# Impact of Health Education Program on Health Related Quality of Life among Patients with End Stage Renal Disease on Hemodialysis and their Caregivers at Ain Shams University Hospitals

Thesis

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By

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**Amal Mahmoud Ibrahim Goda**

# List of Contents

# List of Abbreviations

| Abb. | Full term |
|---|---|

***ACR*****.....** *Albumin-creatinine ratio*

***AER*****.....** *Albumin Excretion Rate*

***ANOVA*****……..** Analysis of Variance

***AVF*****.....** *Arteriovenous Fistula*

***AVG*****.....** *Arteriovenous Graft*

***BMI*****.....** *Body Mass Index*

***BP*****.....** *Blood Pressure*

***CDC*****.....** *Centers for Disease Control and Prevention*

***CKD*****.....** *Chronic Kidney Disease*

***CKD-MBD*****.....** *Chronic Kidney Disease-Mineral Bone Disorder*

***CVC*****.....** *Central Venous Catheters*

***ED*****……** Erectile dysfunction

***ESA*****.....** *Erythropoiesis-stimulating agents*

***ESRD*****.....** *End Stage Renal Disease*

***GFR*****.....** *Glomerular Filtration Rate*

***GN*****.....** *Glomerulonephritis*

***HBV*****.....** *Hepatitis B Virus*

***HD*****.....** *Hemodialysis*

***HIV*****.....** *Human immunodeficiency virus*

***HRQOL*****.....** *Health Related Quality Of Life*

***IQR*****……** *Interquartile Range*

***KDIGO*****.....** *Kidney Disease Improving Global Outcome*

***KDOQI*****.....** *Kidney Disease Outcome Quality Initiative*

***KDQOL-SF*****.....** *Kidney Disease Quality of Life Short Form*

***MCS*****……** *Mental component summary*

# List of Abbreviations (Cont...)

| Abb. | Full term |
|---|---|
| ***MIA syndrome ..*** | *Malnutrition-Inflammation- Atherosclerosis syndrome* |
| ***PCS……..*** | *Physical component summary score* |
| ***PTH.....*** | *Parathyroid Hormone* |
| ***QOL .....*** | *Quality of Life* |
| ***SGA.....*** | *Subjective Global Assessment* |
| ***USRDS .....*** | United States Renal Data System |
| ***WHO .....*** | *World Health Organization* |
| ***WHOQOLgroup*** | *World Health Organization Quality of Life group* |

# List of Tables

# List of Tables (Cont...)

# List of Tables (Cont...)

# List of Tables (Cont...)

# List of Figures

| Fig. No. | Title | Page No. |
|---|---|---|

# Abstract:

**Background:** Patients with renal failure had poorer quality of life than patients with other chronic diseases such as heart failure, diabetes mellitus and even cancer which makes them more susceptible to withdraw dialysis treatment. **Objectives:** The study was carried out to conduct health education program for patients with end stage renal disease on hemodialysis and their caregivers at Ain Shams University Hospitals and measure its effect on their quality of life. **Methods**: A controlled interventional study was carried out on three phases. A sample of 56 patients on chronic regular hemodialysis and their caregivers (HD) were selected from the two hemodialysis units at Ain Shams university hospitals and data were collected at the beginning and after six months of the health education program. **Results:** The intervention group of the patients after the intervention reported significant better quality of life scores than the control group in all the domains except in cognitive function, sexual function, social support, patient satisfaction and dialysis staff encouragement domains and reported also statistically significant higher levels for serum hemoglobin and albumin and there were statistically significant increases in the intervention group of the caregivers than the control group in social function, emotional well-being domains and mental component summary scores. **Conclusion:** it can be concluded that the intervention program not only prevents the deteriorations in the quality of life that may occur over time among the hemodialysis patients and their caregivers but also increases them.

Keyword; quality of life, hemodialysis, caregivers, intervention

# INTRODUCTION

Chronic kidney disease (CKD): is the presence of abnormalities in the kidney structure or function for more than 3 months with implications for health ***(KDIGO, 2013).***

***Worldwide***, the prevalence of CKD including the five stages was 13·4% with the majority stage 3 ***(Hill et al., 2016)*** and it was the 27th in the list of causes of the total number of deaths in 1990, but changed to 18th in 2010 ***(Lozano et al., 2012).*** Hemodialysis is the most commonly used modality as a renal replacement therapy ***(Shafiee et al., 2017)***. Among The United States, about 87.9% of all incident cases in 2014 began renal replacement therapy with hemodialysis, 9.3% started with peritoneal dialysis, and 2.6% underwent kidney transplantation ***(USRDS, 2016).***

WHO defines the quality of life as the individual's perception of his/her position in life, in the cultural context and the values in which he/she lives, in relation to his/her objectives, expectations, standards and concerns ***(WHOQOL Group, 1998).***

In comparison to patients with other chronic diseases such as heart failure, diabetes mellitus, chronic lung disease, arthritis, and even cancer, patients with renal failure had the worst quality of life ***(Ikonomou et al., 2015)*** and in

comparison, to patients with renal failure who were treated with peritoneal dialysis ***(Ogutmen et al., 2006)*** or with kidney transplantation ***(Saad et al., 2015),*** patients with renal failure and on hemodialysis had the worst quality of life.

The presence of the associated co-morbid disorders among hemodialysis patients such as depression (30% of ESRD patients), sexual dysfunction (nearly half of ESRD), and problems with sleep (up to 40%–80%), ranging from insomnia, sleep apnea to restless leg syndrome ***(Lægreid et al., 2014),*** the problematic life situations such as getting up early and waiting for public, collective transport, being weighed, waiting for the installation of the machine, sharing the therapeutic space and the hemofiltration machine and in addition to not being allowed to drink or eat whatever their eyes, nose or taste buds tell them, experiencing sleepless nights, body aches, itching, changes in appearance, hunger, thirst and cold due to metabolic changes, and dealing with the fear of having their blood pass through a machine with the risk of contamination, the incapability of having a paid employment, not being able to simply travel without having to search for alternative dialysis units on the way may be responsible for their poor quality of life ***(Guerra-Guerrerro et al., 2014).***

Assessment of quality of life in patients receiving dialysis helps in the prediction of remaining life time and future hospitalizations ***(Hall et al., 2018)*** and identification of the

factors affecting their quality of life such as socio-demographic and clinical variables are very important to develop

individualized interventions depend on their personal needs ***(Gerasimoula et al., 2015).***

Lack of compliance and adherence to the dietary recommendations among hemodialysis patients increase their morbidity and the mortality ***(Ahrari et al., 2014),*** decrease their quality of life ***(Denhaerynck et al., 2007)*** and increase the financial costs to both the patient and the health system ***(Ikizler et al., 2014),*** increasing the awareness of hemodialysis patients and their caregivers about disabilities associated with hemodialysis treatment about the disease and the treatment may be the main factor of positive adherence to their treatment regimen ***(Browne and Merighi, 2010, Smith et al., 2010, Kamal et al., 2013 and Parvan et al., 2016).***

For example, hyperphosphatemia is associated with renal failure and one of the important solutions to overcome this problem is to receive balanced nutrition ***(Cupisti et al., 2013)*** which can be achieved only by special education ***(Karavetian et al., 2014).*** Hyperkalemia is also common among patients with CKD and this disorder leads to complications in heart rhythm and sudden death and any education on adherence to low potassium level can be effective in decreasing this risk ***(Karaboya et al., 2017).***