

Depression and Psychological Burden in a Sample of Caregivers of Children with Chronic Kidney Disease

Thesis

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By

Yasmine Hassan Abdelhamid
M.B.B.Ch

Under Supervision of

Prof. Dr. Ahmed Saad Mohamed

*Professor of Psychiatry, Neuropsychiatry Department
Faculty of Medicine - Ain Shams University*

Dr. Dalia Abdel Moneim Mahmoud

*Assistant Professor of Psychiatry, Neuropsychiatry Department
Faculty of Medicine - Ain Shams University*

Dr. Yomna Ahmed ElHawary

*Lecturer of Psychiatry, Neuropsychiatry Department
Faculty of Medicine - Ain Shams University*

Faculty of Medicine
Ain Shams University

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بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ

قالوا

سببنا انك لا تعلم لنا
إلا ما علمتنا إنك أنت
العليم العظيم

صدق الله العظيم

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List of Abbreviations

Abb.	Full term
<i>BDI</i>	<i>Beck Depression Inventory</i>
<i>CBT</i>	<i>Cognitive-Behavioral Therapy</i>
<i>CDI-2</i>	<i>Children's Depression Inventory-2</i>
<i>CKD</i>	<i>Chronic Kidney Disease</i>
<i>ESAs</i>	<i>Erythrocyte-Stimulating Agents</i>
<i>ESRD</i>	<i>End Stage Renal Disease</i>
<i>GFR</i>	<i>Glomerular Filtration Rate</i>
<i>HD</i>	<i>Hemodialysis</i>
<i>HRQOL</i>	<i>Health-Related Quality of Life</i>
<i>KDIGO</i>	<i>Kidney Disease Improving Global Outcomes</i>
<i>MAOs</i>	<i>Monoamine Oxidase Inhibitors</i>
<i>MBSR</i>	<i>Mindfulness-Based Stress Reduction</i>
<i>PD</i>	<i>Peritoneal Dialysis</i>
<i>PHQ-9</i>	<i>Pediatric Health Questionnaire-9</i>
<i>QoL</i>	<i>Quality of Life</i>
<i>RCTs</i>	<i>Randomized Controlled Trials</i>
<i>RRT</i>	<i>Renal Replacement Therapy</i>
<i>SCARED</i>	<i>Screen for Child Anxiety Related Emotional Disorders</i>
<i>SCID-I</i>	<i>Structured Clinical Interview for DSM-IV Axis I Disorders</i>
<i>sHPT</i>	<i>Secondary Hyperparathyroidism</i>
<i>SNRIs</i>	<i>Selective Norepinephrine Reuptake Inhibitors</i>
<i>SSRIs</i>	<i>Selective Serotonin Reuptake Inhibitors</i>
<i>TCAs</i>	<i>Tricyclic Antidepressants</i>

Abstract

As regards monthly income, the majority of controls reported barely adequate income 12 (40.0%), as for the cases most of them 21 (70.0%) reported inadequate monthly income.

As for the Residence, the majority of cases 19 (63.3%) as well as controls 28 (93.3%) inhabited urban areas.

As regards Beck depression inventory, 53.3% of cases reported moderate depression and 43.3% of controls reported minimal depression.

As for Zarit burden interview, the majority of cases 80% reported moderate burden and 60% of controls reported minimal burden.

In social readjustment stress scale, the majority 70% of cases reported minimal stress and the majority 40% of the controls reported minimal stress as well.

Keywords: *Beck Depression Inventory - Chronic Kidney Disease*

INTRODUCTION

Many chronic patients suffer, during the treatment of their diseases and its consequences, from a burden and a psychological effect that affects them as well as their families (*Belasco & Sesso, 2002*).

Chronic diseases change family dynamics. They increase the burden on family members and also stress level especially for the primary caregiver. This might also affect family relationships. Besides, having a chronic disease increases children's dependency on parents and caregivers. As a consequence, caregivers, who are usually mothers, tend to face novel problems related to the care for a chronically ill child (*Watson et al., 2013*).

CKD, ESRD and its exacerbations create burden for the patient as well as their caregivers who are usually not enough prepared to carry this new role which makes them suffer from the negative effects as anxiety, depression and stress impacting their own health (*Tang et al., 2012*).

There isn't enough research on caregivers. And owing to recent advances in the area of dialysis treatment and other medical procedures, children with chronic kidney disease (CKD) have a significantly longer survival rate. However, despite being provided with an increasingly effective treatment,

they can never be cured, which means more burden on the caregivers is expected from very long years of treatment and follow up (**Watson, 2014**).

Quality of life in patients undergoing hemodialysis has been studied multiple times before, but mainly in adults. Only some individual studies assessed QoL in children treated with repeated hemodialysis. About 20% of CKD children have a probable psychiatric disorder (**Glazebrook et al., 2003**).

It was reported that 30% of patients with CKD aged 9–18 years fulfill the criteria for depression (**Kogan et al., 2013**).

Caregivers of ESRD patients need to be assessed for burden. Supportive psychosocial interventions should be available to improve the well-being and quality of life of caregivers as well as their ESRD patients throughout this journey of chronic illness. Consequently, both medical and psychosocial aspects must be provided to ensure proper care over pediatric patients with CKD and their caregivers (**Joanne and William, 2017**).

AIM OF THE WORK

- 1- To assess the rate of occurrence of depression and its severity in a sample of Egyptian caregivers of children with chronic kidney disease.
- 2- To demonstrate the rate of occurrence of the psychological burden on caregivers of children with chronic kidney disease.
- 3- To compare with a healthy control group as regards depression and psychological burden in caregivers.

Hypothesis of the study

This study hypothesized that the rate of occurrence of moderate and severe depression would probably be high among caregivers of children with chronic kidney disease than caregivers of healthy children.

Rationale of the study

Due to the increasing rate of burden on caregivers of chronic patients this can lead to the emergence of unhealthy coping strategies, depression and burden that affects the caregivers and their ability to care for their patients.

This study can add to the literature the importance of psychiatric assessment of caregivers of chronically ill patients which can help establish management guidelines and preventive measures.

Chapter 1

AN OVERVIEW ON THE PSYCHIATRIC AND GENERAL MEDICAL PROBLEMS IN CHILDREN WITH CHRONIC KIDNEY DISEASE

Definition of Chronic Kidney Disease (CKD):

As based on the National Kidney Foundation Kidney Disease Outcomes Qualitative Initiative CKD is defined as kidney damage which lasts for at least 3 months with or without a decrease in GFR, or any patient who has a GFR <60 ml/min/1.73 m² for 3 months with or without kidney damage (*National Kidney Foundation, 2002*).

Recently, CKD is defined according to the international guidelines for Kidney Disease Improving Global Outcomes (KDIGO) as an abnormality of renal structure or function present for more than 3 months and having implications for health with decreased kidney function as shown by a glomerular filtration rate (GFR) of less than 60 mL/min per 1.73m², or markers of kidney damage (elevated renal function tests), or both, of at least three months duration, regardless of the underlying cause (*Webster et al., 2017*).

Many patients are not identified or diagnosed until they reach End Stage Renal Disease (ESRD), given that CKD progresses from stage 1 to 5, in terms of providing Renal

Replacement Therapy (RRT), this is costly thus burdening the healthcare system globally, management is complicated due to this unusual progression as well as the late identification of the disease and the presence of comorbid conditions, which leads to many challenges for healthcare professionals as well as patients (*Etheredge and Fabian, 2017; Harvey et al., 2014*).

Epidemiology:

Over the past 30 years, the incidence of pediatric ESRD has been stable worldwide, but there is an increase in prevalence along with dialysis and renal transplant recipients' incidence (*Baum, 2010; Wong et al., 2012*).

Pediatric chronic kidney disease (CKD) differs from that in adults, and the majority of children diagnosed includes congenital anomalies and hereditary diseases. CKD prevalence in children is between 15 and 74.7 cases per million children, which is rare. The incidence of dialysis treatment in children and adolescents is estimated in 15 patients per million inhabitants (*Weschenfelder, 2014*).

Good survival is suggested with data collected from registries around the world, even if dialysis is indicated as early as the neonatal age (*Ingelfinger et al., 2016; Harambat et al., 2012*).

Although Chronic Kidney Disease (CKD) prevalence is debatable in the international literature, it is increasing with time, based on the current sociodemographic trends this makes

the disease a global public health issue (*Raghavan and Eknoyan, 2014*).

Knowing the epidemiology of childhood renal diseases is important because it will assist in health planning, allow for convenient allocation of resources and enable adequate services provision for renal disorders (*Ibeneme et al., 2015*).

The clinical picture of pediatric CKD and its general medical complications:

Growth and Nutrition

During childhood, growth involves a balance of metabolic, nutritional, and endocrine homeostatic processes. If it develops early in life, CKD leads to significant height stunting and disproportionate growth failure (*Clinical Pediatric Nephrology, 2007*).

Metabolic Acidosis and Renal Osteodystrophy

Chronic acidosis in CKD leads to changes in resorption and deposition of bone due to changes in ionic composition, and blunts the trophic effects of GH. The renal generation of 1, 25(OH) 2 D 3 is also reduced which will eventually result in secondary hyperparathyroidism (sHPT) especially in combination with hypocalcemia and retained phosphate (*Clinical Pediatric Nephrology, 2007*).

Cardiovascular Disease and Risk Factors

The leading cause of death in pediatric CKD is CV disease, with a 1, 000 times higher risk in the ESRD population compared to the age-matched non- CKD population (*Wilson et al., 2010; Wilson et al., 2011*). Recent work by the CKiD cohort study and others showed that there is a high prevalence of CV risk factors in children with CKD, even after the renal transplant the risk remains (*Wilson et al., 2011*).

Anemia

Poor outcomes, poor QOL and neurocognitive ability in CKD patients are all linked to anemia (*Wong et al., 2012*).

Neurocognitive Impact and Quality of Life

Some domains of life (emotional, social and functional) are affected in adults with childhood-onset kidney disease (*Gerson et al., 2010*). Even in mild stages, CKD has an impact on neurocognitive ability. These issues cannot be ignored during the most important stages of development (*Moreira et al., 2015*).

Psychiatric comorbidities with CKD in children as a barrier for management

CKD can have repercussions in various aspects of life of children and adolescents. Great changes in the daily lives of the children and their families are caused by the disease and its