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## HEALTH RELATED QUALITY OF LIFE OF PATIENTS ON MAINTENANCE HAEMODIALYSIS AT KENYATTA NATIONAL HOSPITAL

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### ABSTRACT

**Background:** Health related quality of life is increasingly being recognised as a primary outcome measure in treatment of end-stage renal disease. The health related quality of life of patients on maintenance haemodialysis is reduced. Several interventions directed at modifiable risk factors have been shown to improve quality of life of patients on haemodialysis.

**Objective:** To assess the health-related quality of life of patients on maintenance haemodialysis at the Kenyatta National Hospital.

**Design:** Cross sectional descriptive study.

**Setting:** Kenyatta National Hospital, Renal Unit.

**Subjects:** The study was conducted on 96 patients with end-stage renal disease on maintenance haemodialysis. Socio-demographic and clinical factors were recorded for all patients. Health-related quality of life was assessed using the Kidney Disease Quality of Life-36 questionnaire. Two summary scores and three subscale scores were calculated.

**Results:** The mean physical composite summary and mental composite summary scores were  $39.09 \pm 9.49$  and  $41.87 \pm 10.56$  respectively. The burden of kidney disease subscale, symptom and problems subscale and effect of kidney disease on daily life subscale scores were  $16.15 \pm 21.83$ ,  $73.46 \pm 18.061$  and  $67.63 \pm 23.45$  respectively.

**Conclusion:** Health-related quality of life of patients on maintenance haemodialysis is reduced. The physical quality of life is more affected than the mental quality of life. The burden of kidney disease subscale is the most affected subscale score.

### INTRODUCTION

In Sub-Saharan Africa, some 4000 patients with end-stage renal disease (ESRD) are on maintenance haemodialysis (less than 1% of the world total) (1). The availability of renal replacement therapy in Sub-Saharan Africa is limited by high costs, lack of equipment and few trained personnel. Even in countries where renal replacement therapy is available, the prohibitive costs of dialysis are borne by patients and their families (2).

Patients on haemodialysis are also limited by dietary, time, physical and psychological restrictions leading to disruptions in personal relations and social withdrawal. Patients with ESRD on haemodialysis have been noted to frequently suffer from cognitive dysfunction, depression, anxiety, pain, sleep disruption, reduced physical functioning, sexual

dysfunction and reduced social interactions (1). These physical, psychological and social stressors engendered by the disease and its treatment result in impaired quality of life.

Consequently, the assessment of quality of care of patients on haemodialysis should extend beyond the traditional biological measures of urea kinetics and nutritional status to involve explicit measures of the patients' experiences and quality of life. In this regard the Kidney Disease Outcome Quality Initiative (KDOQI) 2002 updated guidelines on management of patients on haemodialysis recommend regular monitoring of functional status and well-being (3). In addition to assessing an individual's well-being and functional status, health-related quality of life (HRQOL) measures are robust predictors of mortality, morbidity and important surrogate markers of quality of care in patients on haemodialysis (4).

Reports indicating impaired quality of life of patients on haemodialysis are consistent globally with physical health particularly more affected than the mental health (5-10).

In South Africa, among 100 patients from ten centres, Becker *et al* found the quality of life of their haemodialysis patients to be significantly lower than that of the general population, with PCS score of  $41.4 \pm 10.35$  and MCS score of  $45 \pm 9.98$  compared to population norms of  $50 \pm 10$  (9).

There are no published studies on the HRQOL of patients on maintenance haemodialysis from Kenya. More importantly, some determinants of HRQOL are modifiable. This study aims to bridge this gap in knowledge. It is the authors' hope that clinicians will be sensitised towards the need for determining HRQOL scores in HD patients as well as target specific interventions that improve patients' perception of their well-being.

## MATERIALS AND METHODS

The study was conducted at the Kenyatta National Hospital (KNH) renal unit after obtaining ethical approval from the KNH ethical and research committee. Patients with ESRD aged 18 years and above on maintenance haemodialysis were considered eligible. Patients who had being on dialysis less than three months, patients hospitalised in the last four weeks and patients with cognitive impairment, psychosis and dementia were excluded from the study.

For each patient, demographic and socio-economic history was obtained through direct questioning and recorded into the study proforma.

HRQOL was measured by the KDQOL-36 questionnaire. The use of the KDQOL-36 questionnaire is recommended by the National Kidney Foundation (7). The KDQOL-36 questionnaire has been validated and used in multiple studies. The instrument is reliable with internal consistency coefficients of  $> 0.80$  in most scales (11).

The first 12 items of the KDQOL-36 are the Medical Outcomes Survey (MOS) SF-12 survey, which measures patients' perceptions of their own physical and mental functioning. In addition, there are 24 kidney-disease specific questions. The five scores derived from the KDQOL-36 are:

1. Physical component summary (PCS) (items 1-12)—an overall measure of physical functioning that assesses physical limitations, energy level and general health.
2. Mental component summary (MCS) (items 1-12)—an overall measure of mental functioning that assesses tasks, depression, anxiety and social activities.
3. Burden of kidney disease subscale (items 13-

16)—how much kidney disease interferes with daily life, takes up time, causes frustration, or makes the respondent feel like a burden.

4. Symptoms and problems subscale (items 17-28b)—how bothered a respondent feels by sore muscles, chest pain, cramps, itchy or dry skin, shortness of breath, faintness/dizziness, lack of appetite, feeling washed out or drained, numbness in the hands or feet, nausea, or problems with dialysis access.
5. Effects of kidney disease on daily life subscale (items 29-36)—how bothered the respondent feels by fluid limits, diet restrictions, ability to work around the house or travel, feeling dependent on doctors and other medical staff, stress or worries, sex life, and personal appearance.

The questionnaire was in English and was interviewer administered. For patients who did not understand English the Principal Investigator (PI) translated the questions to a language they best understood or used a translator. A mark was put against the patient's response. Those questions that the patient did not answer were left blank.

*Data analysis:* The data collected were entered into EXCEL and stored under a password.

*Survey scoring:* An Excel scoring spreadsheet with an example and instructions was obtained from the UCLA website at [www.gim.med.ucla.edu/kdqol](http://www.gim.med.ucla.edu/kdqol). Each question had a maximum of 100 points with a higher scores indicating better health. The scales had a maximum of 100 points with higher scores indicating better health. Scale scores were computed if at least one item in the scale was answered. The scores were computed as the average of the answered items. Continuous variables were summarised into means and standard deviations. Categorical data were summarised into proportions.

## RESULTS

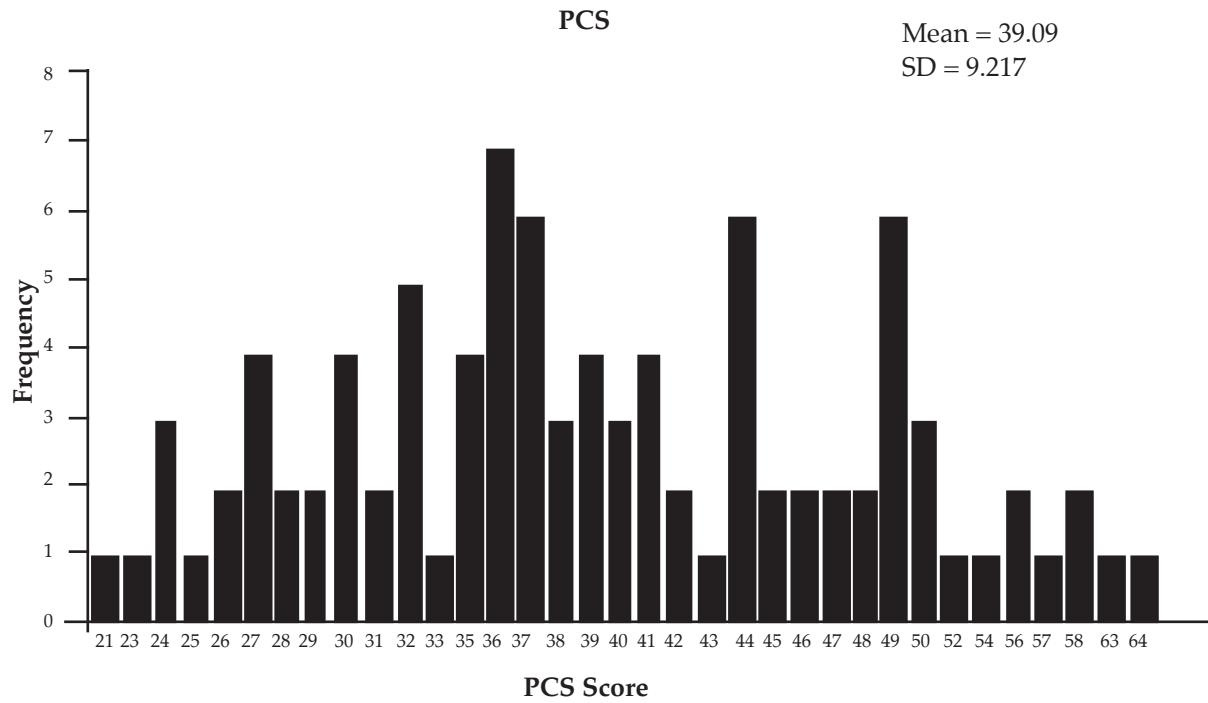
A total of 130 out of 144 patients on maintenance haemodialysis were screened. Ninety six patients (66.7%) met the inclusion criteria and were included in the study.

Males accounted for 65.6% of the study participants while females comprised 34.4%. The mean age of the study participants was  $44 \pm 13.98$  years.

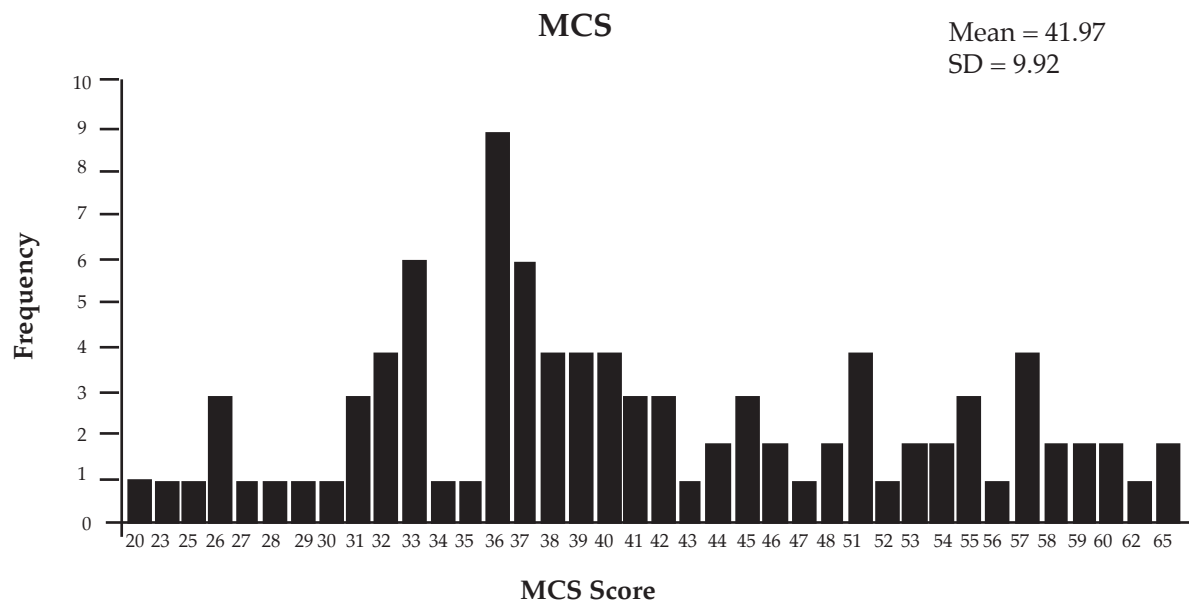
*Health related quality of life:* The mean physical composite summary (PCS) and mental composite summary (MCS) scores were  $39.09 \pm 9.49$  and  $41.87 \pm 10.56$  respectively. The population norms for the PCS and MCS scores are  $50 \pm 10$ .

The distribution of the PCS and MCS scores are shown in figure 1 and 2 respectively.

**Figure 1**  
*Distribution of physical composite scores*

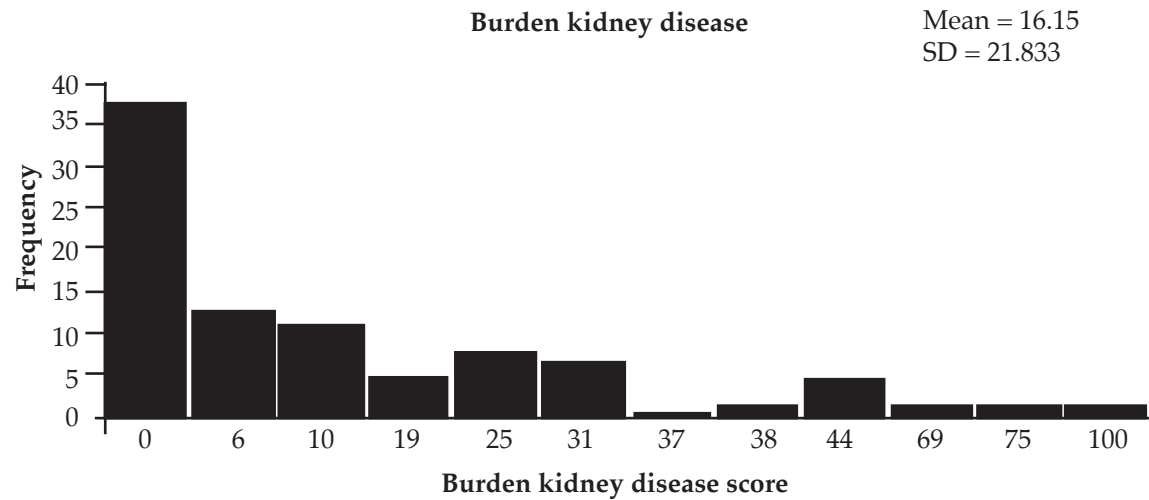


**Figure 2**  
*Distribution of mental composite score*



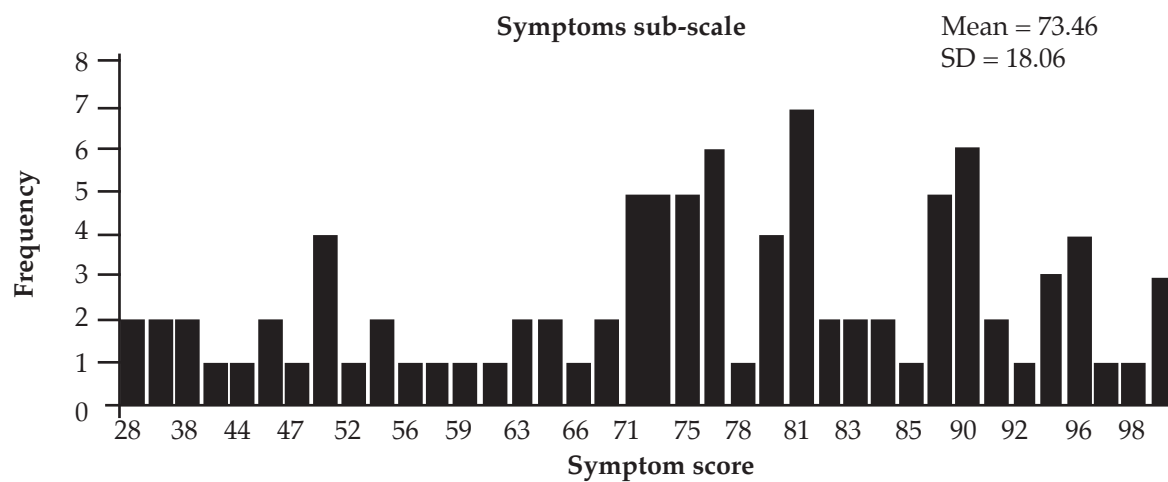
The subscale scores range from 0-100 with higher scores indicating better health. The burden of kidney disease subscale, symptom and problems subscale and effect of kidney disease on daily life subscale scores were 16.15±21.83, 73.46±18.061 and 67.63±23.45 respectively.

**Figure 3**  
*Distribution of burden of kidney disease subscale scores*



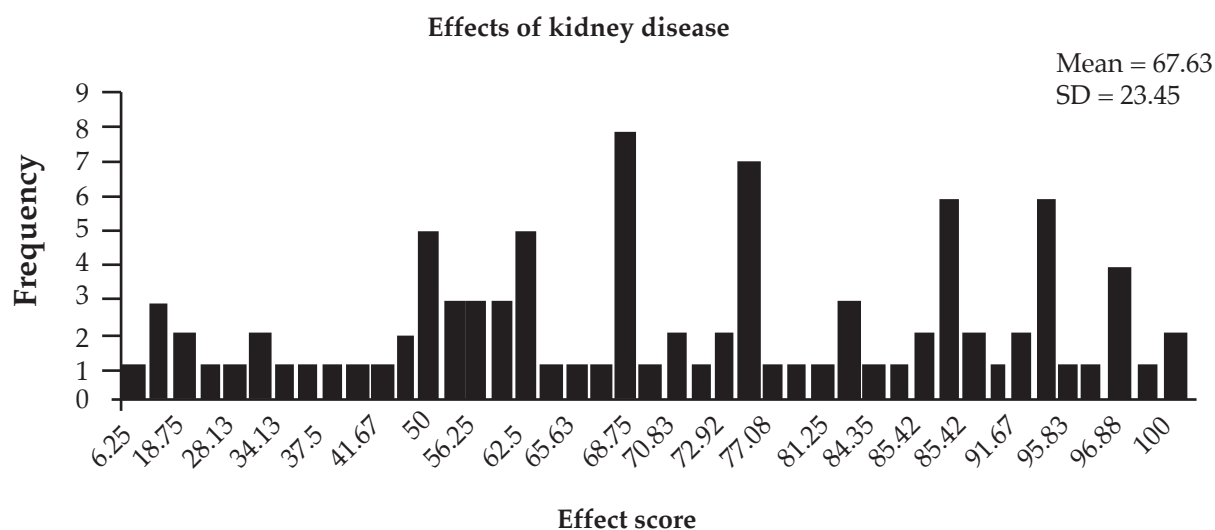
89% of the patients scored less than 40 points in the burden of kidney disease subscale score.

**Figure 4**  
*Distribution of the symptoms and problems subscale score*



78% of the patients scored more than 60 points on the symptoms subscale score.

**Figure 5**  
Distribution of effects of kidney disease on daily life subscale scores



68% of the patients scored over 60 points on the effects of kidney disease on daily life subscale score.

## DISCUSSION

The mean PCS Score was  $39.09 \pm 9.49$  and the mean MCS Score was  $41.87 \pm 10.57$ . This is consistent with multiple studies that have found the HRQOL of life of patients on maintenance haemodialysis to be reduced (4,9, 12,13-15). Seica *et al* while assessing the QOL of 709 Romanian haemodialysis patients found a PCS score of  $46.3 \pm 19.2$  and MCS score of  $55.1 \pm 19.3$  (16). Mittal *et al* found a mean PCS of  $36.9 \pm 8.8$  and MCS of  $48.7 \pm 9.3$  among 134 haemodialysis patients in the USA (12).

To the authors' knowledge, the only published study on HRQOL of patients on chronic haemodialysis in Africa is from South Africa. Becker *et al* assessed the QOL of 100 HD patients and found the mean PCS and MCS to be  $41.4 \pm 10.35$  and  $45 \pm 9.98$  respectively (9).

Studies done in South America, Europe and Asia have found similar results. Bokhe *et al* in Brazil found a mean PCS and MCS of  $44.5 \pm 10.3$  and  $51.2 \pm 11.3$  respectively; Vasilieva *et al* in Russia found PCS and MCS of  $36.9 \pm 9.7$  and  $44.2 \pm 10.5$  respectively; whereas Chieng *et al* in Taiwan found PCS and MCS of  $36.2 \pm 12.4$  and  $37.5 \pm 14.5$  respectively (13-15). These scores were lower than their respective age matched population norms.

Consistent with multiple studies, the PCS scores in this study were lower than the MCS scores. This implies that the physical health is more affected than the mental aspect which could reflect the increased co-morbidity associated with ESRD (17). Studies assessing HRQOL of other chronic conditions such as Rheumatoid arthritis and Congestive Cardiac Failure have found the mental aspect to be less affected than

the physical health. This may reflect the fact that in chronic diseases, aspects of self assessed mental health become blunted with time, as a useful psychological adaptation (12,13).

Direct comparison of HRQOL scores across these different regions may not be feasible owing to differences in patients studied in terms of age, gender, primary renal disease and dialysis duration which significantly affect quality of life. Compared to the Brazilian and Romanian studies, the HRQOL scores in this study were poorer, as the participants had a lower mean age, lower prevalence of diabetes mellitus and a shorter mean duration of dialysis, all predictors of higher HRQOL (13,16). Compared to this study, the Taiwan study had more females (55.3% vs.34.4%), a higher mean age ( $57.8 \pm 13.5$  vs.  $44 \pm 13.95$ ), more diabetics (26% vs. 21%) and a longer dialysis duration ( $58.2 \pm 46.7$  vs.  $23.96 \pm 27.53$  months) all negative predictors of HRQOL (15). These factors could to a large extent explain the lower HRQOL scores among the Taiwanese HD patients.

An MCS of <42 has been shown to detect clinical depression with a sensitivity of 74% and a specificity of 81% (18). Chronic haemodialysis patients who meet standard criteria for depression have been shown to have two fold greater chance of death and hospitalization than patients who are not clinically depressed (18). Using these cut-off values, 60% of the participants in this study, could be deemed to have clinical depression. Seica *et al* in his study of 709 Romanian chronic haemodialysis patients using this cut-off found a prevalence of 21.5% (16). De Oreo while assessing QOL in a USA population found the prevalence of depression to be 25% (18). In comparison to the two studies, the participants in this study had

a much higher risk of these poor outcomes.

The symptoms and problem subscale score was  $73.46 \pm 18.06$ . The effect of kidney disease on daily life subscale score was  $67.63 \pm 23.45$ . The burden of kidney disease subscale score was  $16.15 \pm 21.83$ . A similar trend of very low scores in the burden of kidney disease subscale and relatively good scores in the effect of kidney disease on daily life subscale and symptoms and problem subscale have been noted in other studies conducted in centres with conventional three times a week dialysis. A study done in Japan using the same questionnaire reported a symptoms and problem subscale score of  $85.2 \pm 27.3$ , effect of kidney disease on daily life subscale score of  $76.6 \pm 28.1$  and the burden of kidney disease subscale score of  $31.3 \pm 2.5$  (19).

The burden of kidney disease subscale assesses how much the kidney disease interferes with daily life, takes up time, causes frustration or makes the respondent feel like a burden. Majority of the patients reported that they were extremely bothered by the kidney disease as it grossly interfered with their lives, with most of them unable to sustain employment.

The study participants also felt that they spent so much time dealing with the disease because they had to be in the renal unit at least four days a week (two days to collect the utilities and book a session, and two days for the actual dialysis). They felt frustrated with the disease as most had no hope of a cure or even a better life despite the rigorous treatment and the heavy resources they were spending. Majority of the study participants felt they were a burden to their families. On the contrary the participants appeared to be least bothered by the symptoms of uremia such as dry skin which they considered trivial compared to the burden of the disease. It is also possible that since this is a chronic condition, the patients have devised ways of dealing with some of these problems.

The effect of kidney disease on daily life appeared to get blunted with time, with most patients adapting to the limitations imposed by kidney disease such as fluid restriction, hence the scores in this subscale were fairly good. These findings are very significant in the formulation of policies as programmes that would involve short nocturnal dialysis sessions, home based dialysis sessions and transplantation for the eligible patients would be expected to have the highest impact in the QOL of these patients compared to programmes solely directed at improved biochemical and clinical outcomes.

Contrary to this study, Sieca *et al* found that haemodialysis patients in Romania had higher scores in the burden of kidney disease subscale compared to the other two subscales (16). This is because in Romania, patients with ESRD are considered disabled hence they are eligible for government compensation (16). This results in higher living standards for a large

number of the dialysis patients hence they do not consider ESRD to be such a bother and interference to their lives (16).

In conclusion, the HRQOL of haemodialysis patients at the KNH renal unit is reduced with the physical health more affected than the mental aspect. Among the subscales, the burden of kidney disease subscale is the most affected. Studies to assess factors affecting HRQOL of patients on maintenance haemodialysis in our set-up are needed. This will inform policy on interventions that would most likely have a high impact on this important measure of outcome.

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