

ORIGINAL RESEARCH

A Hospital Based Prospective Study to Assess the Health-Related Quality of Life Among Chronic Kidney Disease Patients on Hemodialysis

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ABSTRACT

Background: Chronic Kidney Disease (CKD) is a Health-Related Quality of Life (HRQOL) deteriorating disease which is not only a public health but also a socio-economic problem of a country. The aim of this study to assess the health-related quality of life among patients with chronic kidney disease who are on maintenance dialysis.

Materials& Methods: A hospital based cross sectional study done on 100 patients with chronic kidney disease on maintenance dialysis at Holy Family Hospital, Okhla, New Delhi, India for one year period. The techniques used for data collection were interview and record analysis. Assessment of health-related quality of life was done by using the KDQOL-SF 1.3 also includes a 36- item health survey (RAND 36- items Health Survey 1.0 or SF-36). Data were analysed using descriptive and inferential statistics.

Results: Among 100 patients with chronic kidney disease 74% were above the age of 50 years. Males (63%) are more affected than female (37%). Majority of them were hailed from urban area (70%). Nearly 2/3rd of them (67%) have been undergoing dialysis for more than 3 years. Diabetes and hypertension were the leading cause of CKD. The overall HRQOL of CKD patients on maintenancedialysis is 35.65±7.19. The HRQOL related to mental health composite(26.12±6.78) is the worst affected followed by kidney disease problem composite(31.56±4.63), physical health composite(34.38±5.60), and patient satisfaction (50.54±11.78).

Conclusion: Monitoring HRQOL is an important indicator to identify impact of CKD on physical, psychological and social wellbeing. So, there is a need for the health care system to develop appropriate evidence-based practice guideline for the assessment and management of HRQOL on CKD.

Keywords: CKD, HRQOL, Hemodialysis, Domain.

INTRODUCTION

Chronic Kidney Disease (CKD) has been increasingly recognized as a global health burden. The prevalence of CKD is 10 – 15% in the general adult population in both high and low income countries.¹ CKD is a complex debilitating disease affecting approximately 7% of all people aged 30 years and older, which translates to more than 70 million people in developed countries worldwide.

CKD involves progressive, irreversible loss of kidney function. It is defined as either the presence of kidney damage or GFR < 60 ml/min for three months or longer.²

CKD is a condition which by its nature has a great impact on Health-Related Quality of Life (HRQOL). From the initial stages of the disease to its end stage, symptoms, restrictions (especially dietary) and its treatment affect the daily life of these patients.³

In 1994 the World Health Organization Quality of Life Group (WHOQOL) was created which defined quality of life as, “an individual’s perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organisation, 1994).⁴

CKD 1 -3 are not usually considered to impact on the individual’s health experience, although some disturbances may already have emerged. However, in CKD stage 4 the individual perceives an increasing amount of symptoms which may affect the HRQOL. Fatigue, muscle weakness, restless legs, cramps, itching, nausea and loss of appetite are frequently reported symptoms. Conditions like malnutrition, anemia, cognitive dysfunction, sleep disorders, depression, reduced social interaction, physical and sexual functioning, and co-morbidities like diabetes and cardiovascular disease (CVD) also impair HRQOL in CKD patients. Impaired HRQOL is well described among patients on dialysis treatment.⁵

Chronic renal failure (CRF) is now recognized as a significant and rapidly growing global health burden, which affects health related quality of life not only for the patient but the family also.^{6,7} It is now widely accepted that lower scores of QOL are associated with higher risk of death and hospitalization in those on dialysis.⁸

There are a number of tools available to measure HRQOL in chronic kidney disease patients such as Quality of Life Index-D (QLI-D), Kidney Disease Quality of Life Short Form (KDQOL-SF), Kidney Disease Questionnaire (KDQ), Renal Quality of Life Profile (RQLP), CHOICE Health Experience Questionnaire (CHEQ), Renal Dependent Individualized Quality of Life Questionnaire and many more. Kidney Disease Quality of Life Short Form – 36 (KDQOL-SF) is the most widely used tool to measure HRQOL among CKD patients.^{6,9,10}

Patient’s perception of their wellbeing and patient-reported outcomes (PROs) and the assessments of the impact of therapeutic intervention are becoming an integral part of evaluation of the human cost of chronic illnesses. Measures of HRQOL have not only become popular investigative tools but have been used in an effort to define and alter models of health care delivery.¹¹

HRQOL is used almost exclusively in clinical studies, with the nephrology community increasingly realizing the potential importance of HRQOL assessment in the clinical care of its patients. HRQOL scores provide additional information on the individual’s well being beyond the information gained from the patient’s clinical and laboratory assessments. HRQOL of CKD patients is generally poorer than the general population due to the high burden of comorbidity and complications; hence the impact of CRF on a patient’s quality of life (QOL) has become increasingly recognized as an important outcome measure^{12,13} and nurses have an important role in assessing the HRQOL among patients with chronic kidney disease on maintenance dialysis. The aim of this study to assess the health-related quality of life among patients with chronic kidney disease who are on maintenance dialysis.

MATERIALS & METHODS

A hospital based cross sectional study done on 100 patients with chronic kidney disease on maintenance dialysis at Holy Family Hospital, Okhla, New Delhi, India for one year period.

INCLUSION CRITERIA

- Patients with chronic kidney disease who were on maintenance dialysis in a selected hospital at Delhi.
- Patients who were more than 18 years of age.

EXCLUSION CRITERIA

- Patients not willing to participate.
- Patients who were critically ill.
- Patients who were unconscious.

METHODS

- 1. Demographical Variable:** This consists of demographic characteristics of patients with chronic kidney disease which includes age, gender, marital status, income level, educational status of patients, and occupation.
- 2. Clinical Profile:** This consists of duration of illness, type of dialysis, duration of treatment, history of comorbid conditions, previous hospitalization, cause of kidney disease, number of hospitalization for treatment of chronic kidney disease, number of medications taken currently.
- 3. Biochemical Profile:** This consists of haemoglobin level, blood urea nitrogen and creatinine of patient with chronic kidney disease who are on maintenance dialysis.

HEALTH RELATED TOOLS¹⁴

KDQOL-SF 1.3

The KDQOL-SF 1.3 disease- targeted items focus on particular health- related concerns of individuals with kidney disease and on dialysis. It includes Symptoms/problems (12 items), Effect of kidney disease on daily life (8 items), Burden of kidney disease (4 items), work status (2 items), Cognitive function (3 items), Quality of social interaction (3 items), Sexual function (2 items), and Sleep (4 items). Also included are three additional quality of life scales: Social support (2 items), Dialysis staff encouragement (2 items) and Patient satisfaction (1 item).

The KDQOL-SF 1.3 also include a 36- item health survey (RAND 36- items Health Survey 1.0 or SF-36) as the generic core¹⁴ consisting of eight multi- item measures of physical and mental health status: Physical Functioning (10 items), Role limitation caused by physical health problems (4 items), Role limitation caused by emotional health problems (3 items), Social functioning (2 items), Emotional well being (5 items), Pain (2 items), Energy/fatigue (4 items), and General health perceptions (5 items). The final item, the overall health rating item, asks respondents to rate their health on a 0- 100 response scale ranging from “worst possible (as bad or worse than being dead)” to “best possible health”. The 80 KDQOL-SF 1.3 items take about 16 minutes to complete.

ESRD targeted domains are divided into 4 and each domain is further subdivided as follows:

- 1. Physical Health Composite (PHC):** (a) Physical functioning, (b) work status, (c) role limitation due to physical function, (d) general health, (e) pain, (f) energy/fatigue and (g) social function
- 2. Mental Health Composite (MHC):** (a) Emotional well-being, (b) quality of social interaction, (c) burden of kidney disease, (d) social support and (e) role limitation due to emotional function
- 3. Kidney Disease Problems Composite (KDPC):** (a) Cognitive function, (b) symptoms/problems, (c) effects of kidney disease, (d) sexual function and (e) sleep
- 4. Patient Satisfaction Composite (PSC):** (a) Patient Satisfaction and (b) staff encouragement.

The 80 KDQOL-SF 1.3 items take about 60 minutes to complete.

SCORING AND INTERPRETATION

The scoring procedure for the Kidney Disease Quality Of Life Short Form (KDQOL-SF) first transforms the raw precoded numeric values of items to a 0- 100 possible range, with higher

transformed scores always reflecting better quality of life. Each item is put on a 0 to 100 range so that the lowest and highest possible scores are set at 0 to 100, respectively. Scores represent the percentage of total possible score achieved.

DATA ANALYSIS

After the data collection, data was organized, tabulated, summarized & analyzed using descriptive statistics and inferential statistics according to the objectives of the study. Descriptive statistics like frequency, percentage, mean, standard deviation were calculated to describe the data. Inferential statistics like Independent t-test, ANOVA and correlation were calculated to infer the data.

RESULTS

Our study showed that majority (74%) were more than 50 years of age. A little less than 2/3rd (63%) were males. Approx 95% of them were literates and only 5% patients were illiterates. An overwhelming majority (70%) were unemployed. A little over half of them (54%) had a monthly income of Rs 5000 – 10,000. Majority of the samples were married (77%) and 3/4th of them were hailing from an urban area (70%) (table 1).

Table 1: Distribution of samples according to Demographic Characteristics

| Demographic Variable | No. of patients | Percentage |
|-----------------------------------|-----------------|------------|
| Age | | |
| a) < 50 years | 26 | 26% |
| b) > 50 years | 74 | 74% |
| Gender | | |
| a) Male | 63 | 63% |
| b) Female | 37 | 37% |
| Education | | |
| a) Literate | 95 | 95% |
| b) Illiterate | 5 | 5% |
| Occupation | | |
| a) Employed | 30 | 30% |
| b) Unemployed | 70 | 70% |
| Income | | |
| a) < Rs 5000 | 33 | 33% |
| b) Rs 5000 – Rs 10,000 | 54 | 54% |
| c) > Rs 10,000 | 13 | 13% |
| Marital Status | | |
| a) Single | 12 | 12% |
| b) Married | 77 | 77% |
| c) Divorced / Widowed / Separated | 11 | 11% |
| Place of Residence | | |
| a) Rural | 30 | 30% |
| b) Urban | 70 | 70% |

Table - 2 depicts that one half of them (50%) took less than five medications and the other half (50%) took more than 5 medications. Majority (52%) of them reported that they received care in a hospital without overnight stay for less than 4 times in the past 6 months. 38% of patients had received less than 5 days of treatment by staying in a hospital in the past six months. Majority (38%) had been suffering from for more than 5 years with CKD. Nearly

2/3rd of them (67%) have been undergoing dialysis for more than 3 years. Diabetes (38 out of 100) was the leading cause of CKD followed by hypertension (35 out of 100).

Table2: Distribution of samples according to their Clinical Characteristics

| Clinical Variable | No. of patients | Percentage |
|--|-----------------|------------|
| No of medications | | |
| a) < 5 medications | 50 | 50% |
| b) >5 medications | 50 | 50% |
| Received care at a hospital, but came home the same day | | |
| a) < 4 times | 52 | 52% |
| b) > 4 times | 48 | 48% |
| Stay in any hospital overnight or longer (days) | | |
| a) < 5 days | 38 | 38% |
| b) >5 days | 62 | 62% |
| Duration of illness | | |
| a) < 6 months | 4 | 4% |
| b) 6 months – 1 year | 13 | 13% |
| c) 1 years – 3 years | 17 | 17% |
| d) 3 years – 5 years | 28 | 28% |
| e) > 5 years | 38 | 38% |
| Years of illness on Dialysis | | |
| a) < 3 Years | 33 | 33% |
| b) > 3 years | 67 | 67% |
| Cause of CKD (N= 100 for each component) | | |
| a)Don't Know | 6 | 6% |
| b) Hypertension | 35 | 35% |
| c) Diabetes Mellitus | 38 | 38% |
| d) Polycystic kidney disease | 4 | 4% |
| e) Chronic Glomerulonephritis | 4 | 4% |
| f) Chronic Pyelonephritis | 4 | 4% |
| g) other causes | 9 | 9% |
| Comorbid Conditions for each component | | |
| a) Hypertension | 30 | 30% |
| b) Diabetes Mellitus | 27 | 27% |
| c) Respiratory Disease | 14 | 14% |
| d) Rheumatologic Disease | 11 | 11% |
| e) Peptic Ulcer | 15 | 15% |
| f) other causes | 3 | 3% |

Our study shows that nearly 1/3rd of the samples (25%) had a haemoglobin level of less than 8 g/dl; 60% had more than 100 mg/dl of blood urea and about 40% of cases had more than 8mg/dl of serum Creatinine (table 3).

Table 3: Distribution of samples according to their Biochemical Characteristics

| Biochemical Variable | No. of patients | Percentage |
|---------------------------|-----------------|------------|
| Hemoglobin (g/dl) | | |
| < 8 | 25 | 25% |
| > 8 | 75 | 75% |
| Blood Urea (mg/dl) | | |
| < 100 | 40 | 40% |
| > 100 | 60 | 60% |

| Serum Creatinine (mg/dl) | | |
|--------------------------|----|-----|
| < 8 | 60 | 60% |
| > 8 | 40 | 40% |

The overall HRQOL of CKD patients on maintenance dialysis is 35.65 ± 7.19 . The HRQOL related to mental health composite (26.12 ± 6.78) is the worst affected followed by kidney disease problem composite (31.56 ± 4.63), physical health composite (34.38 ± 5.60), and patient satisfaction (50.54 ± 11.78) (table 4).

Table 4: Mean and Standard Deviation of Different Domains and Overall HRQOL of Patients with Chronic Kidney Disease on Maintenance Dialysis

| Components of HRQOL | No of questions | Mean | Standard Deviation |
|----------------------------------|-----------------|-------|--------------------|
| Physical Health Composite | 29 | 34.38 | 5.60 |
| Mental Health composite | 17 | 26.12 | 6.78 |
| Kidney Disease Problem Composite | 29 | 31.56 | 4.63 |
| Patient Satisfaction Composite | 3 | 50.54 | 11.78 |
| Overall HRQOL | 78 | 35.65 | 7.19 |

Table 5 depicts Statistically significant positive relationship were found between mental health composite and kidney disease problem composite ($r=0.26, p=0.01$), overall health related quality of life and mental health composite ($r=0.45, p=0.00$), overall health related quality of life and kidney disease problem composite ($r = 0.28, p = 0.01$), overall health related quality of life and patient satisfaction ($r=0.65, p=0.00$).

Table 5: Relationship between overall HRQOL and its subcomponents

| | | PHC | MHC | KDPC | PSC | Overall HRQOL |
|---|----------|-------|--------|-------|--------|---------------|
| Physical Health Composite (PHC) | r' Value | 1.0 | 0.12 | -0.07 | -0.05 | 0.15 |
| | p' Value | | 0.354 | 0.48 | 0.75 | 0.14 |
| Mental Health Composite (MHC) | r' Value | 0.12 | 1 | 0.27* | 0.05 | 0.47** |
| | p' Value | 0.35 | | 0.03 | 0.66 | 0.00 |
| Kidney Disease Problem Composite (KDPC) | r' Value | -0.08 | 0.27* | 1 | -0.01 | 0.26* |
| | p' Value | 0.47 | 0.02 | | 0.87 | 0.01 |
| Patient Satisfaction Composite (PSC) | r' Value | -0.04 | 0.05 | -0.01 | 1 | 0.64** |
| | p' Value | 0.73 | 0.65 | 0.85 | | 0.00 |
| Overall Health Related Quality Of Life | r' Value | 0.15 | 0.45** | 0.26* | 0.65** | 1 |
| | p' Value | 0.14 | 0.00 | 0.01 | 0.00 | |

DISCUSSION

The incidence and prevalence of patients with Chronic Kidney Disease (CKD) is increasing worldwide and in India. CKD is now recognized as a significant and rapidly growing global health burden, which affects HRQOL not only for patient but the family also. The complications of CKD, its treatment and co existing disease have been found to have a significant impact on the physical health of patients. It is well documented that the health status of the renal patient's population is worse than that of the general healthy population, for this reason, the assessment of HRQOL of CKD patient's have received considerable attention.

The present study assessed all the four domains of HRQOL. The overall HRQOL was found to be impaired significantly in the current study (35.65 ± 7.19). The mental health was

significantly affected domain among all the 4 domains of HRQOL and average score was found to be 26.12 ± 6.78 which is the lowest score recorded. The score for mental health was lower than the score for kidney disease problem and physical health. This reflects the excessive burden on mental health compared to other symptoms experienced by patients treated with hemodialysis. The physical health composite score reported in a study by Murali et al (2014)¹⁵ was 24.45 ± 11.85 which is lower than current study findings (34.38 ± 5.6). In another study by Cruz et al., (2011)¹⁶ reported physical health composite score to be 42.2 ± 9.9 , which is higher than the current study finding.

The mental health composite score reported in a study by Abdelghany (2016)¹⁷ was 36.76 ± 10.22 which is higher than the current study finding (26.12 ± 6.78). Various other studies also show higher results than current study [Rahimi (2016)⁹, Cruz et al., (2011)¹⁶]. The subcomponents of mental health composite that contributed significantly to the low mental health composite scores are burden of kidney disease (11.84 ± 9.82), role limitations caused by emotional health problem (17.33 ± 16.76) and emotional wellbeing (27.9 ± 6.15).

The overall kidney disease problem composite score reported in a study by Rahimi et al. (2016)⁹ was 54.00 ± 13.33 which is higher than the current study finding. In a study by Murali et al. (2014)¹⁵ the kidney disease problem composite score was higher 40.75 ± 17.65 than the current study finding (31.56 ± 4.63).

Among all four domains, high scores were recorded for patient satisfaction composite (50.54 ± 11.78) which most likely reflects the efforts of clinical staff as well as family and community members in supporting patients treated with hemodialysis for CKD. In study reported by Murali et al. (2014)¹⁵ the physical composite score was higher than the current study score of (71.93 ± 12.35).

Hemodialysis which is one of the end-stage renal failure treatments is a lifesaving treatment for the patients. Patients encounter many physical, spiritual and social problems. Symptoms such as fatigue, cramp, pain, sleep disorder, dyspnea, pruritis, depression, nausea, vomiting and constipation negatively influence all the areas of daily living and quality of life of individuals. Restriction in social life and physical activity difficulties occur together with these symptoms that are frequently experienced by the hemodialysis patients. It was found that especially fatigue, influenced working, spending free time, nutritional habits, sexual activities, enjoying life, family relations and friendships negatively. Some psychosocial difficulties like the deterioration of the working capacity, decrease in the physical activities, problems inside the family and sexual problem in dialysis patients complicate the maintenance of the treatment and influence the disease process and treatment negatively.¹⁸

Prior researches conducted by Mollaoglu and Deveci (2017)¹⁸, Cruz et al. (2011)¹⁶ and Kuriokose et al. (2012)¹⁰, support the current study findings that HRQOL is affected in CKD patients undergoing dialysis.

Health Related Quality of Life is a critically important clinical outcome for hemodialysis patients. HRQOL measures provide information about the impact of the treatment on perceived well being. A prior study by Mapes et al., (2003)⁸ concluded that lower scores for the 3 major components of HRQOL were strongly associated with higher risk of death and hospitalization in hemodialysis patients, independent series of demographic and co-morbid factors. Poor HRQOL in these patients is a significant predictor of mortality and hospitalization. Hence the practicing nurses in dialysis centers and kidney care centers need to be trained to assess HRQOL in CKD patients using validated instruments.

The current study findings is in the line with the study findings of Masina et al. (2016)¹⁹ who reported that the kidney disease composite score correlated strongly and positively with both mental health composite scores ($p = 0.001$) and physical health composite scores ($p < 0.0001$). The current study findings suggest that addressing kidney specific components of health related quality of life has a potential to improve mental health composite and overall

HRQOL. Patient satisfaction towards treatment in terms of staff support and family support has a bearing on overall HRQOL and this support enables the patient to continue the lifelong treatment.

CONCLUSION

Monitoring HRQOL is an important indicator to identify impact of CKD on physical, psychological and social wellbeing. So, there is a need for the health care system to develop appropriate evidence-based practice guideline for the assessment and management of HRQOL on CKD.

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