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Quality of Life of Patients with Chronic Kidney Disease

Dr. Alazmi, Abdulaziz Hamdan

Dr. ALASMARI, MESHAL ALI S

Dr. ABDULLAH SAAD AL-ASMARI

Dr. SARA NASSER AL-MAZROOA

Dr. Kholoud Khalaf Alharbi

Dr. Nouf Jafar Alzahrani

Abstract

This study aimed at exploring the assessment of Quality of Life (QOL) in patients with Chronic Kidney Disease (CKD), and aiming at assessing the QOL of patients with stages 1–5 Chronic Kidney Disease CKD on conservative treatment in order to identify a possible association between Quality Of Life QOL and progression of kidney insufficiency. The results were compared with those obtained for patients on hemodialysis. Sociodemographic, clinical and laboratory data were also evaluated. And the study concluded that research efforts have expanded significantly to determine the state of pediatric CKD patient HRQOL and the factors that impact HRQOL across all stages of CKD and all modalities of renal replacement therapy. Data from all studies suggest that children with a renal transplant fare better with respect to HRQOL than those receiving dialysis.

1.1 Introduction

Inside each kidney there are about one million tiny units called nephrons. The nephrons are the part of the kidney, which filter the blood. Each nephron is made up of a very small filter called a glomerulus. As blood passes through the nephron, water and waste products are removed. Most of the water returns to the blood and the waste products collect in the bladder then leave the body as urine. Most kidney diseases attack the nephrons.
Assessment of Health-Related Quality Of Life (HRQOL) (*see figure 1*) in patients with Chronic Kidney Disease (CKD) has evolved with treatment advances so that the expectation of patient outcomes has grown from simple survival to achieving a sense of well-being (Abdel-Kader, Myaskovsky, Karpov, Shah, Hess, Dew & Unruh, 2009).

Health-Related Quality Of Life HRQOL has been assessed in Chronic Kidney Disease CKD using multidimensional measures that capture information about function and well-being across predefined domains that are thought to be relevant to an overall assessment of HRQOL. Hence, HRQOL reflects the welfare of a patient on the basis of aspects of functional status (including physical, mental, and social factors) and a relative balance of expectations and experiences in the face of changing health; however, there may be a disconnect between measured HRQOL and patient perceived Quality Of Life QOL, and proxies often fare poorly when trying to assess HRQOL. The potential sources of this disconnect may reflect cultural differences, coping mechanisms, and individual values (Sharpe, Butow, Smith, McConnell & Clarke, 2005).

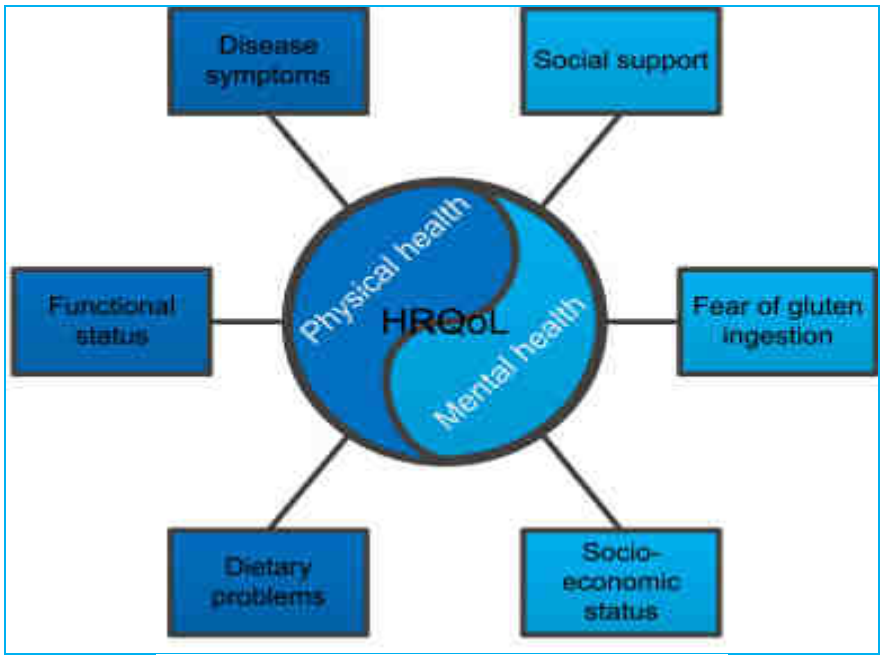

Figure (1): Health-Related Quality Of Life (HRQOL)

Some studies have evaluated the quality of life (QOL) of patients undergoing dialysis, but there is limited information available on the QOL of patients on conservative treatment of CKD and the relationship between QOL and the early stages of the disease. The QOL of these patients seems to be poorer than that of the general population, but better than for patients on dialysis.[2,3] Certain factors such as anemia, associated diseases and early treatment by a nephrologist appear to have an impact on the QOL of these patients (Cruz, Andrade, Urrutia, Draibe, Nogueira-Martins & Sesso, 2011).

Due to the increasing number of patients suffering from end stage renal disease, the high mortality, the life-long care and the increasing treatment costs, more and more studies are focusing on those psychosocial aspects, which are considered to be in relation to the patient's condition and quality of life.

The Kidney Disease Quality of Life (KDQOL-SFTM) questionnaire is a widely applied tool in nephrology, that was used in several large, multinational studies to assess quality of life in populations with chronic kidney disease. However the questionnaire was translated to several languages, the appropriate psychometric validation of these local versions were rarely published.

Medical care advancements for children with chronic kidney disease (CKD) receiving hemodialysis, peritoneal dialysis, or with a renal transplant have resulted in relatively improved long-term patient survival compared with adult patients with CKD.1 As a result, more pediatric patients with CKD are reaching adult age. Thus, optimal care for the pediatric patient with CKD requires attention not only to medical management, but also to the psychosocial and developmental factors that either will ensure or prevent a pediatric patient's successful transition into adulthood. This article describes the scope of the problem with respect to pediatric CKD patient health-related quality of life (HRQOL), reviews the published literature on the topic, and presents current research efforts underway to improve our understanding and measurement of pediatric CKD patient HRQOL (Goldstein, Gerson, Goldman & Furth, 2006).

1.2 Problem Statement

The objectives of this cross-sectional study were to assess the QOL of patients with stages 1–5 Chronic Kidney Disease CKD (*see figure 2*) on conservative treatment in order to identify a possible association between Quality Of Life QOL and progression of kidney insufficiency. The results were compared with those obtained for patients on hemodialysis. Sociodemographic, clinical and laboratory data were also evaluated.

Stages of Chronic Kidney Disease of all Types		
Stage	**Qualitative Description**	**Renal Function (mL/min/1.73 m²)**
1	Kidney damage-normal GFR	≥90
2	Kidney damage-mild ↓ GFR	60-89
3	Moderate ↓ GFR	30-59
4	Severe ↓ GFR	15-29
5	End-stage renal disease	<15 (or dialysis)

Figure (2): 1–5 Chronic Kidney Disease CKD stages

CKD imparts significant constraints and restrictions that have a significant impact on normal psychosocial development. The medical requirements for CKD, including dietary restrictions and dependence on a hemodialysis or peritoneal dialysis machine, isolate children with CKD from their healthy peers. Such interruptions in the normal daily life of a child are a likely primary cause for the relatively low self-esteem and low rates of independent living.

1.3 Chronic Kidney Disease

Chronic kidney disease (CKD) is a long term condition caused by damage to both kidneys. There is no single cause and the damage is usually irreversible and can lead to ill health. In some cases dialysis or transplantation may become necessary. It is only relatively recently that the epidemiology of CKD has been studied in detail with the finding that it is more common than previously thought (de Lusignan, Chan, Stevens, O'Donoghue, Hague & Dzregah, 2005).

Diabetes mellitus, which is also becoming more common, is one cause of CKD. Chronic kidney disease is seen more frequently in older people and therefore is likely to increase in the population as a whole. People with CKD are at higher risk of cardiovascular disease and they should be identified early so that appropriate preventative measures can be taken. In the early stages of CKD people may be unaware that they have any illness and a blood or urine test may be the only way it is discovered. Establishing which conditions predispose to CKD identifies those who should have the necessary blood or urine tests. Early detection of CKD can establish if kidney disease is likely to be progressive allowing appropriate treatment to slow progression.

With chronic kidney disease, the kidneys don't usually fail all at once. Instead, kidney disease often progresses slowly over a period of years. This is good news because if CKD is caught early, medicines and lifestyle changes may help slow its progress and keep you feeling your best for as long as possible.

1.3.1 Glomerular Filtration Rate (GFR)

Glomerular filtration rate (GFR) (*see figure 3*) is the best measure of kidney function. The GFR is the number used to figure out a person's stage of kidney disease. A math formula using the person's age, race, gender and their serum creatinine is used to calculate a GFR.

A doctor will order a blood test to measure the serum creatinine level. Creatinine is a waste product that comes from muscle activity. When kidneys are working well they remove creatinine from the blood. As kidney function slows, blood levels of creatinine rise.

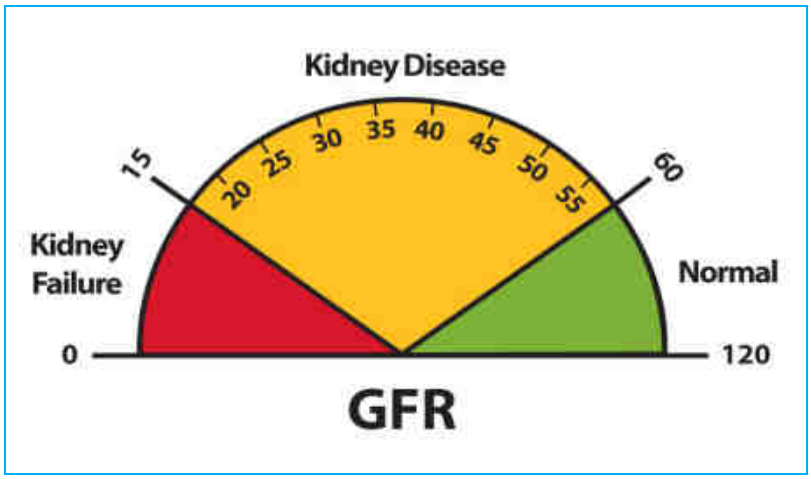

Figure (3): Glomerular filtration rate (GFR)

And below shows the five stages of CKD and GFR for each stage:

- Stage 1 with normal or high GFR (GFR > 90 ml/min)
- Stage 2 Mild CKD (GFR = 60-89 ml/min)
- Stage 3 Moderate CKD (GFR = 30-59 ml/min)
- Stage 4 Severe CKD (GFR = 15-29 ml/min)
- Stage 5 End Stage CKD (GFR <15 ml/min)

1.4 Definition of Health-related Quality of Life (HRQOL

Several definitions of HRQOL have been proposed but the consensus definition is that HRQOL refers to the functional effect of a medical condition and/or its consequent therapy upon a patient (Uwaezuoke & Muoneke, 2015).

It is a multidimensional concept which encompasses domains related to physical and occupational function, psychological/ emotional state, social interaction and somatic sensation (Ferrans, 2005).

HRQOL should be patient-reported and should not be judged by a healthcare professional. The goal of HRQOL assessment is to quantify the degree to which the medical condition or its treatment impacts on the individual's life in a valid and reproducible way. Along with traditional physiologic measures, it is an important indicator to capture the burden of disease. Although the gold standard is for patients to self-report their HRQOL, there may be room for proxy data especially when the patient is too ill or too young. These measurements can then be utilized to assess changes in HRQOL over time especially in clinical trials and healthcare delivery settings, and to compare the HRQOL of patients with different medical conditions or patients who receive different treatment modalities (Aurona & Brophy, 2010).

For instance, in paediatric ESRD, HRQOL is an important clinical measure of the effects of the disease, as well as the beneficial effects of management for children undergoing treatment modalities like haemodialysis (HD), peritoneal dialysis (PD) and renal transplantation (TX).

1.5 Early Pediatric HRQOL Study

Early research into the HRQOL of pediatric CKD patients occurring over 10 years ago showed that although pediatric patients with CKD certainly have some similar developmental and psychosocial issues as children with other chronic illnesses, they also have challenges specifically related to CKD (Hatzmann, Heymans, Ferrer-i-Carbonell, van Praag & Grootenhuis, 2008).

Obstacles common to most chronically ill children include physical changes related to illness, the need to take many medications and undergo medical treatment, and time away from school and peers, which can lead to perceived differences and isolation. Children with CKD have additional challenges such as maintaining a restricted dietary and fluid regimen, chronic dependence on medical equipment to sustain life, very obvious physical changes associated with transplantation, and the knowledge that they will live their whole lives with the recurrent cycle of dialysis and transplantation (Goldstein, 2009).

To date, no follow-up evaluation from these studies has been published. The tools used most often to measure HRQOL in previous studies were not CKD -specific and included the Vineland Social Maturity scale, the Diagnostic Interview for Children and Adolescents, the General Health Questionnaire, the Birleson Depression Inventory, the Lipsitt Self-Concept scale, and a variety of other mental health inventories. The information gathered with these tools showed that children with CKD have psychosocial issues and adjustment problems when compared with healthy children (Barlow & Ellard, 2006).

These studies have shown that transplant patients cope better and have fewer psychologic problems than patients receiving peritoneal dialysis or hemodialysis. Compared with healthy children and children with a renal transplant, children receiving dialysis show increased incidences of depression, behavior disturbances, dependency on caregivers, poor school performance, lack of higher education or vocational training, cognitive delays, separation anxiety disorder, and poor social adjustment and peer relationships. In addition, patients receiving peritoneal dialysis seem to have more advanced coping skills and better emotional and academic adjustment than children receiving hemodialysis.
Finally, parents of children with CKD experience increased stress levels, increased marital strain, decreased support from friends and employers, increased incidences of anxiety and depression, and role confusion related to being both parent and medical caregiver (particularly in the case of parents of patients receiving home peritoneal dialysis) (Tong, Lowe, Sainsbury & Craig, 2010).

1.6 Specific HRQOL Measurement Instruments for Children With Chronic Disease
HRQOL tools including the Short Form 36, a non-ESRD specific tool, and the Kidney Disease Quality of Life, an ESRD-specific tool, have been crucial for evaluation of the impact of medical treatment on adult patients with ESRD (Goldstein, Gerson & Furth, 2007).

Data from adults have shown that the ESRD-specific Kidney Disease Quality of Life tool offered higher discrimination between dialysis modalities than the generic Short Form 36 tool.

Although standard outcome measures used for adult patients such as death and hospitalization rates are important outcome measures for children, they clearly are insufficient. In addition, factors assessed in adult HRQOL including work status and sexual function generally are not appropriate for a pediatric population. Other factors including growth, exercise capacity, school attendance and performance, self-reliance, and functional development are crucial components for assessing the HRQOL for a pediatric patient with ESRD. A number of survey instruments addressing HRQOL have been used in school-based populations and in children with chronic illness; some of which have been studied recently in children with CKD.

1.6.1 Child Health and Illness Profile: Adolescent Edition
The Child Health and Illness Profile Adolescent Edition (CHIP-AE) is a 153-item self-report instrument that assesses 6 domains of health status (discomfort, satisfaction, disorders, achievements, resilience, and risks). The instrument takes about 20 minutes to complete. Reliability (test-retest and internal) and validity (criterion and construct) studies support its use as a generic health status assessment tool for youth aged 11 to 17 years. It has been shown to be sensitive enough to distinguish between healthy and ill adolescents, and different age groups, sexes, and socioeconomic levels. The CHIP-AE has been evaluated in a multicenter cross-sectional study of health status in adolescents with CKD.

1.6.2 The Children's Health Questionnaire
The Children's Health Questionnaire (CHQ) is another generic health status instrument that has been used in adolescents with CKD. It has both parent and child versions. The child version is appropriate for administration to children aged 10 to 19 years and takes about 20 minutes to complete. The CHQ measures 12 domains of health status (physical functioning, limitations in schoolwork and activities with friends, general health, bodily pain and discomfort, limitations in family activities, emotional/time impact on the parent, impact of emotional or behavior problems on school work and other daily activities, self-esteem, mental health, behavior, family cohesion, and change in health).

Because there are both parent and youth forms, use of the CHQ allows for comparison of health status perceptions between children and their parents or guardians. The CHQ has been used previously in a single-center study with children who have kidney disease and are maintained on hemodialysis,22 and more recently in a multicenter study of adolescents with CKD. The CHQ was used to show the negative impact of anemia on several aspects of HRQOL. This cross-sectional study examined the association between anemia and QOL in a prevalent cohort of adolescents with CKD using the parent version of the CHQ (Child Health Questionnaire

Parent Form). The study population included 113 CKD patients (mean age, 14.4 1.9 y) requiring dialysis, with functioning kidney transplants or with advanced stage 2 or stage 3 to 5 CKD, as defined by the National Kidney Foundation's Kidney Disease Outcomes Quality Initiative. Seventy-five patients were found to be anemic, defined by a hematocrit level of 36% or lower. Anemic patients scored lower than nonanemic patients within several categories of QOL, specifically in the CHQ Parent Form 50 subdomains relating to physical functioning, role-physical, and general health. These findings suggest that correction of anemia in adolescents with CKD may significantly improve long-term health outcomes for children with renal disease and their corresponding QOL, and show that the use of a HRQOL measure can show clinical improvement in response to a specific therapy for one of the many complications of CKD in children (Gerson, Wentz, Abraham, Mendley, Hooper, Butler & Warady, 2010).

1.7 Health-related Quality of Life assessment: its clinical application in paediatric CKD

HRQOL assessment is beneficial to patients, clinicians, researchers, health administrators and policy makers. Thus, medical research has focused increasingly on HRQOL as an important variable. A key distinguishing feature of QOL is the incorporation of the patient's values, judgments and preferences. An international group of investigators have suggested six fundamental domains of HRQOL: physical functioning, psychological functioning, social functioning, role activities, overall life satisfaction and perception of health status [38]. Some authors argue that each domain of health can be measured in objective and subjective dimensions (Crosby, Kolotkin & Williams, 2003).

The objective dimension serves to define a patient's degree of health while the patient's subjective evaluation serves to translate that health status into the actual QOL experienced. From the patient's perspective, a meaningful change in HRQOL may be one that results in a meaningful reduction in symptoms or improvement in function while a meaningful change for the clinician may be one that indicates a change in the therapeutic option or in the prognosis of the disease. Early identification of HRQOL problems in children with early stages of CKD and appropriate intervention may decrease the prevalence of poor educational, occupational and social outcomes in adults with childhood onset of CKD (Gerson, Wentz, Abraham, Mendley, Hooper, Butler, Gipson, Lande, Shinar, Moxey-Mims, Warady & Furth, 2010).

In fact, the importance of evaluating the behavioral and social repercussions in children with CKD in order to improve their QOL was buttressed in a study by a group of collaborative researchers (Marciano, Soares, Diniz, Lima, Silva, Canhestro, Gazzinalli, Melo, Dias, Silva, Correa & Oliveira, 2011).

Using Strengths and Difficulties Questionnaire (SDQ) and Pediatric Inventory of Quality of Life Core Scales (PedsQL) as assessment tools for patients and care-givers, the prevalence of behavior disorders and assessment of HRQOL in 136 patients with CKD was done. When compared to healthy controls, the CKD group had significantly lower scores in almost all PedsQL domains. This finding supports the argument that unless assessments of HRQOL come directly from the patient, investigators are not measuring HRQOL. Other researchers have observed that children can perceive their QOL as good, despite living with what others may perceive as severe limitations (Heath, MacKinlay, Watson, Hames, Wirz, Scott, Klewchuk, Milford & McHugh, 2011).

Conclusions

Research efforts have expanded significantly to determine the state of pediatric CKD patient HRQOL and the factors that impact HRQOL across all stages of CKD and all modalities of renal replacement therapy. Data from all studies suggest that children with a renal transplant fare better with respect to HRQOL than those receiving dialysis. As children and adolescents with CKD show improved survival into adulthood, vigorous attention to pediatric CKD patient HRQOL will be essential to provide optimal care and the tools needed for successful transition into the adult health care system. The HRQOL assessment instruments and their associated studies described here represent the first step toward achieving these goals.

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