 and Quittner, 2012).*** The typical parental responses are

shock, devastation, anger, frustration, sorrow and depression. In addition, they often fear divulging their child's epilepsy to their friends and relatives because experience a sense of shame, self-blame and rejection. This leads to withdraw from relatives and social circle ***(Ellis, Upton & Thompson, 2012).***

As the child grows older, parental stress is likely to increase due to management difficulties, financial demands and increased concern about the child's future. Parents may become physically and psychologically exhausted, having to provide almost constant care ***(Hoare & Kerley, 2012).***

Parents play the most significant role in helping the child with epilepsy adapt to his/her condition. In practical terms, their functions include seeking treatment, ensuring the child's compliance with treatment, facilitating the child's functioning in and outside the home, and recognizes the impact of epilepsy on child attitudes ***(Austin, 2011).***

The care of a child who has epilepsy is best achieved by an epilepsy specialist nurse. The nurses play a pivotal role in providing a close link between the children with epilepsy and their families. They are also, in an ideal position to establish a link between the physicians and the affected families and offering valuable advice and support ***(El-Radhi, 2015).***

Nurses must be familiar with the different types of seizure and to ensure pediatric patients are given appropriate care and medication. The nurse should have an understanding of seizures as well as the interventions, and monitoring strategies used to control seizures and to minimize the negative impact on the quality of life of children. Additionally,

providing education and support to children and families to cope with the challenges of living with chronic seizure disorder ***(Hay et al., 2013).***

Significance of the study

Pediatric epilepsy is the most common chronic neurological illness in childhood and adolescence. In Egypt, one hundred patients had a confirmed diagnosis of epilepsy, with a lifetime prevalence of 12.46/1000, while, the age-specific prevalence rate of epilepsy was much higher in infancy and early childhood (62.5 and 37.04/1000, respectively ***(Fawi et al., 2015)***.The prevelance of epilepsy in children at Neurological Out-Patient Clinic in Pediatric Department of Children's Hospitals of Ain Shams University in the last two years 2012 and 2013 were about 300 children **(Statistical Office of Neurological Out-Patient Clinic of Children's Hospitals of Ain Shams University)**. Children with epilepsy are considered to affect the whole family, requiring new modes of organization and structure of the family. The failure of the family members to adapt adequately to the unique demands of illness could be considered a risk factor for the development of psychological stresses and behavioral disturbances that occur in children and their families. So, this study was conducted to assess stressors and coping patterns of mothers having children with epilepsy**.**

Aim of the Study

The aim of this study is to assess stressors and coping patterns of mothers having children with epilepsy.

Research Questions

1- What are the stressors facing mothers having children with epilepsy?

2- What are the coping patterns of mothers regarding their children with epilepsy?

3- Is there a relation between the knowledge of the mothers about epilepsy with their stressors and coping patterns?

4- Are there relations between mothers' characteristics with their stressors and coping patterns of their children with epilepsy?

Review of Literature

Overview about Epilepsy in Children

The term epilepsy derives from a Greek epilepsia, which means "to take hold of" and refer to chronic seizures. The preferred term now is recurrent seizures, because epilepsy carries the stigma of cognitive challenge, behavioral disorders. In the past, words such as fit, spell and blackout were commonly used to describe this entity ***(Leifer, 2015).***

Epilepsy is a neurological disorder caused by malfunctioning nerve cell activity in the brain. These malfunctions caused episode called seizures. It is characterized by recurrent, episodic, paroxysmal, involuntary clinical events associated with abnormal electrical activity from the neurons. The patient may present with motor, sensory or psychomotor phenomena, often with alteration in sensorium ***(Bareness & Gilbert-Barness, 2011).***

Epileptic seizures are episodes that can vary from brief and nearly undetectable to long periods of vigorous shaking. In epilepsy, seizures tend to recur, and have no immediate underlying cause while seizures that occur due to a specific cause are not deemed to represent epilepsy ***(WHO, 2013).***

The prevalence of epilepsy:

Epilepsy affects approximately 70 million people all ages throughout the world. It is responsible for 1% contribution to the global burden of diseases while, this contribution is 80% in the developing countries ***(Russ, Larson & Halfon, 2012).*** This disease is linked to different provocative causes and affects almost all generations,