PSYCHOSOCIAL TROUBLES AND QUALITY OF LIFE IN PARENTS OF CHILDREN WITH CHRONIC KIDNEY DISEASE

THESIS

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Abstract

Introduction: Quality of life in parents of children with chronic kidney disease is affected according to the degree of disease &method of treatement. **Methods :** This study include 75 patients 1-16 years old in 3 groups:group 1 include 40 child on regular HD, group 2 include 20 child on conservative therapy,group 3 include 15 child post transplantation in (Abou Elrish Children Hospital ,Cairo University) , HRQoL was assessed by questionnaire that was filled by parents attended with the childs usually the mother this included: social, physical, cognitive, communications, worry, family relationships, emotional & daily activities. **Results:** There was significant positive correlations between QOL(worry) and chronic maternal illness (P value=0.037) , between emotional functioning and paternal chronic illness (Pvalue=0.040).The higher frequency of visiting hospital the lower social functioning (p value=0.001), emotional functioning (p value=0.039), cognitive functioning (p value=0.017), family relationships (p value=0.000). Increase duration of the disease associated with decrease the daily activities (p value=0.046) and the communications (p value=0.011). Emotional functioning affected with maternal marital status (p value=0.021) **Conclusion:** Quality of life in parents of children with chronic kidney diseases highly affected by their childs illness in its all aspects . The worest QOLwas that of parents of patients on regular hemodialysis, The average was that on conservative therapy, the least affected is that of post transplantation patients.

Key Words: Quality, life, chronic, Hemodialysis, Transplantation, children, Parents.

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Abbreviations

ACEI.....Angiotensin Converting Enzyme Inhibitors

ALG.....antilymphocyte antibody

AV.....Arterio venous

CAPD.....Chronic Ambulatory Peritoneal Dialysis

CKD.....Chronic Kidney Disease

CSA.....cyclosporin A

DP.....Dialysis Patients

ESRD.....End Stage Renal Disease

GFR.....Glomerular Filtration Rate

GI.....Gastro Intistinal

HD.....Hemodialysis

HIV.....Human Immunodeficiencey Virus

HLA.....Human Leucocytic Antigen

HRQOL..... Health-related quality of life

K/DOQI.....Kidney Disease Outcomes Quality Initiative

KDW..... kidney Kisease Wasting

LRD.....Living-Related Donor

LVH.....Left Ventricular Hypertrophy

MI.....Myocardial Infarction

NAPRTCS.....North American Paediatric Renal Transplant.

NSAID's.....Non Steroidal Anti Inflamatory Drugs

Pmp..... per million in the age-related population

PrET.....Pre-emptive transplantation

PTH..... Parathormone

PUV.....Posterior Uretheral Valve

RRT..... Renal Replacement Therapy

(**rhGH)**..... recombinant growth hormone

TR.....Transplant Recipients

USRDS.....United States Renal Data System

UTIs.....Urinary Tract Infections

VUR.....Vesico-Uretric Reflux

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Introduction

Chronic renal diseaseis defind as:"evidence of structural or functional kidney abnormalities (abnormal urine analysis, imaging studies, or histology) that persist for at least 3 months, with or without a decreased glomerular filtration rate (GFR), as defined by a GFR of less than 60 mL/min per 1.73 m2**(Seikaly et al.,2003**)

Once a child develops CKD Stage V, some form of renal replacement therapy (RRT) is required. The choice is limited to a chronic dialysis or renal transplantation. A preemptive transplant is possibly the best option. Besides providing a good renal replacement therapy it ensures better growth and does not drain the family resources**.(Craven et al.,2007**)

Chronic hemodialysis has many complications,cardiovascular,nutritional, Gastrointestinal,hepatic,endocrinal,complications of AVfistula,infections ,nervous system&sleep disorders (**Kawamura et al .,1998)**

Also there is psychosocial issues in hemodialysis patients including: functional Limitations and dietary restrictions ,and fear of death. Common problems include depression,psychosis ,personality changes, anexiety disorders ,and substance abuse(**Patel et al.,2005**)

A high impact on family life was reported by parents whose children on hemodialysis. **(Anthony, 2010).**Parents of pediatric organ transplant recipients experience significant psychological distress and as a consequence show moderate to severe posttraumatic stress symptoms

(Young et al.,2003)), Compared to parents of healthy children, depression is significantly more common in parents of children suffering from renal disease (**Tsai et al.,2006)**

QOL in parents of children with chronic renal disease affected according to the treatement options wheather on regular hemodialysis ,post renal transplantation&on conservative therapy.It was found that QOL in those on regular HD is markedly affected than those of other two groups. (**Goldstein et al** ,**2009**)

Aim Of The Work

Compairing the QOL in parents of children of chronic kidney disease wheather on regular HD, on conservative therapy & post renal transplantation.

Chapter 1

Chronic renal faliure in children

Introduction:

Chronic kidney disease(CKD) is characterized by an irreversible deterioration of renal function that gradually progresses to end-stage renal disease (ESRD). Chronic kidney disease has emerged as a serious public health problem. Data from the United States Renal Data System (USRDS) show that incidence of kidney failure is rising among adults and is commonly associated with poor outcomes and high cost**.** Moreover, in the past 2 decades, the incidence of the chronic kidney disease in children has steadily increased, with poor and ethnic minority children disproportionately affected **(Seikalyet al,2003)**

Definition of chronic renal disease:

Chronic renal failure is "evidence of structural or functional kidney abnormalities (abnormal urine analysis, imaging studies, or histology) that persist for at least 3 months, with or without a decreased glomerular filtration rate (GFR), as defined by a GFR of less than 60 mL/min per 1.73 m2**(Seikaly et al.,2003)**

Note, however, that the above definition is not applicable to children younger than 2 years, because they normally have a

low GFR, even when corrected for body surface area. In these patients, calculated GFR based on serum creatinine can be compared with normative age-appropriate values to detect renal impairment **(Gulati et al.,1999)**

Etiology and Pathophysiology:

The chief causes of chronic kidney disease (CKD) in children include the following

1. Obstructive uropathy
2. Hypoplastic or dysplastic kidneys
3. Reflux nephropathy
4. Focal segmental glomerulosclerosis as a variant of childhood nephrotic syndrome
5. Polycystic kidney disease, autosomal-recessive and autosomal-dominant varieties. **(Gulati et al.,1999)**

Despite the diverse etiologies, once chronic kidney disease develops, the subsequent response of the failing kidney is similar. The kidney initially adapts to damage by increasing the filtration rate in the remaining normal nephrons, a process called adaptive hyperfiltration. As a result, patients with mild chronic kidney disease often have a normal or near-normal serum creatinine concentration. Additional homeostatic mechanisms

(most frequently occurring within the renal tubules) permit the serum concentrations of sodium, potassium, calcium, and

phosphorous and total body water to also remain within the reference range, particularly among those with mild to moderate stages of chronic kidney disease **(Ardissino et al , 2003)**

Adaptive hyperfiltration, although initially beneficial, appears to result in long-term damage to the glomeruli of the remaining nephrons, which is manifested by pathologic proteinuria and progressive kidney insufficiency. This irreversibility appears to be responsible for the development of end-stage kidney failure among persons in whom the original illness is either inactive or cured **(Choi et al.,2009)**

Although the underlying problem that initiated chronic kidney disease often cannot be treated primarily, extensive studies in experimental animals and preliminary studies in humans suggest that progression in chronic renal disease may be largely due to secondary factors that are unrelated to the activity of the initial disease. These include anemia, osteodystrophy, systemic and intraglomerular hypertension,glomerular hypertrophy, proteinuria, metabolic acidosis, hyperlipidemia, tubulointerstitial disease, systemic inflammation, and altered prostanoid metabolism. This common sequence of events in diverse types of chronic kidney disease is the basis for the common management plan for children with chronic kidney disease, irrespective of the etiology**(Ardissino et al.,2003)**

Stages of chronic kidney disease:

1- Kidney damage with: normal or >90 ml/min per1.73 m^2 increased GFR

2- Kidney damage with: mild decrease GFR 60-89 ml/min per 1.73 m^2

3 -Moderate decrease GFR 30-59 ml/min per 1.73 m^2

4- Severe decrease GFR 15-29 ml/min per 1.73 m^2

5- Kidney failure:GFR <15 ml/min per 1.73 m^2

Table (1) : Stages of chronic kidney disease :

Stage	Description	GFR (ml/min/1.73 m^2)
1	Kidney damage with normal or increased GFR	>90
2	Kidney damage with mild decrease GFR	60-89
3	Moderate decrease GFR	30-59
4	Severe decrease GFR	15-29
5	Kidney failure	<15

(**Mouin et al ., 2003)**.

To adopt the system of defining kidney disease according to kidney function, not serum creatinine level. However certain grey areas exist with this classification. The staging takes into consideration normal GFR for a western population. It has been