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Al-Quds University**



**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.

Finally, I appreciate everyone who contributed to make this study a reality, thank you.

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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 – 12 years. 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  $8.86 \pm 1.93$  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**

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