Quality of Life in Childhood Epilepsy

Thesis

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Submitted by

Abdi hakim Shire Mohammed

M.B.B.Ch.
Faculty of Medicine – Shandi University

Supervised by

Prof. Dr. Nahid Salah Adin Ahmed

Professor of Neurology
Faculty of Medicine – Ain Shams University

Prof. Dr. Maha Ali Nada

Assistant Professor of Neurology
Faculty of Medicine – Ain Shams University

Dr. Doaa Abdallah El'aidy

Assistant Professor of Neurology
Faculty of Medicine – Ain Shams University

Faculty of Medicine
Ain Shams University
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بسم الله الرحمن الرحيم
قالوا
سبحانك لا علم لنا
إلا ما علمتنا إنك أنت
العليم الحكيم
صدق الله العظيم
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Abdi hakim Shire Mohammed

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List of Abbreviations

Abbrev.	Full term
AEDs	**:** Antiepileptic drugs
BMI	**:** Body Mass Index
CI	**:** Confidence Interval
CNS	**:** Central nervous system
EEG	**:** Electro-encephalogram
GGEs	**:** Genetic Generalized Epilepsies
HRQOL	**:** Health-related quality of life
IGEs	**:** Idiopathic Generalized Epilepsies
ILAE	**:** International League Against Epilepsy
IM	**:** Intra-Muscular
MRI	**:** Magnetic resonance imaging
NICE	**:** National Institutes for Health and Care Excellence
QOL	**:** Quality of life
RCT	**:** Randomized Controlled Trial
SC	**:** Subcutaneous
SD	**:** Standard Deviation
TDM	**:** Therapeutic Drug Monitoring
US	**:** Ultrasonography
WHO	**:** World Health Organization

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Nahid S. Ahmed, Maha A. Nada, Doaa A. El'aidy, Abdi hakim S. Mohammed

Department of Neurology
Faculty of Medicine – Ain Shams University

Abstract

Background: Epilepsy is a common chronic neurological condition in developing years that can negatively impact one's physical, social and emotional function. **Aim of the Work:** to assess the health-related quality of life (HRQOL) and its predictors in children with epilepsy in Egypt during the period from August 2019 and December 2019. This cross-sectional study was conducted at Ain Shams Neurology Department and included 75 children with epilepsy of 11-18 years. The tools used to assess children's QOL were pediatric QOL questionnaires. Parents' QOL was assessed using SF36 inventory. **Results:** children with epilepsy have an affected quality of life according to the PedQOL assessment tool with a mean PedQOL total score **64.4**±6.9 and ranged from **56.1** to **83.6**. Among the different domains of the PedQOL inventory, the results of our study showed that children with epilepsy have got higher scores in the physical and the school domains than in the emotional and social domains. Our sample was drawn from Ain-Shams University hospital. Patients attending this health facility are usually from low to intermediate socio-economic status which may explain this result. **Conclusion:** Epilepsy in children has a great impact on the quality of life of those children particularly on the emotional and social domains. Some antiepileptic drugs like valproic acid have a better effect on the quality of life than others. The higher the children's quality of life the higher is the parents' quality of life. The highly impacted domains of the parents quality of life according to the SF36 questionnaire were role limitation (physical or social), social functioning and mental health domain.

Key words: quality of life, childhood, epilepsy, health

Introduction

Epilepsy is a common chronic neurological condition in developing years that can negatively impact one's physical, social and emotional function ***(Senanayake, 1993; Freiling, 2006).***

In Austria reported behavioral and emotional problems in 22% of epileptic children, and studies have described feelings of shame, rejection, fear, worry, low self-esteem, and perception of stigma to be common in children with epilepsy ***(de Souza, 2006).***

Epilepsy also has a significant emotional impact on parents of affected children, and parental emotional stability has been found to be a major predictor of the quality of life (QOL) of the epileptic child ***(Connolly, 2006)***. It has been associated with significant psychosocial maladjustment in both the affected children and their families ***(Høie, 2006).***

Increasing attention is being focused on problems experienced by children with epilepsy as a result of stigma, which is associated with poor psychosocial health outcomes and impaired QOL. Epilepsy may interfere with social functioning by limiting educational opportunities, employability, and interpersonal relationships and also increase the risk of death ***(MacLeod, 2003).***

Childhood epilepsy is an elevated hazard for poor psychological outcomes and impacts on quality of life of children but also has a great sway on family functioning ***(Malhi, 2005).*** Children being the high-risk group and in crucial development period during which many cognitive and social skills have to be learned QOL is a significant health outcome to assess children with epilepsy ***(Taylor, 2011).***

The traditional medical goal in the management of epilepsy has focused almost exclusively on seizure control with minimal or no adverse medication effect, whereas the importance of assessing QOL has been ignored ***(Ronen, 2003)***. This is particularly true for Egyptian children, where the QOL is probably affected by the social stigma associated with the disease.

Aim of the Work

The aim of this study was to assess the health-related quality of life (HRQOL) and its predictors in children with epilepsy in Egypt, comparing the relationship between different types of seizures and the HRQOL and increasing the awareness of the importance of assessing physical, psychosocial, and behavioral well-being of children with epilepsy in Egypt.

Revised Terminology and Concepts for Organization of Seizures and Epilepsies

Epilepsy definition:

The activity of the neuron chains is coordinated by electrical and chemical signals. People with epilepsy have recurrent bursts of abnormal electrical activity in the brain. This change in brain activity leads to an epileptic seizure. An epileptic seizure can take a number of different forms – it can cause changes in a person's body movements, awareness, behaviour, emotions or senses (such as taste, smell, vision or hearing). Usually a seizure lasts for only a few seconds or minutes and then the brain activity returns to normal. Having one seizure does not necessarily mean that someone has epilepsy – people can have a 'oneoff' seizure ***(The National Institutes for Health and Care Excellence: NICE, 2019).***

Epilepsy is not a single condition: in the NICE guideline, the term 'the epilepsies' is used to show that not just one but many brain conditions can result in recurrent epileptic seizures. Some epilepsies start in childhood, some start in young people or in adults, while others start in older people; some last for only a short time and others last for a lifetime; some have little impact on a person's life and others can have a major effect on a person's ability to function and live their daily life ***(NICE, 2019).***

Seizures and epilepsy are not the same. An epileptic seizure is a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain. Epilepsy is a disease characterized by an enduring predisposition to generate epileptic seizures and by the neurobiological, cognitive, psychological, and social consequences of this condition. Therefore, a seizure is an event and epilepsy is the disease involving recurrent unprovoked seizures ***(ILAE, 2014).***

There are many different types of epileptic seizure, but they are divided into two main groups (focal or generalised) depending on the source of the seizure within the brain.

- **Focal seizures**: Focal (or partial) seizures are seizures that start in one part of the brain. These seizures may take many different forms depending on the part of the brain that is affected. They may involve a change of movement or behaviour; a person may remain aware of their surroundings during a seizure, or they may lose awareness ***(Fisher et al., 2017).***

- **Generalised seizures**: Generalised seizures are more distributed and affect both sides of the brain at once. There are different types of generalised seizure, the most recognised of which is the 'tonic–clonic seizure' (where the person goes stiff and then has jerking movements). During a generalised seizure, the person may lose consciousness, fall or have muscle spasms ***(Fisher et al., 2017).***

- **Secondarily generalised seizures**: Sometimes a focal seizure spreads from one side of the brain to the other – when this happens this is known as secondary generalisation ***(Fisher et al., 2017).***

- **Possible causes of seizures**: Some people with epilepsy have only one type of seizure, and others have more than one type. The type of seizures a person has may change over time. In this information, the term 'seizure' could mean 'seizures' for people who have more than one type of seizure. With increasing advances in technology, it is possible to give a cause of the epileptic seizures in a growing number of cases (for example, damage to the brain during a difficult birth, or a head injury). However, sometimes there is no known cause ***(Fisher et al., 2017)***.

In the beginning of the current millennium, conceptually, epilepsy was defined in 2005 as "*a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain. Epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures, and by the neurobiologic, cognitive, psychological, and social consequences of this condition*" ***(Fisher et al., 2005).***

The definition of epilepsy requires the occurrence of at least one epileptic seizure." This definition is usually practically

applied as having two unprovoked seizures >24 h apart ***(Fisher et al., 2005).***

Conceptually, epilepsy exists after at least one unprovoked seizure, when there is high risk for another, although the actual required risk is subject to debate ***(Fisher et al., 2014).***

Berg & Shinnar (1991) reported that after a single unprovoked seizure, risk for another is 40–52%. Meanwhile, ***Hauser et al. (1998)*** showed that with two unprovoked non-febrile seizures, the chance by 4 years of having another is 73% (95% confidence interval (CI) of 59–87%).

This epilepsy "two unprovoked seizure" definition has served well, but it is inadequate in some clinical circumstances. A patient might present with a single unprovoked seizure after a remote brain insult, such as a stroke, central nervous system (CNS) infection, or trauma. A patient with such brain insults has a risk of a second unprovoked seizure that is comparable to the risk for further seizures after two unprovoked seizures ***(Hesdorffer et al., 2009).***

Moreover, epilepsy is considered to be resolved for individuals who either had an age-dependent epilepsy syndrome but are now past the applicable age or who have remained seizure-free for the last 10 years and off anti-seizure medicines for at least the last 5 years. "Resolved" is not