A COUNSELLING INTERVENTION FOR FAMILY CAREGIVERS OF CHILDREN WITH EPILEPSY

Thesis

Submitted for Partial Fulfillment of
Doctorate Degree

In

Nursing Science
(Psychiatric Mental Health Nursing)

By

Shahinaz Salah Abd El Moneim
M.Sc., Nursing
Faculty of Nursing
Ain Shams University

Faculty of Nursing
Ain Shams University
2010

A COUNSELLING INTERVENTION FOR FAMILY CAREGIVERS OF CHILDREN WITH EPILEPSY

Thesis

Submitted for Partial Fulfillment of
Doctorate Degree

In

Nursing Science
(Psychiatric Mental Health Nursing)

Under Supervision of

Dr. Sorayia Ramadan

Assistant Professor of Psychiatric Mental Nursing
Faculty of Nursing – Ain Shams University

Dr. Sahar Mohamed

Assistant Professor of Psychiatric Mental Nursing
Faculty of Nursing – Ain Shams University

Faculty of Nursing
Ain Shams University
2010

Acknowledgement

***First of All Thanks to* ALLAH**

I would like to express my deep gratitude, appreciations, thanks and respect to Dr. Sorayia Ramadan, *Assistant Professor of Psychiatric Mental Nursing, Faculty of Nursing, Ain Shams University; where her guidance, patience and kindness were behind the accomplishment of this work.*

Also I would like to extend my appreciation to Dr. Sahar Mohamed, *Assistant Professor of Psychiatric Mental Nursing, Faculty of Nursing, and Ain Shams University; whose guidance, advice and support were behind this work.*

Last but not least, I would like to express my deep thanks and gratitude to all members in my family *for supporting me and pushing me forward all the time.*

Shahinaz Salah

REFERENCES

American Academy of Child and Adolescent Psychiatry. Practice parameters and guidelines available at: http://www.aacap. Org/ publications/ pubcat/ guideline htm.accessed October 14, 2003.

Austin, J.K., Harezlak, J., & Dunn, D.W. (2001): Behavior problems in children before first recognized seizures. Pediatrics; 107 (1): 115-122.

Austin, J.K., Huster, G.A., & Dunn, D.W. (1996): Adolescents with active or inactive epilepsy or asthma: a comparison of quality of life. Epilepsia; 37(12): 1228-1238.

Austin, J.K., Risinger, M.W., & Beckett, L.A. (1999): Correlates of behavior problems in children with epilepsy. Epilepsia; 33 (6): 1115-1122.

Camfield, P., & Camfield, C. (2003): Childhood epilepsy: what is the evidence for what we think and what we do? J Child Neurol; 18(4): 272-287.

Caplan, R., Arbelle, S., Magharious, W., Guthrie, D., Komo, S., Shields, W. D., et al. (1998): Psychopathology in pediatric complex partial and primary generalized epilepsy. Dev Med Child Neurol; 40(12): 805-811.

Cortesi, F., & Giannotti, F. (1999): Sleep problems and daytime behavior in childhood idiopathic epilepsy. Epilepsia; 4: 1557-1565.

Dunn, D. W., & Austin, J. K. (1999). Behavioral issues in pediatric epilepsy. Neurology; 53(5 Suppl 2): S96-100.

Feldman, H., Crumrine, P., Handen, B. L., Alvin, R., & Teodori, J. (1989): Methylphenidate in children with seizures and attention-deficit disorder. Am J Dis Child; 143(9): 1081-1086.

Gross-Tsur, V., Manor, O., van der Meere, J., Joseph, A., & Shalev, R. S. (1997): Epilepsy and attention deficit hyperactivity disorder: Is methylphenidate safe and effective? J Pediatr; 130(4): 670-674.

Harden, C.L., & Goldstein, M.A. (2002): Mood disorders in patients with epilepsy: epidemiology and management. CNS Drugs; 16(5): 291-302.

Hoare, P. (1998): The development of psychiatric disorder among school children with epilepsy. Dev Med Child Neurol; 26: 3-13.

Johnston, J.A. (1998): A 102-center prospective study of seizure in association with bupropion. J Clin Psychiatry; 42:139-145.

Lothman, D.J., & Pianta, R.C. (1998): Mother-child interaction in children with epilepsy relations with child competence. J. Epilepsy; 3: 157-163.

Mitchell, W.G., & Scheier, L.M. (2000): Psychosocial behavioral and medical outcomes in children with epilepsy: a developmental risk factor male using longitudinal data. Pediatrics; 94: 471-477.

Schmiz, B. (2002): Antidepressant drugs. Indications and guidelines for use in epilepsy. Epilepsia; 43(2): 14-28.

Sillanpaa, M., Jalava, M. (1998): Long-term prognosis of seizures with onset in childhood. N Engle J Med; 338(24): 1715-1722.

Tuchman, R. F., & Rapin, I. (1997): Regression in pervasive developmental disorders: seizures and Epileptiform electroencephalogram correlates. Pediatrics; 99(4):560-566.

Wamboldt, M.D. (2002): Role of the family in the onset and outcome of childhood disorders: selected research findings. Journal of the American academy of Child and Adolescent Psychiatry; 39(10): 1212-1219.

INTRODUCTION

EPilepsy is one of the most important neurological disorders in child hood . It affects children at different ages ***(Epilepsy Foundation, 2007).*** In Egypt, epilepsy is affecting approximately 4-6 cases/1000 children ***(Raouf, 2003)***. Epilepsy is a neurological condition that makes people susceptible to seizures. A seizure is a change in sensation, awareness, or behavior brought about a brief electrical disturbance in the brain ***(Robinson&Roberton, 2003).***

The onset of a chronic health condition, such as epilepsy, can interfere with the successful accomplishment of the psychological and developmental tasks. Children with epilepsy are at a special risk for developing psychological problems. They often exhibit lower self-esteem, social withdrawal, and behavior disorder including hyperactivity and attention deficit disorders ***(Austin, 1996; Ferrie et al., 1997).***

Families who have a child with epilepsy experience a significant impact on both the dynamics of child's development, and the family systems in a social context. Knowledge of a family's life experience in dealing with the early stages of their child's illness would provide a deeper

understanding of their life and coping process ***(Mu et al., 2005)***.

When a child has epilepsy, the stereotype of epilepsy affects the family experience in terms of stress and their coping process ***(Mu, 2008)***.

Social attitudes towards epilepsy cause more distress to the patient and his/her caregiver than the disease itself. The major psychosocial issues related to epilepsy that are of concern for the family are the quality of medical management, over protection, education, employment, marriage and pregnancy ***(Shah, 2000).***

A good relationship between patient, family and the health care team is necessary for the optional management of epilepsy. This involves the epileptic child and his/her caregiver being actively involved in decisions and not being dictated to by professionals ***(Russel, 1997).***

Mothers, as the main caregivers in the family are an important part of the health care team. Their knowledge and attitude are crucial to practice in the care of their epileptic children. However, since mothers are not generally well prepared for this role, it is the responsibility of the nurse to counsel them how they can restore the child to good health ***(Shorvon et al., 1996).***

AIM OF THE STUDY

The aim of the study was to help family caregivers of epileptic children to better cope with their children condition, which would have a positive impact on the child and caregiver.

This aim was reached through achievement of the following objectives:

- Assess family caregiver coping pattern.
- Design, implement and evaluate a counselling intervention based on coping patterns.

Hypothesis of the Study

Family caregivers' coping patterns will be improved after implementation of the counselling intervention

AN OVERVIEW OF EPILEPSY

Epilepsy is a neurological condition that makes people susceptible to seizures. A seizure is a change in sensation, awareness, or behavior brought by a brief electrical disturbance in the brain.

Seizures vary from a momentary disruption of the senses, to short periods of unconsciousness or starting spells, to convulsions. Some people have just one type of seizures; while others have more than one type ***(Epilepsy Foundation, 2007).***

Epilepsy may be described basically as an intermittent derangement of the nervous system presumably due to a sudden, excessive, disorderly discharge of cerebral neurons. This was the postulate of Hughlings Jackson, the eminent British neurologist of the nineteenth century, and the modern electrophysiology offers no evidence to the contrary. The discharge results in an almost instantaneous disturbance of sensation, loss of consciousness, impairment of psychic function, convulsive movements, or some combination thereof ***(Raymond&Maurice, 2007).***

A more common and less grave circumstance is for a seizure to be put in an extensive series occurring over a long period of time, with most of the attacks being more or less similar in type. In this instance, they may be the result of a burned out lesion that originated in the past and

remains as a scar. The original disease may have passed unnoticed; or perhaps it occurred in utero, at birth, or in infancy in parts of the brain too immature to manifest signs. Again it may have affected a silent area in a mature brain. Patients with such old lesions probably make up the majority of those with recurrent seizures, but are necessarily classified as having "idiopathic epilepsy" because it is impossible to ascertain the nature of the original disease; and the seizures may be the only sign of brain abnormality. In this sense, all epilepsy is "symptomatic" or "secondary" although the latter term generally indicates that the seizures have an identifiable and usually acquired structural cause ***(Nial, 2005).***

CLINICAL ASPECTS OF SEIZURE AND EPILEPSY

Epilepsy originates in the brain, so do thoughts, feelings, and behaviors. A seizure is a sudden alteration in normal brain activity that causes distinctive changes in behavior and body function ***(Robinson &Roberton, 2003).***

According to ***Droland (1991),*** epilepsy is a paroxysmal transient disturbance of brain function that may be manifested as episodic impairment or loss of consciousness, abnormal motor phenomena, psychic or sensory disturbances, or perturbation of the autonomic nervous system. Symptoms are due to paroxysmal disturbance of the electrical activity of the brain. Unconsciousness or impaired consciousness may be followed by alternate contraction and relaxation of the muscles or by disturbed feelings or behaviors ***(Thompson, 2000).***

Meanwhile, ***Abdel Moneim and Metwaly (1991)*** have defined seizures as a clinical neurological disorder characterized by the recurrence of paroxysmal episodes of abnormal function, either excess or deficit of function, or complex functional disorders. ***Wong (1997)*** added that seizures are brief malfunctions of the brain's electrical system. Abnormal discharge of electrical activity within

the brain can cause altered consciousness; loss of consciousness; involuntary movements; and changes in perception, posture and behavior.

The seizures usually are sudden and transient ***(Smeltzer & Bare, 2000).*** Epilepsy connotes spontaneously recurring seizures. The incidence rates are very high during the first year of life, decline through childhood and adolescence, plateau in middle age, and rise sharply again among the elderly ***(Collier &Lewis., 1996).***

It is crucial to distinguish the tendency to recurrent seizures, which define epilepsy from isolated seizures, which may be provoked by drugs, sleep deprivation, hypoglycemia, inter-current illnesses, syncope (especially if the person is held upright), or other factors ***(Smeltzer & Bare, 2000).*** Seizures resulting in systemic and metabolic disturbances are not considered epilepsy if the seizures cease when the underlying problem is corrected ***(Lewis, 1996).***

Etiology

There are many reasons why seizures occur. Seizures are categorized as cerebral, biochemical, posttraumatic and idiopathic ***(Robinson&Roberton, 2003).*** Age at onset is important. In the newborn, birth injury, congenital malformations, metabolic disorders and infections are common. In adults, identifiable causes include

cerebrovascular disease, brain tumors, head injury, and neuro-degenerative disorders. Table shows examples of the most common precipitating factors of epilepsy. ***(Robinson & Roberton, 2003)***

Behavior Disturbance Associated with Seizures

Behavior disturbance associated with seizure could be grouped into three, pre-ictal, ictal, and post-ictal. Pre-ictal stage is the prodromal states and is accompanied by mood disturbance. Ictal stage of complex partial seizures is accompanied by affective disturbances, hallucinations, experiential phenomena, and automatism. Lastly, post-ictal behavioral changes include impaired consciousness, delirium, psychosis, and Todd's paresis. The last include hemiparesis, dysphasia, and other focal signs ***(Michael, 1991).***

Table (1): Predisposing factors of epilepsy

Precipitating Factor	**Examples**
Genetic Predisposition Birth factors	Chromosomal abnormalities Birth trauma, anoxia, infection Pharmaceutical agents, drugs
Infectious Disorders	Meningitis Encephalitis Fever Brain abscess
Cranio-cerebral Trauma	Anoxia Minor head injury Subdural and epidural Hematoma
Cerebral tumors Primary Intracranial Tumor	Metastatic tumors
Degenerative Diseases	Cerebellar degeneration Multiple Sclerosis
Toxic Disorders	Metallic substances,lead, mercury Allergic reaction to drugs,caffeine Insulin Uremia Carbon monoxide
Idiopathic Precipitating Factors	Alcohol withdrawal Sedative withdrawal Anticonvulsant withdrawal Nontherapeutic drug levels Change in medication regimen Nonadherence to prescription Fatigue Physiologic stress Psychological stress Alcohol ingestion Drug abuse
Cerebrovascular Disease	Hemorrhage Thrombosis Embolism Arteriosclerosis Cerebral Aneurysm Vasospasm
Metabolic Dysfunction	Pregnancy Fluid and electrolyte Imbalance, Hyponatremia Endocrine disorders Menstruation Vitamin deficiency , pyridoxine Acid-base imbalance Hypoxia, acidosis Carbohydrate metabolism, hypoglycemia Fat and protein metabolism

Source: Robinson & Robertson (2003)