Quality of Life for Children Suffering from Chronic Renal Problems: An Assessment Study

Thesis

Submitted in Partial Fulfillment of Requirement of the Master Degree in Pediatric Nursing

By

Noha Abd El-Hamid Hassan
(B.Sc. Nursing Science, 2008)
Faculty of Nursing-Ain Shams University
Quality Specialist at Elganzory Hospital

Faculty of Nursing
Ain Shams University
2018

Quality of Life for Children Suffering from Chronic Renal Problems: An Assessment Study

Thesis

Submitted in Partial Fulfillment of Requirement of the Master Degree in Pediatric Nursing

Supervised by

Prof. Dr. Wafaa El-Sayed Ouda

Professor of Pediatric Nursing
Faculty of Nursing
Ain Shams University

Assist. Prof. Dr. Zeinab Fathy EL-Sayed

Assistant Professor of Pediatric Nursing
Faculty of Nursing
Ain Shams University

Faculty of Nursing
Ain Shams University
2018

Acknowledgement

First, and foremost, my deepest gratitude and thanks should be offered to **"ALLAH",** *the most kind and most merciful, for giving me the strength to complete this work.*

I would like to express my sincere gratitude to ***Prof. Dr. W'afaa El-Sayed Ouda,*** *Professor of Pediatric Nursing, Faculty of Nursing – Ain Shams University, for her continuous support and guidance for me to present this work. I'm really honored to work under her generous supervision.*

I acknowledge with much gratitude to ***Assist. Prof. Dr. Zeinab Fathy EL-Sayed,*** *Assistant Professor of Pediatric Nursing, Faculty of Nursing – Ain Shams University, for her great supervision and unlimited help to accomplish this work. I appreciate her active enthusiasm in providing me a lot of knowledge.*

My thank are extended to all children and their parent who agreed to participate in this study.

The cadidate

Noha Abd El-Hamid Hassan

LIST OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

Abb.	Meaning
ABPM	**:** Ambulatory BP monitoring
ADH	: Anti-Diuretic Hormone
ADLs	: Activities of Daily Living
CAKUT	: Congenital Abnormalities of the Kidney and Urinary Tract
CKD	: Chronic Kidney Disease
CNS	: Central Nervous System
CVD	: CardioVascular Disease
DDS	: Dialysis disequilibrium syndrome
ESA	**:** Erythropoietin-stimulating agents
ESRD	: End-Stage Renal Disease
FGF23	: Fibroblast growth factor-23
FSGS	: Focal Segmental Glomerulo-Sclerosis
GFR	: Glomerular Filtration Rate
HGH	: Human Growth Hormone
HRQOL	: Health-Related Quality of Life
IGF-1	**:** Insulin-like growth factor 1
KDIGO	: Kidney Disease: Improving Global Outcomes
KDOQI	: Kidney Disease Outcomes Quality Initiative
NKF	: National Kidney Foundation
NPY	: Neuropeptide Y
PNS	: Peripheral Nervous System
PTH	: Parathyroid hormone

PTH : Parathyroid Hormone

QOL : Quality of life

RAAS : Renin Angiotensin Aldosterone System

RAAS-I **:** Angiotensin-aldosterone system inhibitors

RHUEPO : Recombinant Human Erythro-Poietin

ROD : Renal osteodystrophy

ROM : Range of motion

ROS : Reactive Oxygen Species

RRT : Renal Replacement Therapy

SNGFR : Single Nephron GFR

SRNS : Steroid-Resistant Nephrotic Syndrome

Abstract

Aim of the study was to assess the quality of life for children suffering from chronic renal problems. **Setting:** The study was conducted at both in and out patient departments/ pediatric hospital affiliated to Ain Shams University hospitals. **Sample size:** The study sample included all available children (154) suffering from confirmed chronic renal problems since 6 months, attending the previously mentioned setting over six months period and satisfying predetermined inclusion criteria (children aged 4-18years old, both genders) with exclusion of children suffering from other chronic illnesses either medical or mental). **Results:** More than half of the studied sample had a negative level of physical domain of quality of life, less than half of them had a negative level of psychological domain of QOL and more than one third of them had positive level of social domain of QOL and less than half of them had a positive level of communication domain of quality of life. **In conclusion** quality of life for children suffering from chronic kidney diseases was affected in all domains especially of physical and school domains.There are many factors related to characteristic of children, health condition, physical status, psychological status, social status, environmental condition and the current health services that affect the quality of life of children suffering from chronic kidney diseases. **Recommendation** emphasize the importance of early case finding, control and management and regular assessment of factors affecting the quality of life for chronic kidney diseases in children.

Keywords: Quality of Life, Children, Nursing, Chronic Renal Problems

Introduction

Chronic kidney disease (CKD) is a major health problem worldwide with increasing incidence and prevalence that is threatening to bring on the onset of a real 'epidemic' **(Bruck et al., 2015).**

Independent of the initial cause, the CKD is a clinical syndrome characterized by a gradual loss of kidney function over time **(KDIGO, 2013)**.

Childhood CKD presents clinical features that are specific and totally peculiar to the pediatric age, such as the impact of the disease on growth. In addition, some of the typical characteristics of pediatric CKD, such as the etiology or cardiovascular complications, represent variables, not only influencing the health of the patient during childhood, but also having an impact on the life of the adult that this child will become. This impact is often under-recognized but should not be neglected. Moreover, CKD has a great psychosocial impact, both on the pediatric patient and his family. The parents not only have to fulfill the role of parents, but also take on many tasks. The increasing survival rates of pediatric patients with CKD, due to the improvement in the clinical and therapeutic management, will lead to a large number of affected adults facing problems that are specific to CKD that have started

during childhood **(Schaefer et al., 2013).**

Worldwide, in pediatric population as aged 19 years and under, the annual rate is only 1-2 new cases in every 100,000 children. The risk increases steadily with age. Moreover, boys are nearly twice as likely as girls to develop chronic renal disease **(Sharma, 2013).**

The total number of children attending children's hospital affiliated to Ain Shams University at outpatient clinic, inpatient ward and hemodialysis unit was 71.000, 8000 and 75 respectively. As regards children suffering from chronic renal problems, it was found that from the above mentioned total number and setting that 1649 (2%), 338 (4%) and 75 respectively children were suffering from chronic renal problems **(Children's Hospital of Ain Shams University Records, 2012-2013).**

Chronic kidney disease burdens the pediatric patients biologically, socially and psychologically and it affects their quality of life. Health-related quality of life is a sub-domain of quality of life and can be defined as the subjective perception of how health-related factors impact the well-being and life satisfaction **(Copelovitch et al., 2011).**

The focus of nursing care for pediatric chronic