**Deanship of Graduate Studies**

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# Quality of Life of School-aged Children with Epilepsy in Gaza Strip

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# Quality of Life of School-aged Children with Epilepsy in Gaza Strip

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# Dedication

I dedicate this work to God Almighty my creator, my strong pillar, my source of inspiration, wisdom, knowledge and understanding.

To my amazing mother and father … without them, I would not be the person that I am today. Thank you for being amazing role models, for always encouraging my dreams, and for all of the sacrifices you made in order for me to live the life I have.

To my wife Rasha and my beloved son Belal for their encouraging smiles.

To my brothers and sisters Basam , Allam, Dr. Mohamed, Dr. Hussam, ,Dr. Rezeq, Saleh, Ahmed Ibtisam and Samar …Thank you for being my cheerleaders and for showing patience and tolerance with my busy time.

To the Holy Land of Jerusalem

To my homeland Palestine

Hamza Khalil Harb

## Declaration

I certify that this thesis submitted for the degree of Master, is the result of my own research, except where otherwise acknowledged, and this study or any its parts has not been submitted for a higher degree to any other university or institution.

Signed:

Hamza Khalil Harb

Date:..../..../....

# Acknowledgement

All praise to Allah, the one to whom all dignity, honor, and glory are due, my lord and creator for the blessing and reconcile me in my scientific and practical life.

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I convey my prayer to all children with epilepsy to heal and have a good health.

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# Abstract

Pediatric epilepsy is the most common neurologic condition associated with high rates of behavioral health comorbidities. The purpose of this study was to assess the quality of life and to determine the factors that affect quality of life among school-age children with epilepsy in Gaza Strip. A descriptive, analytical, cross-sectional design was used. The sample consisted of 144 school-age children with epilepsy, their age ranged between 6 – 12years. Data was collected by using a 16-item Health-Related Quality of Life Epilepsy Module (HRQOL) and Quality of Life in Childhood Epilepsy Questionnaire: QOLCE-55 adapted from Goodwin et al., (2015) and Ferro et al., (2016). Data was collected from the children and their parents by face-to-face interview with each participant. SPSS (version 22) used to analyze data, and statistical analysis included frequencies, percentage, mean scores, standard deviation, independent sample t-test, and One way ANOVA. The results of the study showed that the mean age was 8.86±1.93 years, 47.2% were male children and 52.8% were female children, and half of the children have very good and excellent school achievement. The results also showed that about one-third of fathers and the majority of mothers do not work, and two-thirds of the families have low income. In addition, the children expressed above moderate health related quality of life with mean score 2.41 and weighted percentage 60.25% and moderate level of quality of life (57.56%), the highest was social functioning (60%), followed by physical functioning (57.75%), emotional functioning (57%) and the lowest was cognitive functioning (55.5%). The results also indicated significant association between quality of life and some factors including school achievement, onset of diagnosis and frequency of seizures in the past six months. While age of child, gender, order of child, parents' work, family income, mothers' education, and side effects of drugs were not significant. The researcher recommended that there is a need to multidisciplinary approach to deal with children with epilepsy from the cognitive, emotional, social, and physical aspects to improve their quality of life.

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## List of abbreviations

| | |
|---|---|
| **AEDs** | Anti-epileptic Drugs |
| **CDC** | Centers for Diseases Control and Prevention |
| **CSE** | Convulsive Status Epilepticus |
| **CWE** | Children with Epilepsy |
| **DPH** | Al Durra Pediatric Hospital |
| **GS** | Gaza Strip |
| **HRQOL** | Health related Quality of Life |
| **LMIC** | Low and Middle Income Countries |
| **MOH** | Ministry of Health |
| **NGOs** | Non-governmental Organizations |
| **OCHA** | United Nations Office for the Coordination of Humanitarian Affairs |
| **OPD** | Outpatient Department |
| **PCBS** | Palestinian Central Bureau of Statistics |
| **PHC** | Primary Health Care |
| **PNA** | Palestinian National Authority |
| **QOL** | Quality of Life |
| **QOLCE** | Quality of Life in Children with Epilepsy |
| **RSPH** | Rantisi Specialized Pediatric Hospital |
| **TBI** | Traumatic Brain Injury |
| **UNRWA** | United Nations Relief and Works Agency for the Palestinian Refugees in the Near East |
| **USA** | United States of America |
| **WB** | West Bank |
| **WHO** | World Health Organization |

# Chapter One

## Introduction

### 1.1 Background

Epilepsy is among the most common neurological disorders of childhood, and it is recognized by the transient occurrence of signs and symptoms due to abnormal, excessive, or synchronous neuronal activity in the brain (Bilgic et al., 2018).

Pediatric epilepsy is the most common neurologic condition associated with high rates of behavioral health comorbidities, which can affect quality of life (Guilfoyle et al., 2017). Epilepsy is a chronic medical condition with many co-morbid features. Observation showed that children with epilepsy (CWE) have a compromised quality of life (Nadkarni et al., 2011).

Childhood epilepsy increases the hazards for poor psychological outcomes and impacts on quality of life (QOL) of children and has a great impact on family functioning. Children are at high risk because they are in crucial developmental period, during which the children learn many cognitive and social skills, so, management of epilepsy requires recognition of potential effects of epilepsy and all aspects of life (Sruijana et al., 2017).

Quality of life is a broad concept used to emphasize an individual's emotional reaction to life occurrences, personality, life fulfillment and satisfaction with work and personal relationships; otherwise known as well-being (Theofilou, 2013). QOL is an important measurable outcome of care for conditions that do not threaten life. QOL is affected by frequency of seizure episodes, type of epilepsy, cognition, emotional functions and concentration, and maternal education (Adla et al., 2017). Various studies have focused on assessment and determinants of QOL outcomes in pediatric epilepsy, the findings of these studies consistently showed that CWE are more likely to have poorer QOL than the general population (Bompori et al., 2014; Moreira et al., 2013).

## 1.2 Research Problem

Epilepsy alters the conscious, behavior, motor activity, and autonomy function that leads to compromised QOL in children, and comprehensive care needs to go beyond the attempt of controlling seizures (Sruijana et al, 2017; Nadkarni et al., 2011).

In GS, two main governmental hospitals are specialized for treatment of CWE; Rantisi Specialized Pediatric Hospital (RSPH) and Al Durra Pediatric Hospital (DPH). The two hospitals receives patients referred from public and private sectors as well as primary health care centers. CWE are under continuous stress caused by frequent visits and long-time consumed each visit. Moreover, CWE are facing many problems that may affect their treatment regimen, such as the nature of the disease, shortage of medical supplies, medication, parents' lack of knowledge about the disease and lack of follow up. All these conditions collectively affect physical, social, and emotional well-being of these children, which in turn will affect their QOL.

This study highlighted the status of QOL among CWE in GS, and encouraged other researchers to conduct future studies related to epilepsy and its consequences. Finally, it also provided recommendations to improve the QOL of school-age children with epilepsy.

## 1.3 Justifications of the study

From my experience in outpatient department (OPD) at RSPH, I noticed many problems that facing CWE who are attending the OPD for treatment and follow up. Many patients come from southern parts of the GS (Khanyounis and Rafah) and others come from northern areas (Beit Hanoon and Beit Lahia). Patients wait long time in the hospital because they have to do some laboratory investigations, then they have to wait for the results, and then they see the physician for examination and prescribing of medication.

Many of those children are school-age children and that affects their attendance in the school and may affect their academic achievement. In addition, some of the medication make the child sleepy and unable to concentrate, and this will affect their ability to study. Within the researcher's knowledge, CWE did not gain adequate attention from researchers, and this study would be the first one of its kind in the GS.

## 1.4 General Objective

To assess the quality of life among school-age children with epilepsy in Gaza Strip.

## 1.5 Specific Objectives

1. To assess the quality of life among school-age children with epilepsy in Gaza Strip.
2. To assess the health-related quality of life among school-age children with epilepsy in Gaza Strip.
3. To determine the association between socio-demographic factors, health-related quality of life, and quality of life among school-age children with epilepsy in Gaza Strip.
4. To suggest recommendations that will improve quality of life among school-age children with epilepsy in Gaza Strip.

## 1.6 Research Questions

1. What is the level of quality of life among school-age children with epilepsy in Gaza Strip?
2. What is the level of health-related quality of life among school-age children with epilepsy in Gaza Strip?
3. Is there an association between socio-demographic factors, health-related quality of life, and quality of life among school-age children with epilepsy in Gaza Strip?

## 1.7 Context of Study

### 1.7.1 Demographic characteristics of Gaza governorates

The State of Palestine consists of two geographically separated areas; WB and GS. GS is a narrow zone of land bounded by Egypt at south, at west by the Mediterranean Sea, and at the east and north by the occupied territories in 1948 (Annex 1). GS has a total area of 365 sq. km with 46 kilometers length and 5–12 kilometers wide and representing 6.1% of the total area of the Palestinian state, with estimated population of 2 million. GS is one of the most overcrowded areas in the world with a population density of 5,154 inhabitants/sq.km (Palestinian Central Bureau of Statistics - PCBS, 2017).

### 1.7.2 The socio-economic situation

The economic status in the GS is very low, and suffers from continuous pressure caused by long-term siege imposed by Israelis' occupation for more than 12 years. Because of this siege, a significant increase in poverty rates has occurred in GS from 38.8% in 2011 to 53% by the end of 2017 (United Nations Office for the Coordination of Humanitarian Affairs - OCHA, 2018).

In GS, there are three main types of localities of residence; namely, urban, rural and camps. Around 70% of the total population are refuges. Moreover, the socio-economic status in the GS is severely suppressed by high population density, limited land access, effects of Israeli occupation military operations and restriction on labor and trade access across the border by the siege imposing since 2007. These factors have dramatically increased the rates of unemployment and poverty in GS. The average unemployment rate is well over 41.7 % – one of the highest in the world, according to the World Bank. The number of Palestinian refugees relying on UNRWA for food aid has increased from fewer than 80,000 in 2000 to almost one million today (UNRWA, 2017).

These numbers create long term adverse effect on all aspect of life in GS, and it affects the health condition, QOL among all Gaza’s people, and those negative effects peak when it comes to patients. This increase imposes more challenges and load over health care providers in GS.

### 1.7.3 Health care system

The healthcare system in Palestine is complex, unique and strongly influenced by the Israeli occupation. The consequences of the closures and separation imposed a great challenge for the MOH by creating obstacles regarding the accessibility to health care services and affected the unity of the health care system in all Palestinian governorates (UNRWA, 2017).

There are four main health care providers; MOH, United Nations Relief and Works Agency for the Palestinian Refugees in the Near East (UNRWA), Non-Governmental Organization (NGOs), and the private sector. With such multitude of service providers, there are numerous challenges in providing a well-coordinated, standardized health service provision during normal times and frictions are deemed to exacerbate during emergencies (WHO, 2018). UNRWA provides health-care services to the vast majority of the over 1.3 million Palestine refugees in GS through 22 medical centers, providing Primary health care (PHC), secondary and tertiary health care services (UNRWA, 2017).

MOH is the main health care provider in the governorates; it provides PHC, secondary and tertiary services for the whole population. The number of hospitals owned by MOH in GS is 13 hospitals with capacity 1664 beds (MOH, 2018). It provides advanced medical services through referring patients to the neighboring countries and other private and NGO healthcare facilities. MOH has seriously affected by the financial crisis experienced by the Palestinian National Authority (PNA). In fact, there have been reductions in the numbers of patients referred outside the occupied Palestinian territory for specialized treatment and there have been growing and substantial shortages of medicines and disposables (WHO, 2018).

### 1.7.4 Epilepsy health service providers

Ministry of Health is the main provider of health services for CWE through two hospitals that provide therapeutic care; namely, RSPH and DPH. In each hospital, the physicians see the patients in the OPD, and severely sick children are admitted to inpatient departments. RSPH is the only specialized pediatric hospital in GS, providing care to children with chronic disease. The hospital provides specialized health services to children from all parts of GS including pediatric patients with epilepsy, oncology and blood disorders, renal failure and hemodialysis, and electroencephalogram. DPH offers health services to a variety of medical health problems including respiratory health problems, epilepsy, diarrhea, and renal disease.

## 1.8 Definition of terms

### Health Related Quality of Life

Health related quality of life defined as an individual’s or group’s perceived physical and mental health over time. It includes physical and mental health perceptions (e.g., energy level, mood) and their correlates, including health risks and conditions, functional status, social support, and socioeconomic status (Centers for Diseases Control and Prevention - CDC, 2018).

*The researcher defines HRQOL operationally* as the response of children with epilepsy on the HRQOL scale and measured by the average of total scores obtained using HRQOL epilepsy scale.

### Quality of Life

Quality of Life is an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment (WHO, 2019).

*The researcher defines quality of life operationally* as the child’s response on QOL scale, and calculated by the average of scores obtained on the QOL scale with its domains including, cognitive functioning, social functioning, emotional functioning, and physical functioning.

### Child with Epilepsy

*The researcher defined child with epilepsy operationally* as any child who has confirmed diagnosis of epilepsy by a physician, aged between 6 and 12 years (school-age), has a medical file in the hospital records, and receiving treatment for epilepsy.

# Chapter Two

## Conceptual framework and literature review

### 2.1 Conceptual framework

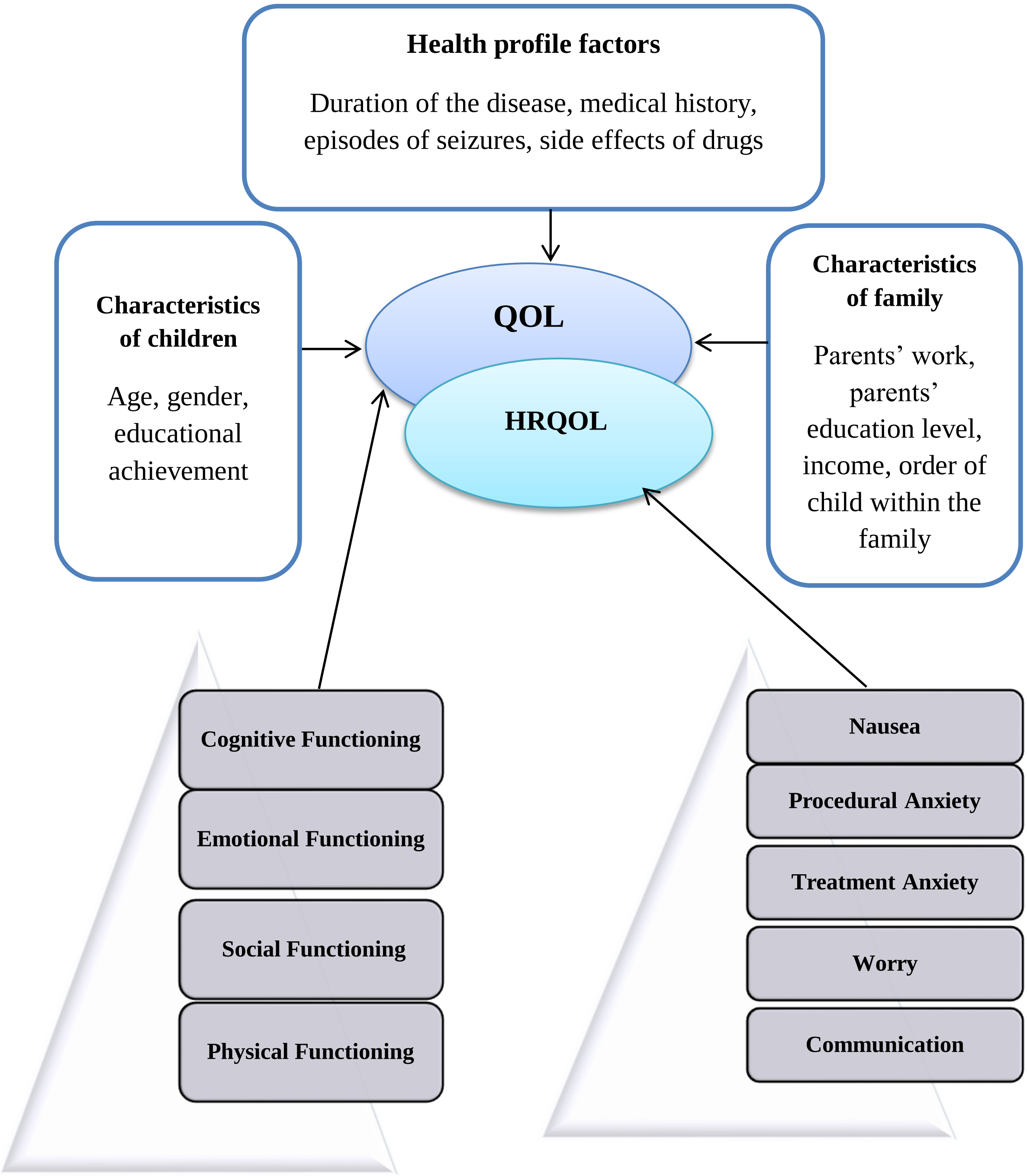

Figure (2.1): Diagram of conceptual framework

The conceptual framework is a basic element in scientific research. It connects and clarifies the relationship between the study variables. In the above diagram, several factors affect the quality of life and health-related quality of life among CWE:

**Health profile factors:** These factors related to the disease itself and other diseases that may encounter in addition to epilepsy. Duration of the disease affects children's QOL and it is assumed that having the disease for long years with accompanied frequent seizures will reduce QOL of the affected patients. In addition, having a history of other diseases such as cardiac disease will complicate the health status of the child and compromise his life. Moreover, consumption of anti-epileptic drugs with its side effects may decrease adherence to the prescribed treatment, which in turn will increase the frequency of seizure episodes and reduce the child's QOL.

**Characteristics of children:** This part includes factors such as gender, age of the child, and number of children in the family. It is assumed that these factors interacted collectively in the QOL, as older children have higher understanding of their life and the restrictions imposed due to fear of seizures may reduce the child's QOL. In addition, being in a big family with high number of children make the parents busy with the other children and decrease the time they spend with the CWE and that may affect his QOL. Moreover, the burden of the disease on ability to read and understand what he reads, besides being away from school due to appointments in the hospital for follow up will affect school achievement and reduce the child's QOL.

**Characteristics of the family:** This part includes parents' level of education, work and family income. The researcher assumes that highly educated parents will have better understanding and awareness of the disease and the needed precautions to be taken at home, and that will be reflected positively on the child's health and well-being. In addition, if the parents are working and the families have adequate income, they can afford for medication and healthy food, which will decrease the complications of the disease and improve the child’s QOL.

**Health-related quality of life:** This part includes suspected problems that related to HRQOL such as feeling nauseated, unpleasant smell and taste of food, and abdominal cramps, and these factors will affect eating patterns. In addition, medical interventions and procedures such as injections and blood test will increase the child’s anxiety and fear from the hospital and the healthcare providers, which will prohibit them to communicate their worries about their disease and treatments.

**Quality of life:** This part includes the four domains of QOL; cognitive functioning which is affected by the disease process, and frequency and severity of seizures. In addition, emotional functioning which focus on issues related to feelings of anxiety and depression and ability to express their feelings and worries. Moreover, social functioning focusing in inability of the child to interact with other children and that will provoke feelings of minority and isolation from his peers. The last one is physical functioning related to activities of daily living, ability to play and recreations. All these domains are components of QOL and how much the child achieves from these domains will shape his life and determine the level of QOL for those children who have epilepsy.

## 2.2 Literature review

### 2.2.1 Background

Epilepsy is a chronic disorder of the brain that affects people worldwide. The disease characterized by recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body or the entire body, and sometimes accompanied by loss of consciousness and loss of control of bowel or bladder function. Seizures can vary from the briefest lapses of attention or muscle jerks to severe and prolonged convulsions, also, vary in frequency, from less than one per year to several episodes per day (WHO, 2017). Epilepsy is a common neurologic disease with a lifetime cumulative risk of 1% to 2%; approximately one-half of epilepsy in the population first occurs during childhood (Linehan and Berg, 2011).

To diagnose epilepsy, the child should have at least two unprovoked or reflex seizures occurring greater than 24 hours apart, or having one unprovoked or reflex seizure and a probability of further seizures after two unprovoked seizures, occurring over the next 10 years (Fisher, 2014).

Beyond seizures, CWE face many challenges including high burden of psychiatric and behavioral comorbidities that often go untreated or even unrecognized. Such comorbidity might predate the onset of epilepsy or persist in the setting of seizure remission, thereby suggesting that epilepsy is a pervasive condition encompassing more than seizures (Baca et al., 2011).

### 2.2.2 Causes and predisposing factors

Epilepsy develops due to a variety of causes, some of the common causes include tumor of the brain, chemical imbalance such as low blood sugar or sodium, head injuries, certain toxic chemicals or drug abuse, and birth injuries (Huff, 2017). Epilepsy is approximately two-times higher in low- and middle-income countries compared to high-income countries. This is likely due to the increased risk of endemic conditions such as malaria, intracranial infections, higher incidence of road traffic injuries, birth-related injuries, and variations in medical infrastructure, availability of preventative health programs and accessible care (WHO, 2017). Moreover, family history of epilepsy and parental consanguinity were evident in 73.9% and 21.7% of the epileptic children (Alshahawy et al., 2018).

### 2.2.3 Epidemiology of epilepsy in children

Reports from WHO indicated that, more than 50 million people worldwide have epilepsy, making it one of the most common neurological diseases globally, and nearly 80% of people with epilepsy live in low- and middle-income countries (WHO, 2019).

Childhood epilepsy is among the most prevalent and important neurological conditions in the developing years, affecting 3.6 to 4.2 per 1000 children in developed countries, and approximately double these rates in developing countries ranging from 4 to 8 per 1000 children (Bilgic et al., 2018; Mathiak et al., 2010). There is a lack of updated information about incidence and prevalence of epilepsy in many countries, therefore, knowledge about the overall incidence and burden of childhood epilepsy is also insufficient (Fisher et al., 2014; Camfield and Camfield, 2014). Moreover, despite ongoing research and treatment advances, approximately one-third of individuals with epilepsy continue to have difficult-to-control seizures (England et al., 2012).

The worldwide prevalence of epilepsy is variable and varied among countries, with high prevalence found in early age group population. In north, central and south America high prevalence is found in male except in New York, Bolivia, Honduras and Argentina where prevalence is high in female. In Asian countries such as China, India, Turkey and Saudi Arabia the prevalence is high in Male except in Pakistan the prevalence is high in female.

In Japan, a cross-sectional study carried out in Japan aimed to estimate incidence and prevalence of epilepsy found that prevalence of epilepsy was 8.8 per 1000 in children younger than 13 years (Nakano and Inoue, 2014). In the United States of America (USA), according to report published by Child and Adolescent Health Measurement Initiative (CAHMI), there are approximately 470,000 children aged birth to 17 years with epilepsy accounting for 1.2/1000 population (CAHMI, 2018).

In Norway, a nationwide cohort study found that the incidence rate of epilepsy was 1.44 per 1000 person-years in the first year of life and 0.58 per 1000 for ages 1 to 10 years. The cumulative incidence of epilepsy was 0.66% at age 10 years, with 0.62% having active epilepsy. The study concluded that approximately one out of 150 children is diagnosed with epilepsy during the first 10 years of life, with the highest incidence rate observed during infancy (Aaberg et al., 2017).

In Egypt, a door-to-door community-based survey study aimed to estimate the epidemiological features of epilepsy. The results reflected that the active prevalence rate of epilepsy was 2.12/1000, while the incidence rate was 1.23/1000. The age-specific prevalence rate of epilepsy was much higher in infancy and early childhood (62.5 and 37.04/1000, respectively), which regressed steadily with age (Fawi et al., 2015).

In Egypt, a cross-sectional school-based survey study aimed to identify the prevalence of idiopathic epilepsy among schoolchildren. The study included 9,545 students aged 6-14 years. The results showed that the prevalence of idiopathic epilepsy was 7.2/1000. Higher prevalence reported in males 7.7/1000 and in children from urban areas 8.25/1000 (Alshahawy et al., 2018).

In Sudan, analytical population-based, cross-sectional study conducted in Khartoum, aimed to determine the prevalence of epilepsy in school-aged children. The study included 74,949 pupils in the primary schools aged 6-12 years. The results showed that 398 of pupils identified initially as having seizures and 332 of them (83.4%) identified by a pediatric neurologist. Among the 332 students, 303 (91.3%) proved to have epileptic seizures, 250 (82.5%) were known to have epilepsy, and 53 (17.5%) were newly diagnosed during the survey. The male to female ratio was 1.5:1. The total prevalence of epilepsy estimated to be 4/1000 (Mohamed et al., 2017).

In Palestine, the overall prevalence of epilepsy accounted for 0.8% in WB and GS, at a rate of 0.66/1000 population. According to MOH reports, 206 new pediatric cases registered in WB and 36 new cases registered in GS aged 0 to 15 years old (MOH, 2018).

### 2.2.4 Association between Epilepsy and Quality of Life

Health-related quality of life (HRQOL) is recognized as an important outcome in epilepsy treatment. HRQOL, which encompasses the impact of an illness and associated treatment on an individual's physical, emotional, social, and role functioning is compromised for many children with chronic medical conditions (Russ et al., 2012).

Seizure is the main feature of epilepsy in children, and different symptoms may occur depending on the type of seizure. The general symptoms or warning signs of a seizure can include staring, stiffening of the body, jerking movements of the arms and legs, loss of consciousness, and loss of bowel or bladder control. Other symptoms include breathing disturbances or apnea, falling suddenly for no apparent reason, especially when associated with loss of consciousness, not responding to noise or words for brief periods, appearing confused or in a haze, Periods of rapid eye blinking and staring, and nodding head rhythmically, when associated with loss of awareness or consciousness (Johns Hopkins Medicine, 2019).

Epilepsy can be associated with profound physical, psychological, and social consequences. Therefore, its impact on the patient's QOL can be greater than that of other chronic diseases. Patients with epilepsy reported a poorer QOL because they are more likely to have poor self-esteem and a high level of anxiety and depression. In some patients, the social stigma and impact on QOL can pose a greater challenge than the severity of clinical symptoms (Pimpalkhute et al., 2015). In addition, children with epilepsy face many challenges including physical restrictions due to seizures, antiepileptic drug (AED) side effects, and comorbid conditions, such as attention-deficit/hyperactivity disorder and learning problems (Morita et al., 2012).

In India, a cross-sectional hospital-based prospective study conducted to assess the QOL by using Quality of Life in Children with Epilepsy (QOLCE) questionnaire. The sample of the study consisted of 110 children aged 4 to18 years. The results showed that the mean total QOL score was 72.6 ± 13.6. The results also indicated that there was no significant association of the total QOL score with the socio-demographic variables such as gender, place, socioeconomic status, paternal/maternal education, or family type. Children with more severe seizures had significantly lower energy and QOL subscale scores and greater depression and anxiety. Prolonged duration of epilepsy, frequent seizures, and recent seizures had a significant negative correlation with the mean total QOL score. Children with epilepsy who are on multiple anti-epileptic drugs (AEDs), prolonged duration of AED intake, or poor adherence to AEDs have significantly lower total QOL score. Children manifesting adverse effects to AEDs had significantly lower overall QOL affecting all domains (Nagabushana et al., 2019).

In Canada, a cross-sectional, structural, equation model study included six Canadian child epilepsy ambulatory programs. The study aimed to assess the perspective of QOL among CWE. The sample of the study consisted of 3,481 children aged 8 to 14 years. The Result showed that epilepsy-specific QOL is strongly related to their mental health and social support but not to their seizures. The study concluded that controlling seizures is insufficient for influencing the children's perception of their life and mental health and social support should be areas of focus in the assessment of QOL (Fayed et al., 2015).

Another prospective cohort study conducted in Canada, aimed to assess HRQOL among children with new-onset epilepsy. The results showed that about one-half of children experienced clinically meaningful improvements in HRQL, one-third maintained their same level, and one-fifth declined. After controlling for baseline HRQOL, cognitive problems, poor family functioning, and high family demands were risk factors for poor HRQOL. The study concluded that HRQOL was relatively good but with highly variable individual trajectories. At least one-half of children did not experience clinically meaningful improvements or declined over 2 years (Speechley et al., 2012).

Another study conducted in Canada, aimed to examine the association between convulsive status epilepticus (CSE) and HRQOL during a 24-month follow-up in a multisite incident cohort of children with epilepsy. In this study, 359 families of children with newly diagnosed epilepsy completed the 24-month assessment questionnaire. The results indicated that 6.1% of children had experienced CSE during the follow-up. Children with and without CSE were similar, except a larger proportion of children with CSE had partial seizures. The study reflected that children with CSE have significantly poorer HRQL compared with their non-CSE counterparts (Ferro et al., 2014).

In Poland, a study conducted in Warsaw hospital aimed to determine QOL in childhood epilepsy. The study included 31 parents of CWE who filled the Health-Related Quality of Life in Childhood Epilepsy Questionnaire (QOLCE). The results found a significant correlation between seizures and reduced QOL. Children with right hemispheric foci exhibited lower overall QOL, particularly in five areas: anxiety, social-activities, stigma, general-health, and quality-of-life. The study concluded that lateralization of epileptic focus can affect psychosocial functioning and lead to diminished QOL in children and right-hemispheric foci may result in lower QOL (Mathiak et al., 2010).

In USA, a descriptive, cross sectional study carried out to identify two-year trajectories difference between USA and Canada of epilepsy-specific HRQOL among children newly diagnosed with epilepsy and to evaluate the predictive value of a comprehensive set of medical, psychosocial, and family factors. Caregivers completed the Quality of Life in Childhood Epilepsy (QOLCE) questionnaire. The results reflected that QOLCE provides a comprehensive predictive model of two-year trajectories of overall, physical, emotional, behavioral, social, and neurocognitive HRQOL for children following the initiation of epilepsy treatment (Loiselle et al., 2016).

In India, a cross-sectional study carried out to assess the QOL and to evaluate the influence of demographic and clinical factors on QOL in CWE. The results showed that the educational status, socioeconomic status, and maternal education were the demographic characters that significantly affected the QOL of study subjects. Type of seizures, early childhood history of seizures, duration of therapy and duration of epilepsy were the most important clinical characteristics that could significantly affect the QOL of study subjects (Sruijana et al, 2017).

A case-control study conducted in India aimed to assess QOL among asthmatic and epileptic children undergoing treatment. In this study, 269 children including 75 asthmatics, 94 epileptics and 100 controls enrolled from the OPD. Comparison of the two groups on four domains of quality of life: physical, emotional, social, and educational. The finding showed that children with epilepsy had a relatively more compromised quality of life in the emotional, social, and educational domains. There was no significant correlation between age at onset, duration of illness or family history with QOL in any domain except for the negative impact of family history on parent score on social and educational domains in epileptic children. However, family history of epilepsy had no correlation with child self-reported QOL. The study concluded that CWE have a relatively compromised QOL, and focusing simply on control of primary illness may not address the full range of child’s emotional and behavioral difficulties (Gandhi et al., 2013).

In Sudan, a descriptive, cross-sectional study conducted at the Epilepsy and Neurodisability Outpatient Clinic at Saad Abualila University Hospital. The study aimed to assess the QOL among children with epilepsy and their family caregivers. The study included 100 CWE (aged 6 – 18 years old) and their caregivers. The results showed that seizure duration was more than one year, and there was a significant decline in the QOL among CWE (Abbas et al., 2014).

In Egypt, a cross-sectional, case control study carried out to assess the HRQOL and its predictors among children with epilepsy. The results showed that diminished HRQOL was a common feature of epilepsy. In addition, highly significant lower overall QOL scores of all functioning domains of HRQOL. The study concluded that epileptic patients were at a higher risk of impaired QOL (Monir, 2013).

# Chapter Three

## Methodology

This chapter presents the method of the study to answer the research questions. In this chapter different items were explained: study design, study population, sample size and sampling method, setting of the study, period of the study, inclusion and exclusion criteria, study tools, pilot study, validity and reliability, data collection, data management and analysis, ethical consideration, and limitation of the study.

### 3.1 Study design

This study utilized descriptive, analytical, cross-sectional design. This design is appropriate for describing the status of phenomena or for describing relationships among phenomena and involves the collection of data once the phenomena under study are captured during a single period of data collection (Polit and Beck, 2012).

### 3.2 Study Population

The study population consisted of all school-age children with confirmed diagnoses of epilepsy that receive treatment and follow up at Al-Rantisi Specialized Pediatric Hospital and Al Durra Pediatric Hospital. Their total number was 230 children with epilepsy.

### 3.3 Sample Size and Sampling Method

According Medical records of the two hospitals, there are 128 children with epilepsy registered in the medical records at RSPH and 102 at DPH. The Proportional sample obtained. The researcher used Survey system, 2012 (Annex 2) for sample size calculation. The sample size was 144 children. According to proportion for each hospital, 80 children from RSPH and 64 children from DPH included in the study. The researcher selected the sample subjects from the OPD at the two hospitals during their visit for treatment and follow up (convenience sample) who met inclusion criteria.

### 3.4 Setting of the study

The study conducted at the main two governmental hospitals that offer health services to children with epilepsy in Gaza Strip; Al Rantisi Specialized Pediatric Hospital and Al Durra Pediatric Hospital in Gaza.

### 3.5 Period of the Study

The study has been commenced during the period from September 2018 to March 2019. Data collection took place from November 2018 to January 2019.

### 3.6 Eligibility Criteria

#### 3.6.1 Inclusion criteria

- Every school-age child patient with confirmed diagnosis of epilepsy by a physician.
- Oriented and able to communicate.
- Registered in the hospital medical records of the hospital.

#### 3.6.2 Exclusion criteria

- Patients who have communication impairment.
- Children with intellectual impairment.
- Children with cerebral palsy.
- Newly discovered patients of less than three months.

### 3.7 Instruments of the Study

After review of available literature and previous studies, the researcher used three face-to-face structured interview questionnaires. The first one related to demographic characteristics, the second questionnaire measures health related quality of life (HRQOL), and the third questionnaire measures quality of life for school-age children with epilepsy. Description of questionnaires as illustrated below:

### 3.7.1 Demographic Characteristics.

- Personal information: Age, gender, class, school achievement, number of children, and order of the child in his family.
- Family characteristics: parents' education level, parents' work, and family income.
- Medical history: duration of epilepsy, frequency of seizure attacks, frequency of admissions, presence of other disease, and presence of adverse effects from medication(Annex 4).

### 3.7.2 Health Related Quality of Life Epilepsy Module (HRQOL)

The questionnaire designed for school age children. It consists of 16 items distributed on four domains as the following: (Annex 5 + 6)

- First domain: Nausea (problems with…) consisted of 5 items.
- Second domain: Procedural anxiety (problems with…) consisted of 3 items.
- Third domain: Treatment anxiety (problems with…) consisted of 2 items.
- Fourth domain: Worry (problems with…) consisted of 3 items.
- Fifth domain: Communication (Problems with ...) consisted of 3 items.

Items of the questionnaire are rated on a five point Likert scale: (0) very often, (1) fairly often, (2) sometimes, (3) almost never, (4) never.

Higher scores indicating better HRQOL.

| Low | Moderate | Good | Very good | Excellent |
|---|---|---|---|---|
| < 50% | 50 – 65% | 66 – 80% | 81 – 90% | ≥ 91% |

### 3.7.3 Quality of Life in Childhood Epilepsy Questionnaire: QOLCE-55

The QOLCE- 55 is a modified version, which assesses parent reported QOL of CWE aged 4–18 years of age. The questionnaire developed by Goodwin et al., (2015). It is self-administered questionnaire, and has excellent psychometric properties.

The original questionnaire consisted of 55 items, and due to cultural issues in GS, two items omitted, therefore, the questionnaire in this study consisted of 53 items distributed on four main domains: (Annex 7)

- First domain: cognitive functioning consisted of 22 items
- Second domain: emotional functioning consisted of 16 items.
- Third domain: social functioning consisted of 7 items.
- Fourth domain: physical functioning consisted of 8 items.

Items of the questionnaire are rated on a five-point Likert scale: (0) Very often, (1) fairly often, (2) sometimes (3) almost never, (4) never.

The composite QOL score is the weighted percentage average score of the four domains. Higher scores indicate better QOL.

| Low | Moderate | Good | Very good | Excellent |
|---|---|---|---|---|
| < 50% | 50 – 65% | 66 – 80% | 81 – 90% | ≥ 91% |

### 3.8 Validity and reliability of study instruments

#### 3.8.1 Face Validity

To examine clarity of questionnaires, the researcher distributed the questionnaire to a group of experts in health research for face and judged content validity. (Annex 8)

#### 3.8.2 Reliability

The researcher conducted a pilot study on 14 participants selected randomly to examine its reliability. Those who participated in the pilot study were included in the actual sample. The researcher used Cronbache alpha method as presented in table (3.1) and (3.2).

**Table (0.1): Cronbache alpha coefficient for HRQOL**

| **Domain** | **No. of items** | **Coefficient value** |
|---|---|---|
| Nausea (problems with…) | 5 | 0.809 |
| Procedural anxiety (problems with…) | 3 | 0.857 |
| Treatment anxiety (problems with…) | 2 | 0.759 |
| Worry (problems with…) | 3 | 0.824 |
| Communication (Problems with ...) | 3 | 0.919 |
| **Total score** | **16** | **0.867** |

Table (0.2): Cronbache alpha coefficient for QOL

| Dimension | No. of items | Coefficient value |
|---|---|---|
| Cognitive functioning | 22 | 0.940 |
| Emotional functioning | 16 | 0.687 |
| Social functioning | 7 | 0.835 |
| Physical functioning | 8 | 0.644 |
| **Total score** | **53** | **0.887** |

The results showed that the two questionnaires were highly reliable, therefore, no questions omitted from the questionnaires.

### 3.9 Data Collection

Data collected through a face-to-face interview by the researcher. The researcher interviewed each child and his / her parent during their presence in the OPD at Al Rantisi hospital and Al Durra hospital. Each interview took about 20 minutes.

All questionnaire forms were prepared, organized, and classified with serial numbers to confirm the availability of the needed information.

The researcher explained the purpose of the questionnaire to the participants and their parents and obtain consent form them (annex 3).

### 3.10 Data management and Analysis

The researcher got assistance from a statistician for data entry and analysis. SPSS program (version 22) used for data analysis. The process of data entry and statistical analysis included the following process: Overview of filled questionnaires, designing data entry model, coding and data entry into the computer, and data cleaning to ensure accurate entry of data. These process achieved by checking out a random of questionnaires and performing descriptive statistics for all the variables.

**Data analysis included:**

Frequencies, percentage, mean and standard deviation for distribution of the study variables. In addition, the researcher used independent sample (t) test, and One-Way ANOVA.

### 3.11 Ethical and Administrative Considerations

Approval obtained from Al-Quds University for the study preparation, approval from Helsinki Committee (annex 9), permission from MOH (annex 10) to conduct the study. All participants were asked for voluntary participation in the study. In addition, the researcher assured the participants about confidentiality of obtained data for the purpose of research only.

### 3.12 Limitations of the Study

- The researcher faced difficulty in data collection from the participants because the neurology clinic is available two days per week in Al Rantisi hospital and one day per week in Al Durra hospital.
- Limited literature about the study locally, since it is the first study targeting children with epilepsy in Gaza strip.

# Chapter Four

## Result & Discussion of the study

This chapter presented the results of the study. The researcher used tables and figures to make the results more clear and easy to understand. In addition, the researcher discussed the results in relation to literature and previous studies.

### 4.1 Socio-Demographic Characteristics of Study Participants

In this study, 144 children with confirmed diagnosis of epilepsy participated in the study. Their characteristics illustrated below.

**Table (4.1): Distribution of study participants by socio-demographic characteristics (N= 144)**

| Variable | Category | n | % |
|---|---|---|---|
| **Hospital** | Al Rantisi | 80 | 55.6 |
| | Al Durra | 64 | 44.4 |
| **Gender** | Male | 68 | 47.2 |
| | Female | 76 | 52.8 |
| **Age** | 6 – 9 years | 86 | 59.7 |
| | 10 – 12 years | 58 | 40.3 |
| | Mean age 8.86±1.93 years | | |
| **School achievement** | Fair | 30 | 20.8 |
| | Good | 42 | 29.2 |
| | Very good | 52 | 36.1 |
| | Excellent | 20 | 13.9 |
| **Child order** | First – third child | 82 | 56.9 |
| | Fourth – sixth child | 48 | 33.3 |
| | Seventh child and more | 14 | 9.8 |

Table (4.1) showed that 55.6% of the study participants from Al Rantisi hospital, and 44.4% from Al Durra hospital. Concerning gender, 52.8% were female patients and 47.2% were male patients, their age ranged between 6 – 12 years with mean age 8.86±1.93 years; of them 59.7% aged between 6 – 9 years and 40.3% aged between 10 – 12 years old. In addition, 36.1% have very good school achievement and 13.9% have excellent school achievement.

Other studies reflected variations in socio-demographic characteristics. The results obtained by Sruijana et al., (2017) showed that more than two-thirds of participants were male subjects, age ranged between 6 – 15 years, age group was more or less equally distributed between 6–10 and 11–15 years. The largest portion of study participants was from the low economic class. Moreover, more than two-thirds of the study participants has at least minimum level of education, and maternal education was very low. Furthermore, Mohamed et al., (2017) found that male to female ratio was 1.5:1. Another study carried out in Iran found that mean age of CWE was 11.8 years, 55.8% were male children and 44.2% were female, 42.5% were the first child and 25% were the second child in the family, less than half of them were from the first to third class (Shamsaei et al., 2016). Moreover, epilepsy affects school attendance and achievement. In this regard, a study carried out by Pastor et al., (2015) showed that students with epilepsy were more likely to miss 11 or more days of school in the past year. In addition, they were more likely to have difficulties in school, use special education services, and have activity limitations such as less participation in sports or clubs.

**Table (4.2): Distribution of study participants by family characteristics (N= 144)**

| Variable | Category | n | % |
|---|---|---|---|
| **Fathers' education** | Preparatory and less | 54 | 37.5 |
| | Secondary | 50 | 34.7 |
| | University | 40 | 27.8 |
| **Mothers' education** | Preparatory and less | 39 | 27.1 |
| | Secondary | 57 | 39.6 |
| | University | 48 | 33.3 |
| **Fathers' work** | Working | 97 | 67.4 |
| | Not working | 47 | 32.6 |
| **Mothers' work** | Working | 5 | 3.5 |
| | Not working | 139 | 96.5 |
| **Family income** | Less than 1000 NIS | 88 | 61.1 |
| | 1000 NIS and more | 56 | 38.9 |
| | Mean 830.20±578.55 NIS | | |

Table (4.2) showed that 37.5% of fathers and 27.1% of mothers have low education of preparatory school and less, while 27.8% of fathers and 33.3% of mothers have university education. In addition, 67.4% of fathers and 3.5% of mothers are working, 61.1% have low income of less than 1000 NIS, 38.9% have monthly income of 1000 NIS and more, and the mean monthly income was 830.20±578.55 NIS.

The results obtained by Sruijana et al., (2017) who found that the largest portion of study participants was from the low economic class, and maternal education was very low. These results were inconsistent with the situation in Palestine as the prevalence of epilepsy was 0.8/1000 in WB and 0.66 in GS.

The incidence and prevalence of epilepsy in low and middle-income countries (LMIC) is higher than in high-income countries (HIC). Ngugi et al., (2010) reported that the median lifetime epilepsy prevalence for developed countries is 5.8 per 1.000, whereas in rural areas of developing countries is 15.4 per 1.000. Moreover, Ngugi et al., (2011) found that the incidence of epilepsy is 45/100.000/year in HIC, compared to 81.7/100.000/year in LMIC.

These results reflected the economic situation in GS with shortage of work opportunities and those who are working usually get very low salary. In addition, those children need close monitoring and special precautions by family members because they may have epileptic attacks suddenly and may harm themselves. This situation will affect the ability of families to afford essential health needs of their sick children and would impose negative impact on their QOL.

**Table (4.3): Distribution of study participants by medical conditions**

| Variable | Category | n | % |
|---|---|---|---|
| **Presence of other diseases** | None | 106 | 73.6 |
| | Renal | 12 | 8.3 |
| | Cardiac | 7 | 4.9 |
| | Cancer and blood disorders | 12 | 8.3 |
| | Gastrointestinal | 4 | 2.8 |
| | Other diseases | 3 | 2.1 |
| **Number of admissions in the last year** | None | 73 | 50.7 |
| | One time | 61 | 42.4 |
| | 2 times and more | 10 | 6.9 |
| **History of previous illness** | None | 41 | 28.5 |
| | Fever | 12 | 8.3 |
| | Meningitis | 9 | 6.3 |
| | Head trauma | 64 | 44.4 |
| | Post-term | 6 | 4.2 |
| | Encephalitis | 12 | 8.3 |
| **Number of epileptic attacks in the last 6 months** | None | 40 | 27.8 |
| | One attack | 49 | 34.0 |
| | 2 attacks | 27 | 18.8 |
| | 3 attacks and more | 28 | 19.4 |

Table (4.3) showed that the majority of study participants 73.6% did not have another disease, 50.7% have not been admitted to the hospital, while less than one-half 42.4% have been admitted to the hospital one time during the last year. In addition, 44.4% had a history of head trauma, and 34% had at least one epileptic attack in the past 6 months.

These results indicated that the majority of study participants do not have any accompanied disease, and about half of them admitted to the hospital one time and or more than one time during the past year. In addition, less than half of study participants had a history of head trauma, and more than one-third had at least one epileptic attack in the past 6 months.

Lower results obtained by Ferro et al, (2014) who found that 6.1% of children had experienced convulsive status epilepticus (CSE) during the follow-up, and larger proportion of them had partial seizures. Furthermore, Abbas et al., (2014) found that seizure duration was more than one year.

Different studies found that head trauma, Traumatic brain injury (TBI), central nervous system (CNS) infections and perinatal injuries were among the common risk factors for epilepsy (Newton and Garcia 2012; Del Brutto et al., 2005; Burton et al., 2012; Kannoth et al., 2009). Therefore, we can say that children need close monitoring to avoid exposure to trauma and consequently reduce the chance to develop epilepsy.

**Table (4.4): Presence of side effects caused by medication (N= 144)**

| Variable | Category | n | % |
|---|---|---|---|
| **Presence of side effects** | Yes | 40 | 27.8 |
| | No | 104 | 72.2 |
| **Symptoms caused by side effects** | Headache | 10 | 25.0 |
| | Abdominal pain | 8 | 20.0 |
| | Nervousness | 7 | 17.5 |
| | Weight gain | 7 | 17.5 |
| | Hyperactivity | 6 | 15.0 |
| | Delay of speech | 2 | 5.0 |
| | Total | 40 | 100.0 |

Table (4.4) showed that 27.8% of study participants complained from side effects caused by consumption of medication. Side effects included headache 25.0%, abdominal pain 20.0%, nervousness, and weight gain 17.5% for each, hyperactivity 15.0%, and delayed speech 5.0%.

Antiepileptic drugs (AEDs) cause some degree of adverse drug reactions. Thigpen et al., (2013) reported that side effects of AEDs include agitation, aggression, psychosis, behavioral disorders, hyperactivity, and restlessness.

Presence of side effects may lead to noncompliance to prescribed medication and that may provoke the progression of the disease and increase frequency of seizures. This situation will complicate the health status of the patients and consequently decrease their HRQOL and QOL. It is important to act towards alleviating the side effects of medication through following the instructions of their healthcare provider, taking medication as prescribed in relation to dose and time of medication.

## 4.2 Descriptive Results

### 4.2.1 Health related quality of life

**Table (4.5): Health related quality of life among study participants (N= 144)**

| Items | | Never (4) | Seldom (3) | Sometimes (2) | Often (1) | Always (0) | Mean | SD | % | Rank |
|---|---|---|---|---|---|---|---|---|---|---|
| **Nausea (problems with ….)** | | | | | | | | | | |
| 1 | I become sick to my stomach when I have medical treatments. | 48.6 | 31.9 | 11.1 | 5.6 | 2.8 | 3.18 | 1.02 | **79.5** | 1 |
| 2 | Food does not taste very good to me. | 27.1 | 32.6 | 20.1 | 7.6 | 12.5 | 2.54 | 1.30 | **63.5** | 5 |
| 3 | I become sick to my stomach when I think about medical treatments. | 45.8 | 13.9 | 13.2 | 23.6 | 3.5 | 2.75 | 1.34 | **68.7** | 4 |
| 4 | I feel too sick to my stomach to eat. | 36.1 | 34.7 | 13.2 | 9.7 | 6.3 | 2.84 | 1.19 | **71.0** | 3 |
| 5 | Some foods and smells make me sick to my stomach. | 45.1 | 30.6 | 13.2 | 6.3 | 4.9 | 3.04 | 1.13 | **76.0** | 2 |
| **Procedural anxiety (problems with ….)** | | | | | | | | | | |
| 6 | Needle sticks (i.e. injections, blood tests, IV's) hurt. | 35.4 | 26.4 | 18.1 | 15.3 | 4.9 | 2.72 | 1.23 | **68.0** | 3 |
| 7 | I get scared when I have to have blood tests. | 50.0 | 20.8 | 14.6 | 4.9 | 9.7 | 2.96 | 1.31 | **74.0** | 2 |
| 8 | I get scared about having needle sticks (i.e. injections, blood tests, IV's). | 45.1 | 28.5 | 10.4 | 11.1 | 4.9 | 2.97 | 1.20 | **74.2** | 1 |
| **Treatment anxiety (fear with …..)** | | | | | | | | | | |
| 9 | I get scared when I am waiting to see the doctor. | 13.9 | 22.2 | 19.4 | 13.2 | 31.3 | 1.74 | 1.45 | **43.5** | 2 |
| 10 | I get scared when I have to go to the doctor. | 22.9 | 22.2 | 16.7 | 23.6 | 14.6 | 2.15 | 1.39 | **53.7** | 1 |
| **Worry (problems with …..)** | | | | | | | | | | |
| 11 | I worry about side effects from medical treatments. | 29.9 | 25.0 | 16.7 | 14.6 | 13.9 | 2.42 | 1.40 | **60.5** | 1 |
| 12 | I worry about whether or not my medical treatments are working. | 16.7 | 32.6 | 21.5 | 18.8 | 10.4 | 2.26 | 1.24 | **56.5** | 2 |
| 13 | I worry that my epilepsy will come back or relapse. | 11.1 | 8.3 | 16.0 | 22.2 | 42.4 | 1.23 | 1.36 | **30.7** | 3 |
| **Communication (problems with …..)** | | | | | | | | | | |
| 14 | I find it difficult to tell doctors or nurses how I feel. | 22.9 | 31.3 | 27.8 | 9.7 | 8.3 | 2.50 | 1.18 | **62.5** | 2 |
| 15 | I find it difficult to ask questions to doctors or nurses. | 25.7 | 31.3 | 22.9 | 17.4 | 2.8 | 2.59 | 1.13 | **64.7** | 1 |
| 16 | I find it difficult to explain my illness to others. | 17.4 | 16.7 | 25.0 | 24.3 | 16.7 | 1.93 | 1.33 | **48.2** | 3 |

Table (4.5) showed that 79.5% of children stated that they became stomach sick when taking medical treatment, 76% said that the smell of some foods make them sick, 74.2%

said that they get scared of having injections. In addition, 53.7% stated that they get scared when they go to the doctor, 60.5% mentioned that they get worry about side effects of medication, and 64.7% said that they find it difficult to ask questions to the doctors or nurses.

Jacoby and Baker (2008) reported that patients with epilepsy are at increased risk for poor HRQOL, which have an impact on the overall perception of an individual's position in life. In addition, Taylor et al., (2011) found that depression and anxiety, along with seizure frequency, appeared to be consistently predictive of poor levels of HRQOL among patients with epilepsy.

Health related quality of life regarded as the most important health outcome in any chronic health condition, and the primary goal of the management of CWE is to both improve and prevent potential declines in their HRQOL. These results reflected above moderate level in most of HRQOL items and that would reflect their general health and wellbeing.

In my opinion, it is obvious that being a sick child with epilepsy that requires strict adherence to long-term treatment regime is a very sensitive event that complicates the child’s life. Anti-epileptic drugs usually interferes with activities such as ability to concentrate in the study and doing the school homework, ability to play like other children of his age, and the adverse effects of drugs. Usually, the child will dislike the hospital and will be frighten from some procedures such as blood tests and injections which is painful to him. All these conditions will give the child a feeling of minority compared to his peers and that would be reflected in his behavior and his future life in general. These children would develop mental health disturbances such as anxiety and depression, therefore, they need special psychosocial care to avoid their feeling of minority and accept their life, looking for better future.

**Table (4.6): Overall health related quality of life among study participants**

| Domains of HRQOL | No. of items | Mean | SD | % | Rank |
|---|---|---|---|---|---|
| Nausea (problems with ….) | 5 | 2.87 | 0.86 | 71.75 | 2 |
| Procedural anxiety (problems with ….) | 3 | 2.89 | 1.10 | 72.25 | 1 |
| Treatment anxiety (fear with …..) | 2 | 1.95 | 1.33 | 48.75 | 5 |
| Worry (problems with …..) | 3 | 1.96 | 1.11 | 49.00 | 4 |
| Communication (problems with …..) | 3 | 2.35 | 0.97 | 58.75 | 3 |
| **Overall (Total)** | **16** | **2.41** | **1.07** | **60.25** | |

As presented in table (4.6), CWE expressed moderate health related quality of life with mean score 2.41 and weighted percentage 60.25%. The highest was procedural anxiety (72.25%) and the lowest was treatment anxiety (48.75%).

Health related quality of life reflects the impact of dysfunctions associated with the illness, injury, or medical treatment among patients with chronic health disorders such as epilepsy. Comparing our results with previous studies showed that some results were consistent with our results and other studies showed inconsistent results. Our results were consistent with the results of Monira et al., (2013) which showed that diminished HRQOL is a common feature of epilepsy, and highly significant lower overall QOL scores of all functioning domains of HRQOL were present between patients. In addition, Ovsonkova and Mahutova, (2014) mentioned that medication treatment is associated with possible side effects, which have an influence on a child´s overall behavior. The child feels often tired and sleepy, their overall activity and attention are on the decrease, and vice versa, irritability increases and they tend to suffer from mood swings. These symptoms have negative impact on the child’s wellbeing and lead to poor long-term HRQOL (Ramsey et al., 2016), while Speechley et al., (2012) showed that CWE expressed good HRQOL, and with treatment about one-half of children experienced meaningful improvements in HRQL. Furthermore, the results obtained by Ferro et al., (2014) reflected that children with CSE have significantly poorer HRQL.

### 4.2.2 Quality of Life

**Table (4.7a): Quality of life among study participants (Cognitive functioning)(N= 144)**

| No. | Item | Very often (0) | Fairly often (1) | Some-times (2) | Almost never (3) | Never (4) | Mean | SD | % | Rank |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | Had difficulty attending to an activity. | 7.6 | 10.4 | 27.8 | 19.4 | 34.7 | 2.36 | 1.26 | 59.0 | 8 |
| 2 | Had difficulty reasoning or solving problems. | 10.4 | 17.4 | 24.3 | 29.9 | 18.1 | 2.72 | 1.24 | 68.0 | 4 |
| 3 | Had difficulty making plans or decisions. | 6.3 | 17.4 | 36.1 | 27.8 | 12.5 | 2.22 | 1.07 | 55.5 | 13 |
| 4 | Had difficulty keeping track of conversations. | 6.9 | 17.4 | 20.1 | 43.8 | 11.8 | 2.63 | 1.11 | 65.7 | 6 |
| 5 | Had trouble concentrating on a task. | 12.5 | 15.3 | 34.7 | 31.9 | 5.6 | 2.02 | 1.09 | 50.5 | 17 |
| 6 | Had difficulty concentrating on reading. | 17.4 | 17.4 | 33.3 | 21.5 | 10.4 | 1.90 | 1.22 | 47.5 | 18 |
| 7 | Had difficulty doing one thing at a time. | 10.4 | 11.8 | 30.6 | 36.8 | 10.4 | 2.25 | 1.25 | 56.2 | 11 |
| 8 | Reacted slowly to things being said and done. | 7.6 | 20.1 | 29.9 | 27.8 | 14.6 | 2.21 | 1.12 | 55.2 | 14 |
| 9 | Found it hard remembering things. | 11.8 | 18.1 | 22.9 | 36.8 | 10.4 | 2.15 | 1.19 | 53.7 | 15 |
| 10 | Had trouble remembering names of people. | 6.9 | 4.9 | 15.3 | 42.4 | 30.6 | 2.84 | 1.12 | 71.0 | 2 |
| 11 | Had trouble remembering where s/he put things. | 3.5 | 6.9 | 19.4 | 47.2 | 22.9 | 2.79 | 0.98 | 69.7 | 3 |
| 12 | Had trouble remembering things people told him/her. | 9.7 | 19.4 | 20.8 | 37.5 | 12.5 | 2.23 | 1.18 | 55.7 | 12 |
| 13 | Had trouble remembering things he read hours or days before. | 33.3 | 19.4 | 18.8 | 25.7 | 2.8 | 1.54 | 1.26 | 38.5 | 20 |
| 14 | Planned to do something then forgot. | 13.2 | 9.0 | 37.5 | 30.6 | 9.7 | 2.14 | 1.14 | 53.5 | 16 |
| 15 | Had trouble finding the correct words. | 6.3 | 14.6 | 20.8 | 38.2 | 20.1 | 2.51 | 1.15 | 62.7 | 7 |
| 16 | Had trouble understanding following what others were saying. | 2.8 | 16.0 | 34.0 | 37.5 | 9.7 | 2.35 | 0.95 | 58.7 | 9 |
| 17 | Had trouble in understanding directions. | 9.0 | 5.6 | 21.5 | 31.9 | 31.9 | 2.72 | 1.22 | 68.0 | 4 |
| 18 | Had difficulty following simple instructions. | 2.1 | 2.1 | 13.2 | 43.8 | 38.9 | 3.15 | 0.87 | 78.7 | 1 |
| 19 | Had difficulty following complex instructions. | 34.0 | 33.3 | 25.7 | 6.3 | 0.7 | 1.06 | 0.95 | 26.5 | 22 |
| 20 | Had trouble understanding what s/he read. | 27.1 | 21.5 | 27.1 | 18.1 | 6.3 | 1.54 | 1.23 | 38.5 | 21 |
| 21 | Had trouble writing. | 21.5 | 19.4 | 24.3 | 27.8 | 6.9 | 1.79 | 1.25 | 44.7 | 19 |
| 22 | Had trouble talking. | 9.7 | 11.1 | 29.2 | 38.9 | 11.1 | 2.30 | 1.11 | 57.5 | 10 |
| **Average** | | | | | | | **2.22** | **0.70** | **55.5** | |

Table (4.7a) presented cognitive functioning among study participants. The results showed that 34.7% of children never had difficulty attending to an activity, and 36.1% sometimes had difficulty making plans or decisions. In addition, 34.7% sometimes had trouble concentrating on a task, 17.4% very often had difficulty concentrating on reading and 20.1% very often reacted slowly to things being said and done. Moreover, 42.4% almost never had trouble remembering names of people, 47.2% almost never had trouble remembering where s/he put things and 33.3% very often had trouble remembering things heard hours or days before. Furthermore, 37.5% sometimes planned to do something then forgot, 34% sometimes had trouble understanding following what others were saying, 34% very often had difficulty following complex instructions, and 27.1% very often had trouble understanding what s/he read. In general, children who have epilepsy expressed moderate level of cognitive functioning (55.5%).

Cognitive functions are very important for some abilities such as reading understanding, and thinking. Our result is supported by Stong (2010) who reported that seizures cause chronic and progressive effects on brain structure and cognition, caused by progressive thinning of the neocortex with an increasing duration of epilepsy, which lead to loss of cognitive functioning among patients with epilepsy. Moreover, cognitive problems in epilepsy are frequent. They can have multiple causes, the most important being brain lesions, seizures, epileptic dysfunction, and treatment (Helmstaedter, 2013). According to Epilepsy Foundation of Michigan survey, 90% of respondents indicated that memory and thinking problems limited their QOL. The impact of these problems on QOL was even greater than the impact of seizures. Several factors associated with epilepsy can all affect memory and thinking including, medication side effects, effects of seizures, abnormal electrical activity in the brain between seizures, structural changes in the brain associated with epilepsy, stress and depression, and sleep problems (Epilepsy Foundation of Michigan, 2018).

**Table (4.7b): Quality of life among study participants (Emotional functioning) (N= 144)**

| No. | Item | Very often (0) | Fairly often (1) | Some-times (2) | Almost never (3) | Never (4) | Mean | SD | % | Rank |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | Felt down or depressed. | 15.3 | 13.2 | 29.2 | 30.6 | 11.8 | 2.10 | 1.23 | 52.5 | 12 |
| 2 | Felt happy. | 41.7 | 25.7 | 27.1 | 4.9 | 0.7 | 3.02 | 0.97 | 75.5 | 3 |
| 3 | Wished s/he were dead. | 7.6 | 8.3 | 30.6 | 33.3 | 20.1 | 2.50 | 1.13 | 62.5 | 6 |
| 4 | Felt frustrated. | 6.9 | 18.1 | 25.7 | 36.1 | 13.2 | 2.30 | 1.12 | 57.5 | 10 |
| 5 | Worried a lot. | 9.0 | 18.8 | 41.0 | 25.7 | 5.6 | 2.00 | 1.01 | 50.0 | 13 |
| 6 | Felt confident. | 21.5 | 32.6 | 30.6 | 11.1 | 4.2 | 2.56 | 1.07 | 64.0 | 5 |
| 7 | Felt excited or interested in something. | 48.6 | 40.3 | 7.6 | 2.8 | 0.7 | 3.33 | 0.79 | 83.2 | 2 |
| 8 | Felt pleased about achieving something. | 63.9 | 20.8 | 11.8 | 3.5 | 0 | 3.45 | 0.83 | 86.2 | 1 |
| 9 | Felt nobody understood him/her. | 6.9 | 11.8 | 42.4 | 27.1 | 11.8 | 2.25 | 1.04 | 56.2 | 11 |
| 10 | Felt valued. | 22.2 | 50.7 | 18.1 | 9.0 | 0 | 2.86 | 0.86 | 71.5 | 4 |
| 11 | Felt no one cared. | 9.0 | 11.8 | 29.9 | 36.1 | 13.2 | 2.32 | 1.12 | 58.0 | 9 |
| 12 | Was socially inappropriate (said or did something out of place in a social situation). | 8.3 | 9.0 | 33.3 | 38.9 | 10.4 | 2.34 | 1.05 | 58.5 | 8 |
| 13 | Angered easily. | 62.5 | 18.8 | 11.1 | 6.9 | 0.7 | 0.64 | 0.97 | 0.1 | 16 |
| 14 | Hit or attacked people. | 27.8 | 24.3 | 30.6 | 13.2 | 4.2 | 1.41 | 1.14 | 35.2 | 14 |
| 15 | Was obedient. | 16.0 | 22.2 | 46.5 | 11.8 | 3.5 | 2.35 | 0.99 | 58.7 | 7 |
| 16 | Demanded a lot of attention. | 31.9 | 35.4 | 18.1 | 14.6 | 0 | 1.15 | 1.03 | 28.7 | 15 |
| **Average** | | | | | | | **2.28** | **0.49** | **57.0** | |

Table (4.7b) presented emotional functioning among the study participants. The results showed that 86.2% of children were pleased about their achievements, 83.2% were interested in doing things, 75.5% felt happy, and 71.5% felt valued. In addition, 64% felt confident, and 58.7% were obedient. While 58.5% were socially inappropriate, and 58% felt no one cared.

In general, children who have epilepsy expressed moderate emotional functioning (57%).

Living with epilepsy is one of the important causes of mental health problems such as lack of adequate confidence, conduct disorder, anxiety, and hyperactivity. There were statistically significant differences between CWE compared to healthy children as for attention-deficit hyperactivity disorder, generalized anxiety disorder, major depression, separation anxiety, and social phobia (Shamsaei et al., 2016).

The impact of epilepsy on emotional well-being can be significant. Fear of seizures, anxiety, depression, family conflict, and struggles with independence are all common among CWE (Epilepsy Foundation of Michigan, 2018). Emotional and behavioral difficulties are also disproportionately high in children with epilepsy. Psychiatric disorders were identified in 34.6% of children with seizures compared to 6.6% in the general population and 11.6% in children with other chronic illnesses (Hauser and Hesdorffer, 2001). Another study showed that 24.6 % of CWE had higher than expected rates of behavioral problems especially attention deficit (Austin et al., 2001).

In my opinion, the patients and their families are emotionally under pressure caused by fear of seizures that may occur suddenly. Being under stress will affect their behavior and social activities; they tend to be socially isolated, and that will impose negative impact on their QOL.

## Table (4.7c): Quality of life among study participants (Social functioning) (N= 144)

| No. | Item | Very often (0) | Fairly often (1) | Some-times (2) | Almost never (3) | Never (4) | Mean | SD | % | Rank |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | Limited his/her social activities (visiting friends, close relatives, or neighbors). | 6.3 | 4.9 | 24.3 | 54.9 | 9.7 | 2.56 | 0.95 | 64.0 | 3 |
| 2 | Affected his/her social interactions at school or work. | 10.4 | 16.0 | 32.6 | 33.3 | 7.6 | 2.11 | 1.09 | 52.7 | 6 |
| 3 | Limited his/her leisure activities (hobbies or interests). | 9.7 | 13.9 | 35.4 | 33.3 | 7.6 | 2.15 | 1.07 | 53.7 | 5 |
| 4 | Isolated him/her from others. | 6.3 | 9.0 | 11.1 | 52.8 | 20.8 | 2.72 | 1.08 | 68.0 | 1 |
| 5 | Made it difficult for him/her to keep friends. | 6.9 | 11.1 | 26.4 | 44.4 | 11.1 | 2.41 | 1.05 | 60.2 | 4 |
| 6 | Frightened other people. | 5.6 | 4.9 | 22.9 | 56.3 | 10.4 | 2.61 | 0.93 | 65.2 | 2 |
| 7 | How limited are your child's social activities compared with others his/her age because of his/her epilepsy or epilepsy-related problems? | A lot | Some | Little | Rare | Not limited | Mean | SD | % | |
| | | 0 | 11.8 | 54.2 | 29.2 | 4.9 | 2.27 | 0.73 | 56.7 | |
| **Average** | | | | | | | **2.40** | **0.65** | **60.0** | |

Table (4.7c) presented social functioning among study participants. The results showed that 68% of children isolated themselves from other people, 65.2% frightened other people, and 64% limited their social activities. In addition, 60.2% had difficulty in keeping friends, and 53.7% limited their leisure activities. In general, the results indicated that CWE expressed above moderate social functioning (60%).

This result was supported by a study carried out in USA, which found that CWE have behavioral and social problems, and higher rates of social isolation (Child Neurology Foundation, 2019). Moreover, Rantanen et al., (2012) pointed out that epilepsy-related factors may affect social competence in CWE.

Participation and engagement in social activities with peers is particularly important during childhood development. In my opinion, fear of seizures and its associated secondary problems, often prohibit CWE from participation in recreational and social events. In addition, family concerns for the safety of their child lead to restriction of normal activities as children of their age, which in turn increases the child’s sense of social isolation. Moreover, social isolation further enhances a negative perception of self. In this regard, it is important that parents should facilitate the child’s participation in social activities at school and at home, and encourage their children to interact with other children. It is worth to say that involvement in social activities will have positive impact on the child and fostering his sense of emotional well-being well as promoting physical development.

**Table (4.7d): Quality of life among study participants (Physical functioning) (N= 144)**

| No. | Item | Very often (0) | Fairly often (1) | Some-times (2) | Almost never (3) | Never (4) | Mean | SD | % | Rank |
|---|---|---|---|---|---|---|---|---|---|---|
| 1 | Needed more supervision than other children his/her age. | 19.4 | 27.8 | 34.7 | 16.0 | 2.1 | 1.53 | 1.04 | 38.2 | 8 |
| 2 | Played freely in the house as other children his/her age. | 34.7 | 46.5 | 14.6 | 2.8 | 1.4 | 3.10 | 0.85 | 77.5 | 2 |
| 3 | Played freely outside the house as other children his/her age. | 5.6 | 26.4 | 32.6 | 26.4 | 9.0 | 1.93 | 1.05 | 48.2 | 6 |
| 4 | Participated in sports activities. | 11.8 | 33.3 | 40.3 | 9.0 | 5.6 | 2.36 | 0.99 | 59.0 | 4 |
| 5 | Stayed out overnight (with friends or family). | 9.0 | 47.2 | 23.6 | 15.3 | 4.9 | 1.59 | 1.01 | 39.7 | 7 |
| 6 | Played with friends away from you or your home. | 4.2 | 12.5 | 27.8 | 34.7 | 20.8 | 2.55 | 1.08 | 63.7 | 3 |
| 7 | Gone to parties without you or without supervision. | 1.4 | 6.9 | 10.4 | 41.7 | 39.6 | 3.11 | 0.94 | 77.7 | 1 |
| 8 | Been able to do the physical activities other children his/her age do. | 6.9 | 33.3 | 47.2 | 10.4 | 2.1 | 2.32 | 0.83 | 58.0 | 5 |
| **Average** | | | | | | | **2.31** | **0.37** | **57.75** | |

Table (4.7d) presented physical functioning among study participants. The results showed that 77.7% of children stayed out overnight with friends or family, 77.5% played freely in the house as other children of their age, and 63.7% played with friends away from their home. In addition, 59% participated in sports activities, 58% are able to do the physical activities like other children of age do, and 48.2% played freely outside the house as other children of their age. In general, children who have epilepsy expressed moderate physical functioning (57.75%).

Epilepsy and its treatment can be associated with a number of physical symptoms other than seizures. Furthermore, epilepsy increases the risk for several chronic health conditions, and patients with epilepsy have worse physical health, more activity limitation, more falls, and less physical activity compared to healthy individuals. Some of these physical symptoms related to epilepsy and some of which may be medication side effects, such as headaches, drowsiness, fatigue or weakness, dizziness, and sleep disturbances (Epilepsy Foundation of Michigan, 2018).

In my opinion, it is important that patients who experience such symptoms should discuss these symptoms with their healthcare provider to determine if these are due to medication side effects, the effects of seizures and epilepsy, or another health condition. If the healthcare provider is aware of these symptoms, that would help him adjusting and modifying treatment to suite the patient and avoid these symptoms that may prevent the patient from exercising, getting enough sleep, and eating well.

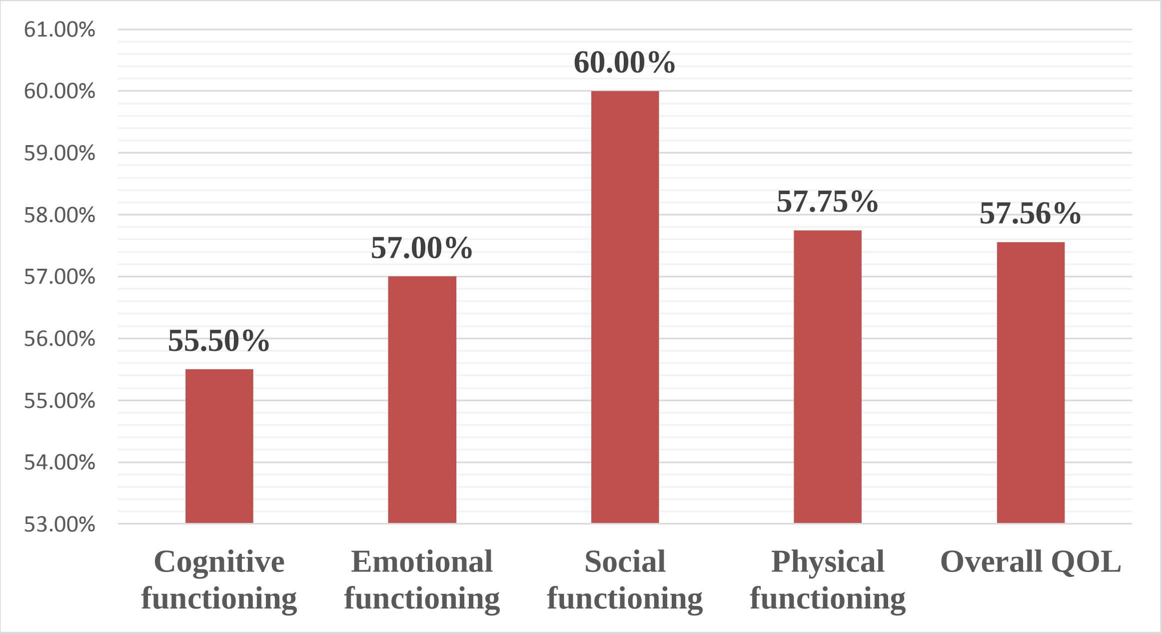

**Figure (4.1): Summary of QOL subscales and overall QOL**

Figure (4.1) showed that children who have epilepsy expressed moderate level of quality of life (57.56%). The highest was social functioning (60%), followed by physical functioning (57.75%), emotional functioning (57%) and the lowest was cognitive functioning (55.5%).

Assessment of QOL is an important component of the clinical management of any disease, and QOL improvement is one of the most important goals for healthcare providers. Various studies focused on QOL assessments and the determinants of QOL outcomes in CWE. The findings of these studies consistently show that children with epilepsy are more likely to have poorer QOL than their counterpart children (Bompori et al., 2014; Moreira et al., 2013). QOL has been introduced recently to modern medicine and needs more attention. QOL perspective can identify sensitive child issues that may be affected by illness or disability of treatment. The results obtained by Gandhi et al., (2013) showed that chronic morbidities such as epilepsy form a high risk factor for poor psychosocial outcomes; low self-esteem, behavioral problems and academic difficulties, which will lead to poor QOL, and that CWE had a relatively more compromised QOL in the emotional, social, and educational domains.

## 4.3 Inferential results

### 4.3.1 Differences in quality of life related to socio-demographic variables

**Table (4.8): Demographic profile and its relation with HRQOL and overall QOL (N= 144)**

| Domain | Age | n | Mean | SD | t | P value |
|---|---|---|---|---|---|---|
| **HRQOL** | 6 – 9 years | 86 | 2.55 | 0.54 | 1.742 | 0.084 |
| | 10 – 12years | 58 | 2.39 | 0.55 | | |
| **Overall QOL** | 6 – 9 years | 86 | 2.29 | 0.47 | 0.220 | 0.826 |
| | 10 – 12 years | 58 | 2.27 | 0.50 | | |
| **Domain** | **Gender** | **n** | **Mean** | **SD** | **t** | **P value** |
| **HRQOL** | Male | 68 | 2.57 | 0.47 | 1.791 | 0.075 |
| | Female | 76 | 2.41 | 0.60 | | |
| **Overall QOL** | Male | 68 | 2.21 | 0.53 | - 1.549 | 0.124 |
| | Female | 76 | 2.34 | 0.42 | | |

Table (4.8) showed that there were no statistical significant differences in HRQOL and overall QOL related to age of children (P= 0.084 and 0.826 respectively).

Similar results obtained by Gandhi et al., (2013) which showed that there was no significant correlation between age at onset of disease and QOL, while the results of Monira et al., (2013) indicated that age at onset of seizures was significantly a strong predictor of poorer HRQOL in CWE. In addition, Guerrini, (2006) reported that 40% of CWE are less than fifteen years old.

In this study, the target group was school-age children from 6 to 12 years old. There was a narrow gap between ages of these children and that explained this result of having no significant differences in HRQOL and QOL among study participants related to age. In my opinion, if the participants of the study had a wider gap in age such as including infants in the study or adolescents, the results could be different and show significant differences in QOL.

In addition, the results showed that there were no statistical significant differences in HRQOL and overall QOL related to gender of children (P= 0.075 and 0.124 respectively).

Our results indicated that the number of female patients with epilepsy was higher than the number of male patients, but the difference in numbers was not statistically significant. Similar results obtained by Christensen et al., (2005) who found that generally there was no gender difference in rate of epilepsy, but more females than males were diagnosed with idiopathic generalized epilepsy. It is worth to say that epilepsy is a condition that affects each person differently. Gender can be a factor in how epilepsy will affect the particular person. Therefore, care also needs to consider gender-related differences in epilepsy, other health considerations, hormonal changes, and social function. In many ways, epilepsy is different for female patient than male patient. The differences arise because of biological differences between males and females, and also because of the different social roles of each gender (Sirven and Shafer, 2014).

**Table (4.9): Differences in quality of life related to school achievement (N= 144)**

| **Domain** | **School achievement** | **n** | **Mean** | **SD** | **F** | **P value** |
|---|---|---|---|---|---|---|
| **HRQOL** | Fair | 30 | 2.26 | 0.71 | 2.378 | 0.072 |
| | Good | 42 | 2.54 | 0.51 | | |
| | Very good | 52 | 2.54 | 0.46 | | |
| | Excellent | 20 | 2.60 | 0.50 | | |
| **Overall QOL** | Fair | 30 | 1.80 | 0.36 | 22.516 | 0.000 * |
| | Good | 42 | 2.23 | 0.47 | | |
| | Very good | 52 | 2.49 | 0.38 | | |
| | Excellent | 20 | 2.57 | 0.32 | | |

*significant at 0.05

Table (4.9) showed that there were statistically significant differences in overall QOL (P= 0.000) related to school achievement. Post hoc Scheffe test reflected that lowest QOL was among children who have fair school achievement and those who have excellent achievement expressed higher QOL. However, there were no statistical significant differences in HRQOL related to school achievement (P= 0.072).

This result was logic because all the school-age children with epilepsy have to follow a long-term treatment regime with frequent follow up in the hospital. In addition, part of those children admitted to the hospital for some days, and that make them away from the school for several days, which in turn will affect their school achievement. This result was consistent with the results obtained by Mushi et al., (2012) who found that carers reported many adverse effects of epilepsy on educational opportunities and achievement. Half the children did not attend school regularly and the main factors that prevented CWE from attending school were ongoing seizures, learning difficulties, behavioral problems and poor access to school. Although overall intellectual ability in children with epilepsy is comparable to the normal childhood population, they are at greater risk for learning problems and academic under achievement. Even in those with normal intelligence, reports of deficits in specific areas related to thinking and learning abilities are common, particularly in the areas of attention and concentration, memory, organizational skills and academic achievement. Indeed, many children do not fit the typical school definition of learning disabilities, as their reading, spelling and math skills may be appropriately developed (Williams, 2003).

**Table (4.10): Differences in quality of life related to order of child in his family (N= 144)**

| **Domain** | **Order of the child** | **n** | **Mean** | **SD** | **F** | ***P value*** |
|---|---|---|---|---|---|---|
| **HRQOL** | 1 – 3 | 82 | 2.43 | 0.55 | 2.824 | 0.063 |
| | 4 - 6 | 48 | 2.64 | 0.52 | | |
| | 7 and more | 14 | 2.34 | 0.58 | | |
| **Overall QOL** | 1 – 3 | 82 | 2.21 | 0.49 | 2.564 | 0.081 |
| | 4 - 6 | 48 | 2.34 | 0.42 | | |
| | 7 and more | 14 | 2.47 | 0.54 | | |

Table (4.10) showed that there were no statistical significant differences in HRQOL and overall QOL related to order of the child (P= 0.063 and 0.081 respectively).

The researcher believes that other factors rather than number of children in the family determine the QOL among CWE. These factors directly related to conditions surrounding the disease itself such as frequency and duration of seizures, number of prescribed medication, and effectiveness of medication in preventing seizures. In addition, parents awareness and understanding of the disease symptoms and precautions to avoid injury if seizures occur. Moreover, health education either at school or at health centers is valuable for better management of the disease and improvement of QOL.

**Table (4.11): Differences in quality of life related to parents' level of education (N= 144)**

| **Domain** | **Mothers' education** | **n** | **Mean** | **SD** | **F** | ***P value*** |
|---|---|---|---|---|---|---|
| **HRQOL** | Prep-school and less | 39 | 2.36 | 0.60 | 1.728 | 0.181 |
| | Secondary | 57 | 2.49 | 0.50 | | |
| | University | 48 | 2.58 | 0.55 | | |
| **Overall QOL** | Prep-school and less | 39 | 2.15 | 0.49 | 1.910 | 0.152 |
| | Secondary | 57 | 2.30 | 0.52 | | |
| | University | 48 | 2.35 | 0.40 | | |

Table (4.11) showed that there were no statistical significant differences in HRQOL related to mothers' education (P= 0.181 and 0.152 respectively).

In India, a cross-sectional study carried out to assess the QOL and to evaluate the influence of demographic and clinical factors on QOL in CWE. The results showed that the educational status, socioeconomic status, and maternal education were the demographic characters that significantly affected the QOL of study subjects (Srujana et al, 2017).

**Table (4.12): Differences in Quality of life Related to Onset of Disease (N= 144)**

| **Domain** | **When diagnosed** | **n** | **Mean** | **SD** | **F** | ***P value*** |
|---|---|---|---|---|---|---|
| **HRQOL** | < one year | 39 | 2.69 | 0.43 | 3.538 | 0.032 * |
| | one – 4 years | 77 | 2.41 | 0.61 | | |
| | > 4 years | 28 | 2.43 | 0.47 | | |
| **Overall QOL** | < one year | 39 | 2.25 | 0.46 | 1.292 | 0.278 |
| | one – 4 years | 77 | 2.33 | 0.49 | | |
| | > 4 years | 28 | 2.17 | 0.46 | | |

Table (4.12) showed that there were statistical significant differences in HRQOL related to time of confirmation of diagnosis with epilepsy (P= 0.032), and Post hoc Scheffe test indicated that children diagnosed since one year and less had better HRQOL compared to other children. In addition, there were no statistical significant differences in overall QOL related to time of diagnosis (P= 0.278).

Consistent results obtained by Bilgic et al., (2018) which indicated that the onset of epilepsy and duration of the seizure-free period showed positive correlations with the Pediatrics QOL. In addition, Guekht et al., (2007) found positive correlation between duration of epilepsy and QOL. Furthermore, Monira et al., (2013) found that age at onset of seizures was a significant predictor of HRQOL. On the other hand, Gandhi et al., (2013) reported that there was no significant correlation between age at onset, duration of epilepsy and QOL.

In my opinion, CWE who have the disease for longer time will have poorer HRQOL as a result to frequency of seizure attacks and progression of the disease, which will have traumatizing effect on the brain with consequent intellectual and cognitive functioning.

**Table (4.13): Differences in quality of life related to number of epileptic attacks in the last 6 months (N= 144)**

| Domain | Number of epileptic attacks | n | Mean | SD | F | *P value* |
|---|---|---|---|---|---|---|
| **HRQOL** | None | 40 | 2.71 | 0.52 | 4.545 | 0.005 * |
| | One attack | 49 | 2.44 | 0.48 | | |
| | Two attacks | 27 | 2.52 | 0.48 | | |
| | Three and more | 28 | 2.23 | 0.40 | | |
| **Overall QOL** | None | 40 | 2.48 | 0.52 | 4.107 | 0.008 * |
| | One attack | 49 | 2.24 | 0.46 | | |
| | Two attacks | 27 | 2.26 | 0.47 | | |
| | Three and more | 28 | 2.08 | 0.36 | | |

Table (4.13) showed that there were statistical significant differences in HRQOL and overall QOL related to number of epileptic attacks in the last 6 months (P= 0.005 and 0.008 respectively), and Post hoc Scheffe test reflected that those who has no attacks and no previous admissions had better HRQOL and QOL.

This result reflected that children who are free of seizures and have not been admitted to the hospital before, have better QOL compared to those who have frequent seizures and previous admissions. This result was consistent with Mathiak et al., (2010) who found significant correlation between seizures and reduced QOL. In addition, Guekht et al., (2007) found that frequency of seizures was the most significant parameter related to QOL. Moreover, Srujana et al, (2017) reported that type of seizures, early childhood history of seizures, duration of therapy and duration of epilepsy were the most important clinical characteristics that could significantly affect the QOL. Furthermore, Edmundo et al., (2009) found that both seizure severity and frequency were independently associated with QOL. In addition, Piperidou et al., (2008) reported that admission to the hospital is related to frequency of seizures and duration of the disease and that will have negative impact on QOL.

In my opinion, frequency and severity of seizures are the most common factors that affect QOL in CWE, because frequent episodes of seizures making the child fatigue, unable to participate in social activities and interfere with his cognitive abilities such as reading, understanding, and thinking. The child will feel isolated from his peer friends, with many restrictions from his parents. All these conditions will put the child under constant pressure and will decrease his QOL.

Moreover, the majority of children do not like admission to the hospital. During hospitalization, the child will be exposed to many procedures and blood test, receiving injections and medication. In addition, there are restrictions on free movement, recreation, and the child will be away from his family and his friends. These conditions interferes with social activities of the child and affect his QOL negatively.

# Chapter Five

## Conclusion and Recommendations

### 5.1 Conclusion

Epilepsy is a complex disorder that has an impact on many aspects of a child's development and functioning. As a result, many of these children are at increased risk for unsuccessful school experiences, difficulties in social engagement with peers, inadequate social-skills, and poor self-esteem. This study aimed to assess health-related quality of life and overall quality of life among school-age children with epilepsy in Gaza Strip. The sample of the study consisted of 144 children aged 6 to 12 years old, with confirmed diagnosis of epilepsy, receive treatment, and follow up at the main two governmental pediatric hospitals in Gaza Strip; Al Rantisi hospital and Al Durra hospital.

The results of the study indicated that study participants have above moderate health-related quality of life. In addition, the results showed that the study participants expressed moderate level of overall quality of life. The results also showed that some factors have significant association with quality of life such as school achievement, fathers’ level of education, onset of diagnosis, number of admissions, and frequency of seizures in the past six months. Other factors were not significant predictors of quality of life such as age of child, gender, class, number of children in the family, order of child, parents’ work, family income, mothers’ education, and side effects of drugs.

In conclusion, the results reflected above moderate health-related quality of life and moderate level of quality of life. These results raised the need to multidisciplinary approach to deal with children with epilepsy from the cognitive, emotional, social, and physical aspects to improve their quality of life.

## 5.2 Recommendations

In the light of the study results, the researcher recommends the following:

- The need to act towards improving the quality of life for children with epilepsy by focusing on cognitive and emotional functions of these children.
- Collaboration between Ministry of Health and Ministry of Education to design special educational programs suitable to these children to enable them to continue their education, taking in consideration differences in their abilities.
- The need for multidisciplinary approach including a partnership between educators, family members, and healthcare providers should be instituted to put a plan for school achievement, as well as a plan for safety at schools.
- The need to integrate mental health and counseling to manage of emotional or behavioral dysfunctioning and enhance social integration with peer groups.
- The need to increase parents' awareness and understanding of the nature of the disease and appropriate interventions when seizures occur at home.
- Teach the children and their parents about conditions that provoke seizures including some types of foods, extreme exercise, and highly emotional events.

## 5.3 Suggestions for further research

- To carry out a study aiming to determine compliance to treatment regime among children with epilepsy.
- To conduct a study aiming to identify risk factors associated with the development of epilepsy among children.
- To carry out a study aiming to assess the psychosocial impact of having a child with epilepsy on the parents and family members.

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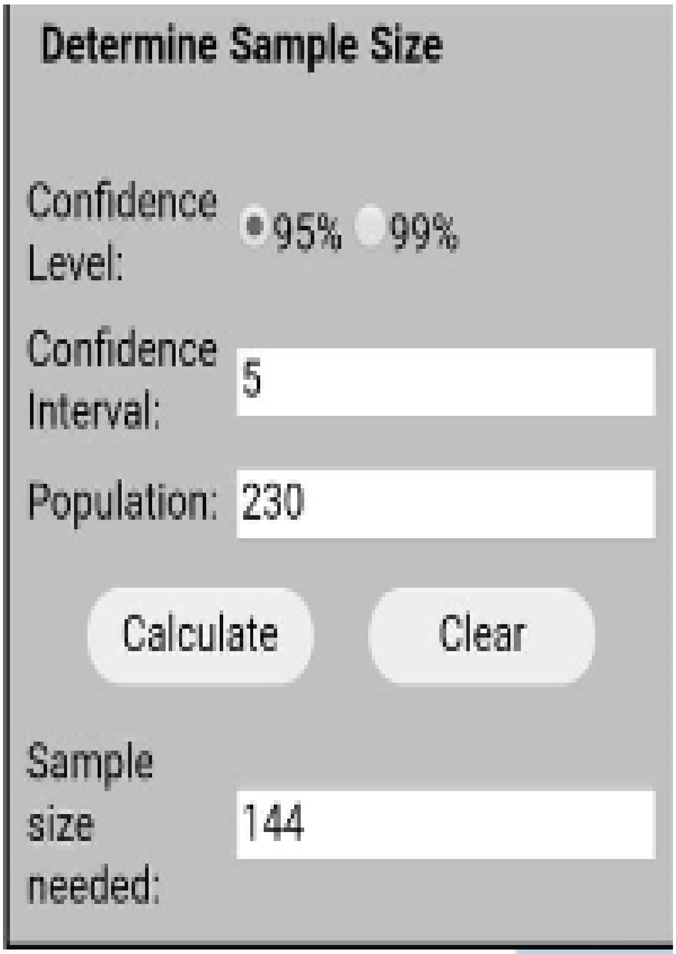
# Annexes

## Annex (1): Map of Palestine

## Annex (2): Sample size calculation



Determine Sample Size

Confidence Level: ● 95% ○ 99%

Confidence Interval: 5

Population: 230

Sample size needed: 144

**Annex (3): Consent form**

# نموذج موافقة

**عزيزي/عزيزتي ... تحية طيبة وبعد ،،،**

أنا الباحث/ حمزة خليل حرب، الملتحق ببرنامج ماجستير تمريض أطفال، جامعة القدس – أبو ديس، أقوم بإعداد بحث بعنوان: **جودة الحياة لدى الأطفال في سن المدرسة الذين يعانون من مرض الصرع في قطاع غزة.**

نأمل من سيادتكم التكرم والمشاركة في تعبئة هذا الاستبيان والذي يهدف إلى تقييم جودة حياة الأطفال في سن المدرسة الذين يعانون من مرض الصرع في قطاع غزة.

ستتم هذه الدراسة من خلال جمع البيانات من المقابلة الشخصية وتعبئة الاستبانة، ومن المقرر أن تستغرق المقابلة 15–20 دقيقة وستكون لمرة واحدة مع كل طفل وأمه.

الموافقة طوعية وليست إجبارية ولكن يسعدنا موافقتكم ولكم الحق في قبول أو رفض الإجابة عن الأسئلة، كما ستحترم سرية المعلومات التي سيدلى بها ولن تنشر هذه الدراسة أي أسماء أو عناوين أو أن يلمح بشي من ذلك. ستفيد نتائج الدراسة في تحديد وتقييم بعض المشاكل المتعلقة بجودة حياة الأطفال الذين يعانون من مرض الصرع في قطاع غزة، مما يساعد على تحسين الجهود التي من شأنها تحسين جودة الحياة وجودة الخدمات وما هي الاحتياجات اللازمة لهؤلاء المرضى.

ليست هذه الدراسة ممولة من أي جهة كانت، ولا تستهدف تحقيق مكاسب مادية، ولن يترتب عليك أي التزامات مادية معينة.

**شاكرين لكم حسن تعاونكم ،،،**

**الباحث /حمزة خليل حرب**

| **توقيع المشارك** | **توقيع الباحث** | **التاريخ** |
|---|---|---|
| ____________ | ____________ | ______/___/___ |

## Annex (4): Demographic characteristics

**المعلومات الشخصية:**

1- التسلسل: ................ 2- المستشفى: ☐ الرنتيسي ☐ الدرة

3- العمر(بالسنوات): ................. 4-الجنس: ☐ ذكر ☐ أنثى

5- السنة الدراسية (للطفل):......................

6- التحصيل العلمي للطفل بالعام الأخير من الدارسة :☐مقبول ☐ جيد ☐ جيد جدا ☐ ممتاز

7-عدد الأخوة و الأخوات: ...........................

8- الأب يعمل: ☐ نعم ☐ لا 9- الأم تعمل: ☐ نعم ☐ لا

10- دخل الأسرة الشهري: ............ شيكل تقريباً.

11- المؤهل العلمي للاب: ☐اقل من ثانوي ☐ ثانوي ☐ جامعي ☐غير متعلم

12- المؤهل العلمي للام: ☐اقل من ثانوي ☐ ثانوي ☐ جامعي ☐غير متعلم

13- ترتيب الطفل بين أفراد الأسرة:....................

14- هل أحد الوالدين متوفي: ☐ نعم ☐لا - اذا كانت الإجابة( نعم)،حدد ☐أب ☐أم

**التاريخ المرضي:**

15- متى تم تأكيد تشخيص الحالة:......................

16- أمراض أخرى: ☐ امراض الكلى ☐ أمراض القلب ☐ أمراض الدم والأورام ☐ أمراض الجهاز الهضمي ☐ أخرى: .......................... ☐لا يوجد

17- عدد مرات دخول المستشفى اخر سنة من المرض الحالي: ..........................

18- التاريخ الطبي والجراحي (للطفل): ☐ حرارة ☐ التهاب السحايا ☐ إصابة في الراس ☐ولادة متأخرة ☐استسقاء ☐ التهاب بالدماغ ☐ أخرى: ..........................

19- عدد مرات حدوث النوبة في آخر 6أشهر:..................................مرة.

20- مدة الإصابة بالمرض (بالسنوات):..................سنة.

21- هل يوجد أعراض جانبية للأدوية ☐ نعم ☐لا - اذا كانت الإجابة نعم، حدد الأعراض................................................

## Annex (5): HRQOL Epilepsy Module (Arabic version)

### استبانة جودة الحياة الصحية لدى الأطفال في سن المدرسة المصابون بالصرع

على الصفحة التالية قائمة بأشياء قد تكون مشكلة لك، الرجاء اخبارنا حجم المشكلة لكل منها خلال الشهر الماضي.

| **الغثيان** (مشاكل مع...) | أبداً | نادراً | أحياناً | غالباً | تقريباً دائماً |
|---|---|---|---|---|---|
| 1.أشعر بألم في بطني عندما اتلقى العلاج | 4 | 3 | 2 | 1 | 0 |
| 2. مذاق الطعام غير محبب لي | 4 | 3 | 2 | 1 | 0 |
| 3.أشعر بألم في بطني عند التفكير في العلاج الطبي | 4 | 3 | 2 | 1 | 0 |
| 4. أشعر بألم في بطني لدرجة تمنعني عن الطعام | 4 | 3 | 2 | 1 | 0 |
| 5.بعض الأطعمة والروائح تشعرني بألم في بطني | 4 | 3 | 2 | 1 | 0 |
| **توتر من الإجراءات (مشاكل مع...)** | أبداً | نادراً | أحياناً | غالباً | تقريباً دائماً |
| 6.الإبر(مثل الحقن وفحوصات الدم والمحاليل) تسبب لي الألم | 4 | 3 | 2 | 1 | 0 |
| 7. أشعر بالخوف عند سحب الدم | 4 | 3 | 2 | 1 | 0 |
| 8.أشعر بالتوتر من التعرض للإبر ( مثل الحقن وفحوصات الدم والمحاليل) | 4 | 3 | 2 | 1 | 0 |
| **خوفاتوتر من جراء العلاج (مشاكل مع...)** | أبداً | نادراً | أحياناً | غالباً | تقريباً دائماً |
| 9.أشعر بالتوتر عند انتظار الطبيب | 4 | 3 | 2 | 1 | 0 |
| 10.أشعر بالتوتر عند الذهاب للطبيب | 4 | 3 | 2 | 1 | 0 |
| **القلق (مشاكل مع..)** | أبداً | نادراً | أحياناً | غالباً | تقريباً دائماً |
| 11.أشعر بالقلق من الأثار الجانبية للعلاج الطبي | 4 | 3 | 2 | 1 | 0 |
| 12.أشعر بالقلق حول فعالية العلاجات التي أتناولها | 4 | 3 | 2 | 1 | 0 |
| 13.أشعر بالقلق من (تفاقم) مرض الصرع | 4 | 3 | 2 | 1 | 0 |
| **التواصل (مشاكل مع...)** | أبداً | نادراً | أحياناً | غالباً | تقريباً دائماً |
| 14. أجد صعوبة في إخبار الأطباء أو التمريض بما أشعر به | 4 | 3 | 2 | 1 | 0 |
| 15.أجد صعوبة في توجيه أسئلة للأطباء أو التمريض | 4 | 3 | 2 | 1 | 0 |
| 16.أجد صعوبة في شرح مرضي للأخرين | 4 | 3 | 2 | 1 | 0 |

**Annex (6): HRQOL Epilepsy Module (English version)**

| **Domain** | **Never** | **Almost never** | **Sometimes** | **Often** | **Very often** |
|---|---|---|---|---|---|
| **NAUSEA** ***(problems with…)*** | | | | | |
| 1. I become sick to my stomach when I have medical treatments | 4 | 3 | 2 | 1 | 0 |
| 2. Food does not taste very good to me | 4 | 3 | 2 | 1 | 0 |
| 3. I become sick to my stomach when I think about medical treatments | 4 | 3 | 2 | 1 | 0 |
| 4. I feel too sick to my stomach to eat | 4 | 3 | 2 | 1 | 0 |
| 5. Some foods and smells make me sick to my stomach | 4 | 3 | 2 | 1 | 0 |
| **PROCEDURAL ANXIETY** ***(problems with…)*** | | | | | |
| 1. Needle sticks (i.e. injections, blood tests, IV's) hurt | 4 | 3 | 2 | 1 | 0 |
| 2. I get scared when I have to have blood tests | 4 | 3 | 2 | 1 | 0 |
| 3. I get scared about having needle sticks (i.e. injections, blood tests, IV's) | 4 | 3 | 2 | 1 | 0 |
| **TREATMENT ANXIETY** ***(problems with…)*** | | | | | |
| 1. I get scared when I am waiting to see the doctor | 4 | 3 | 2 | 1 | 0 |
| 2. I get scared when I have to go to the doctor | 4 | 3 | 2 | 1 | 0 |
| **WORRY** ***(problems with…)*** | | | | | |
| 1. I worry about side effects from medical treatments | 4 | 3 | 2 | 1 | 0 |
| 2. I worry about whether or not my medical treatments are working | 4 | 3 | 2 | 1 | 0 |
| 3. I worry that my epilepsy will come back or relapse | 4 | 3 | 2 | 1 | 0 |
| **Communication** ***(Problems with ...)*** | | | | | |
| 1. I find it difficult to tell doctors or nurses how I feel | 4 | 3 | 2 | 1 | 0 |
| 2. I find it difficult to ask questions to doctors or nursing | 4 | 3 | 2 | 1 | 0 |
| 3. I find it difficult to explain my illness to others | 4 | 3 | 2 | 1 | 0 |

**Annex (7): Quality of Life in Childhood Epilepsy Questionnaire: QOLCE-55**

SECTION 1: YOUR CHILD'S COGNITIVE FUNCTIONING

| Domain | Very often (0) | Fairly-Often (1) | Some-Times (2) | Almost Never (3) | Never ( 4) |
|---|---|---|---|---|---|
| a. had difficulty attending to an activity? | ☐ | ☐ | ☐ | ☐ | ☐ |
| b. had difficulty reasoning or solving problems? | ☐ | ☐ | ☐ | ☐ | ☐ |
| c. had difficulty making plans or decisions? | ☐ | ☐ | ☐ | ☐ | ☐ |
| d. had difficulty keeping track of conversations? | ☐ | ☐ | ☐ | ☐ | ☐ |
| e. had trouble concentrating on a task? | ☐ | ☐ | ☐ | ☐ | ☐ |
| f. had difficulty concentrating on reading? | ☐ | ☐ | ☐ | ☐ | ☐ |
| g. had difficulty doing one thing at a time? | ☐ | ☐ | ☐ | ☐ | ☐ |
| h. reacted slowly to things being said and done? | ☐ | ☐ | ☐ | ☐ | ☐ |
| i. found it hard remembering things? | ☐ | ☐ | ☐ | ☐ | ☐ |
| j. had trouble remembering names of people? | ☐ | ☐ | ☐ | ☐ | ☐ |
| k. had trouble remembering where s/he put things? | ☐ | ☐ | ☐ | ☐ | ☐ |
| l. had trouble remembering things people told him/her? | ☐ | ☐ | ☐ | ☐ | ☐ |
| m. had trouble remembering things s/he read hours or days before? | ☐ | ☐ | ☐ | ☐ | ☐ |
| n. planned to do something then forgot? | ☐ | ☐ | ☐ | ☐ | ☐ |
| o. had trouble finding the correct words? | ☐ | ☐ | ☐ | ☐ | ☐ |

| | | | | | |
|---|---|---|---|---|---|
| p. had trouble understanding following what others were saying? | ☐ | ☐ | ☐ | ☐ | ☐ |
| q. had trouble understanding directions? | ☐ | ☐ | ☐ | ☐ | ☐ |
| r. had difficulty following simple instructions? | ☐ | ☐ | ☐ | ☐ | ☐ |
| s. had difficulty following complex instructions? | ☐ | ☐ | ☐ | ☐ | ☐ |
| t. had trouble understanding what s/he read? | ☐ | ☐ | ☐ | ☐ | ☐ |
| u. had trouble writing? | ☐ | ☐ | ☐ | ☐ | ☐ |
| v. had trouble talking? | ☐ | ☐ | ☐ | ☐ | ☐ |

## SECTION 2: YOUR CHILD'S EMOTIONAL FUNCTIONING

2.1 <u>During the past 4 weeks</u>, how much of the time do you think your child:

| Domain | Very often (0 | Fairly-Often (1) | Some-Times (2) | Almost Never (3) | Never ( 4) |
|---|---|---|---|---|---|
| a. felt down or depressed? | ☐ | ☐ | ☐ | ☐ | ☐ |
| b. felt happy? | ☐ | ☐ | ☐ | ☐ | ☐ |
| c. wished s/he was dead? | ☐ | ☐ | ☐ | ☐ | ☐ |
| d. felt frustrated? | ☐ | ☐ | ☐ | ☐ | ☐ |
| e. worried a lot? | ☐ | ☐ | ☐ | ☐ | ☐ |
| f. felt confident? | ☐ | ☐ | ☐ | ☐ | ☐ |
| g. felt excited or interested in something? | ☐ | ☐ | ☐ | ☐ | ☐ |
| h. felt pleased about achieving something? | ☐ | ☐ | ☐ | ☐ | ☐ |
| i. felt nobody understood him/her? | ☐ | ☐ | ☐ | ☐ | ☐ |
| j. felt valued? | ☐ | ☐ | ☐ | ☐ | ☐ |
| k. felt no one cared? | ☐ | ☐ | ☐ | ☐ | ☐ |

Please try to answer all questions as well as you can, even if some do not seem to apply to your child.

2.2 Compared to other children his/her own age, how often during the past 4 weeks do each of the following statements describe your child?

| Domain | Very often (0) | Fairly-Often (1) | Some-Times (2) | Almost Never (3) | Never ( 4) |
|---|---|---|---|---|---|
| a. was socially inappropriate (said or did something out of place in a social situation) | ☐ | ☐ | ☐ | ☐ | ☐ |
| b. angered easily | ☐ | ☐ | ☐ | ☐ | ☐ |
| c. hit or attacked people | ☐ | ☐ | ☐ | ☐ | ☐ |
| d. was obedient | ☐ | ☐ | ☐ | ☐ | ☐ |
| e. demanded a lot of attention | ☐ | ☐ | ☐ | ☐ | ☐ |

## SECTION 3: YOUR CHILD'S SOCIAL FUNCTIONING

Below are statements that describe some children's social interactions and activities.

| Domain | Very often (0) | Fairly-Often (1) | Some-Times (2) | Almost Never (3) | Never ( 4) |
|---|---|---|---|---|---|
| a. limited his/her social activities (visiting friends, close relatives, or neighbours)? | ☐ | ☐ | ☐ | ☐ | ☐ |
| b. affected his/her social interactions at school or work? | ☐ | ☐ | ☐ | ☐ | ☐ |
| c. limited his/her leisure activities (hobbies or interests)? | ☐ | ☐ | ☐ | ☐ | ☐ |
| d. isolated him/her from others? | ☐ | ☐ | ☐ | ☐ | ☐ |
| e. made it difficult for him/her to keep friends? | ☐ | ☐ | ☐ | ☐ | ☐ |
| f. frightened other people? | ☐ | ☐ | ☐ | ☐ | ☐ |

| | | | | | |
|---|---|---|---|---|---|
| g. During the past 4 weeks, how limited are your child's social activities compared with others his/her age because of his/her epilepsy or epilepsy-related problems? | ☐<br>Yes, limited a lot | ☐<br>Yes, limited some | ☐<br>yes, limited a little | ☐<br>Yes, but rarely | ☐<br>No, not limited |

Please try to answer all questions as well as you can, even if some do not seem to apply to your child.

3.1 During the past 4 weeks, how often has your child's epilepsy:

SECTION 4: YOUR CHILD'S PHYSICAL FUNCTIONING

The following questions ask about physical activities your child might do.

4.1. In his/her daily activities during the past 4 weeks, how often has your child:

| Domain | Very often (0 | Fairly-Often (1) | Some-Times (2) | Almost Never (3) | Never ( 4) |
|---|---|---|---|---|---|
| a. needed more supervision than other children his/her age? | ☐ | ☐ | ☐ | ☐ | ☐ |
| b. played freely in the house like other children his/her age? | ☐ | ☐ | ☐ | ☐ | ☐ |
| c. played freely outside the house like other children his/her age? | ☐ | ☐ | ☐ | ☐ | ☐ |
| d. participated in sports activities? | ☐ | ☐ | ☐ | ☐ | ☐ |
| e. stayed out overnight (with friends or family)? | ☐ | ☐ | ☐ | ☐ | ☐ |
| f. played with friends away from you or your home? | ☐ | ☐ | ☐ | ☐ | ☐ |
| g. gone to parties without you or without supervision? | ☐ | ☐ | ☐ | ☐ | ☐ |

**Annex (8): Name of panels of expert**

| | |
|---|---|
| Dr. Ali Alkhteab | University College of Applied Sciences |
| Dr. Hatem Al Dbakah | University College of Ability Development |
| Dr. Ahmed Najm | Al Azhar University |
| Dr. Mohamed Abu Nada | Al-Rantisi Specialized Pediatric Hospital |
| Dr. Hamza Abd El-Jawad | Palestine College of Nursing |
| Dr. Samer Al-Nawajha | University College of Applied Sciences |

## Annex (9): Approval from Helsinki Committee

المجلس الفلسطيني للبحث الصحي

Palestinian Health Research Council

تعزيز النظام الصحي الفلسطيني من خلال مأسسة استخدام المعلومات البحثية في صنع القرار

Developing the Palestinian health system through institutionalizing the use of information in decision making

### Helsinki Committee

For Ethical Approval

**Date: 05/02/2018** **Number:** PHRC/HC/306/18

**Name:** HAMZA K. HARB الاسم:

We would like to inform you that the committee had discussed the proposal of your study about:

نفيدكم علماً بأن اللجنة قد ناقشت مقترح دراستكم حول:

**Quality of Life of School-aged Children with Epilepsy at Gaza City.**

The committee has decided to approve the above mentioned research. Approval number PHRC/HC/306/18 in its meeting on 05/02/2018

و قد قررت الموافقة على البحث المذكور عاليه بالرقم والتاريخ المذكوران عاليه

**Signature**

**Member** **Member**

5/2/2018

**Chairman**

**Genral Conditions:-**

1. Valid for 2 years from the date of approval.
2. It is necessary to notify the committee of any change in the approved study protocol.
3. The committee appreciates receiving a copy of your final research when completed.

**Specific Conditions:-**

E-Mail:pal.phrc@gmail.com

Gaza - Palestine غزة - فلسطين
شارع النصر - مفترق العيون

## Annex (10): Approval from MOH

State of Palestine
Ministry of health

دولة فلسطين
وزارة الصحة

التاريخ:21/02/2019
رقم المراسلة 290368

**السيد : رامي عيد سليمان العبادله المحترم**

مدير عام بالوزارة /الإدارة العامة لتنمية القوى البشرية ـ /وزارة الصحة

**السلام عليكم ,,,**

**الموضوع/ تسهيل مهمة الباحث//حمزة حرب**

التفاصيل //
بخصوص الموضوع أعلاه، يرجي تسهيل مهمة الباحث/ **حمزة خليل حرب**
الملتحق ببرنامج ماجستير التمريض – تخصص تمريض الأطفال – كلية الصحة العامةـ جامعة القدس أبوديس في
إجراء بحث بعنوان:ـ
**Quality of Life of School-Aged Children with Epilepsy at Gaza City"**
حيث الباحث بحاجة لتعبئة استبانة من عدد من الأطفال –وذويهمـ الذين يعانون من مرض الصرع المراجعين لمستشفى
الرنيسي ومستشفى الدرة.
تأمل توجيهاتكم لذوي الاختصاص بضرورة الحصول على الموافقة المستنيرة من أولياء أمور المرضى الذين هم على
استعداد لمشاركة أطفالهم في الدراسة ومن ثم تمكين الباحث من التواصل معهم، بما لا يتعارض مع مصلحة العمل
وضمن أخلاقيات البحث العلمي، ودون تحمل الوزارة أي أعباء أو مسئولية.
وتفضلوا بقبول التحية والتقدير،،،
ملاحظة / تسهيل المهمة الخاص بالدراسة أعلاه صالح لمدة 6 شهر من تاريخه.

**محمد ابراهيم محمد السرساوي**
**مدير دائرة/الإدارة العامة لتنمية القوى البشرية ـ**

**التحويلات**

- محمد ابراهيم محمد السرساوي(مدير دائرة) ← رامي عيد سليمان العبادله(مدير عام بالوزارة) للإفادة(21/02/2019)

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**عنوان الدراسة: جودة الحياة لدى الأطفال في سن المدرسة الذين يعانون من مرض الصرع في قطاع غزة.**

**إعداد: حمزة خليل حرب**

**إشراف: د. يوسف عوض ود. أسامة عليان**

## ملخص الدراسة

هدفت هذه الدراسة إلى تقييم مستوى جودة الحياة لدى أطفال المدارس الذين يعانون من مرض الصرع في قطاع غزة، كما هدفت إلى التعرف على العوامل التي تؤثر في جودة الحياة لديهم. لتحقيق أهداف الدراسة استخدم الباحث المنهج الوصفي التحليلي. تكونت عينة الدراسة من 144 طفلاً من الصف الأول حتى الصف السادس، وقد تراوحت أعمارهم بين 6 – 12 سنة. لجمع البيانات فقد استخدم الباحث مقياس جودة الحياة الصحية المعدل (HRQOL) المكون من 16 فقرة، ومقياس جودة الحياة لدى أطفال الصرع (QOLCE) مكون من 53 فقرة، وقد تم التأكد من صدق محتوى المقاييس من خلال مجموعة من المحكمين، ولتحليل البيانات فقد تم استخدام برنامج الرزم الإحصائية للعلوم الإنسانية SPSS version 22، وتضمنت المعالجات الإحصائية التكرارات، النسب المئوية، المتوسط الحسابي، الانحراف المعياري، اختبار (ت) واختبار تحليل التباين الأحادي.

بينت نتائج الدراسة أن متوسط أعمار الأطفال المشاركين في الدراسة بلغ 8.86 بانحراف معياري 1.93 سنة، وكان 47.2% من الأطفال المشاركين في الدراسة من الذكور و52.8% من الإناث، كما أن نصف الأطفال كان تحصيلهم الدراسي بين جيد جداً وممتاز. كما بينت النتائج أن ثلث الآباء والغالبية العظمى من الأمهات لا يعملون، كما أن ثلثي عائلات الأطفال كانوا من ذوي الدخل المتدني.

وأظهرت نتائج الدراسة أن مستوى جودة الحياة الصحية كان فوق المتوسط (60.25%)، كما أن مستوى جودة الحياة لدى أطفال الصرع كان متوسطاً (57.56%)، وكانت أعلى الدرجات في البعد الخاص بالوظائف الاجتماعية (60%)، يليه الوظائف الجسدية (57.75%)، الوظائف الانفعالية (57%)، وكانت أدنى الدرجات في الوظائف العقلية (55.5%).

كما بينت النتائج وجود علاقة دالة إحصائياً بين جودة الحياة وكل من التحصيل الدراسي، المدة الزمنية لتشخيص المرض وعدد مرات نوبات الصرع في الأشهر الستة الأخيرة، بينما بينت النتائج عدم وجود علاقة دالة إحصائياً بين جودة الحياة وكل من عمر الطفل، الجنس، ترتيب الطفل بين إخوته، عمل الوالدين، الدخل الشهري للأسرة، المستوى التعليمي للأم، والأعراض الجانبية الناتجة عن تناول الأدوية.

في الإجمال فقد أظهرت الدراسة الحاجة إلى وجود نظام متعدد الاتجاهات للعناية بالأطفال المصابين بالصرع من عدة جوانب تشمل الجانب العقلي، الجانب الانفعالي، الجانب الاجتماعي والجانب الجسدي وذلك بهدف رفع مستوى جودة الحياة لديهم.