International Journal of Research in Medical Sciences
Goyal A et al. Int J Res Med Sci. 2025 Nov;13(11):4634-4640
www.msjonline.org
pISSN 2320-6071 | eISSN 2320-6012

DOI: https://dx.doi.org/10.18203/2320-6012.ijrms20253312

Original Research Article

Assessment of quality of life in patients undergoing maintenance hemodialysis in a tertiary care hospital

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Received: 19 September 2025
Revised: 03 October 2025
Accepted: 04 October 2025

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ABSTRACT

Background: The increasing prevalence of end-stage renal disease (ESRD) in India necessitates a deeper understanding of its impact on patient well-being. This study aimed to assess the quality of life (QOL) among hemodialysis (HD) patients in a North Indian setting using the kidney disease QOL-36 (KDQOL-36) instrument and to explore the associated demographic and clinical factors influencing their QOL.
Methods: We conducted an observational, cross-sectional study over two months (May-June 2024) at a tertiary care hospital in Jammu, India. A total of 100 patients aged 18-75 years, diagnosed with ESRD and undergoing maintenance HD for at least three months, were included after providing informed consent. Data was collected using a demographic questionnaire and the validated KDQOL-36 instrument. Statistical analysis was performed using SPSS ver 25.0.
Results: The study cohort comprised 100 patients (66% male) with a mean age of 58.08±12.3 years. The mean QOL scores indicated significant impairment across multiple domains: Physical component summary (PCS) was 41.19±8.24, mental component summary (MCS) was 42.52±7.84, symptom/problem list was 77.75±14.57, and effects of kidney disease was 56.56±16.48. The most profoundly affected domain was the burden of kidney disease, with an exceptionally low mean score of 24.00±15.24. A majority of patients reported that the disease interfered with their life (88%), felt like a burden to their family (74%), and were bothered by fluid (94%) and dietary (88%) restrictions.
Conclusions: This study highlights a profound impairment in the QOL among HD patients in North India, particularly concerning the overwhelming burden of the disease. The findings underscore the urgent need for renal healthcare systems in India to integrate routine QOL assessments into standard practice. Shifting towards a more holistic, patient-centered approach that includes targeted psychosocial support is crucial to alleviate the immense disease burden and improve overall well-being in this vulnerable population.

Keywords: Renal dialysis, Quality of life, Kidney failure, Cross-sectional studies, Hemodialysis

INTRODUCTION

The increasing global burden of chronic kidney disease (CKD) poses a significant public health challenge, with the noticeable rise in cases attributed to the growing prevalence of “civilized diseases" such as hypertension, diabetes, and obesity.[1] End-stage renal disease (ESRD), the most advanced stage of CKD, necessitates renal replacement therapy (RRT) for survival, with hemodialysis (HD) being a widely adopted modality worldwide.[2] While HD offers a life-sustaining treatment, its inherent demands including time-intensive sessions, stringent dietary and fluid restrictions, and potential complications can profoundly impact patients' daily lives and overall well-being.[3]

Quality of life (QOL) has emerged as a crucial point in assessing the efficacy of interventions for chronic conditions like ESRD.[4] The World Health Organization (WHO) defines QOL as an individual's perception of their position in life within their cultural context, influenced by their physical and psychological health.[5] Patients undergoing HD frequently report symptoms such as fatigue, sleep disturbances, and depression, alongside limitations in physical activities, work and hobbies.[6] Consequently, QOL assessment tools have been developed to evaluate patient status beyond traditional morbidity and mortality indicators, with higher scores generally correlating with improved QOL and reduced adverse outcomes.[7]

In India, the concepts of QOL and quality adjusted life years in chronic diseases are still evolving. Factors such as cost constraints often lead to reduced frequency of dialysis sessions, the use of less expensive dialyzers and dialyzer reuse, with erythropoietin therapy not being universally received.[8] These challenges underscore the potential for a compromised QOL among Indian HD patients, making its augmentation a key area of interest for renal healthcare teams. While numerous studies have explored QOL in dialysis patients globally, particularly in developed countries, there remains a paucity of published research on this topic specifically in the Indian context.[1]

The KDQOL-36, a widely recognized and validated self-reported questionnaire, has been extensively used to assess QOL in patients with kidney disease on dialysis. Derived from the original KDQOL™, the KDQOL-36 incorporates the generic SF-12 Health Survey along with 24 kidney specific items, making it a comprehensive tool for evaluating health related QOL in this population. Given the increasing preference of CKD in India and the significant impact of HD on patients' lives, this study aims to assess the quality of life among HD patients in India using the KDQOL-36, and to explore the associated demographic, clinical and social factors influencing their QOL. By employing the KDQOL™-36 instrument, we aim to delve into various facets of health-related quality of life (HRQOL) and determine the sociodemographic and clinical factors influencing it.

METHODS

Study design and setting

We conducted this observational cross-sectional study over a period of two months from May to June 2024, at our institution, Acharya Shri Chander College of Medical Sciences and Hospital, Sidhra, Jammu. All participants were recruited from the institution's dialysis unit, which serves both outpatient (OPD) and inpatient (IPD) populations.

Inclusion and exclusion criteria

Inclusion criteria were defined as patients diagnosed with stage 5 CKD aged between 18 and 75 years, receiving maintenance HD for a minimum of three months, and who provided willing consent to participate.

Exclusion criteria included patients with acute kidney injury (AKI), those on HD for less than three months, and individuals with neurological disabilities that would prevent them from responding to the questionnaire. Patients who refused to provide consent were not included in the study.

Material/ instrument

Two questionnaires were used in the study, the first collected basic demographic data, including age and gender.

The second and primary questionnaire was the KDQOL-36 instrument, which was developed by RAND and the University of Arizona, is validated to measure the quality of life of patients with kidney disease. This questionnaire consists of 36 items divided into two main categories, the 12 items short form (SF-12) and 24 kidney disease specific items. The physical component summary (PCS) and mental component summary (MCS) were assessed using the SF-12 items. The burden of kidney disease, symptoms and problems of kidney disease, and the effect of kidney disease on daily life were assessed by the 24 kidney-related items. The responses were scored from 0 to 100, where higher scores reflect a better quality of life.

Sampling technique

All patients undergoing HD at our institution were evaluated for eligibility. After this initial screening, 104 patients met the inclusion criteria. Investigators briefed these potential participants on the study's goals and procedures, emphasizing that participation was entirely voluntary. After obtaining informed consent, the questionnaires were administered. Each participant was allowed a single submission. From the 104 consenting participants, 4 were subsequently excluded from the final analysis due to incomplete responses, resulting in a final sample size of 100 patients.

Ethical approval

The necessary ethical approval was acquired from the institutional ethical committee of Acharya Shri Chander College of Medical Sciences and Hospital prior to the commencement of the study. A pilot study was first conducted with 10 patients to ensure the clarity and feasibility of the protocol and these patients were not included in the main study analysis. Written informed consent was obtained from all participants included in the final study. All patients were assured that their data would be kept confidential and that their participation was voluntary.

Statistical analysis

The data entry was done in the Microsoft excel spreadsheet and the final analysis was performed with the use of statistical package for social sciences (SPSS) software, IBM manufacturer, Chicago, USA, ver 25.0.

RESULTS

The study comprised 100 patients with ESRD, with a demographic profile showing a male predominance (66%) and mean age of 58.08±12.3 years. The age distribution was concentrated among older adults, with 30% of participants in the 51-60 years age bracket, 30% in the 61-to-70-year bracket and 18% aged over 70 years (Table 1). Initial analysis of KDQOL^{TM}-36 instrument revealed a significant impact on patients' wellbeing. The mean scores for the primary domains were 77.75±14.57 for symptom/problem list, 56.56±16.48 for the effects of kidney disease, 42.52±7.84 for the SF-12 MCS, and 41.19±8.24 for the SF-12 PCS. The most profoundly affected domain was the burden of disease, which yielded a markedly low mean score of 24.00, indicating this to be the most significant area of concern for this patient population.

The low SF-12 PCS score was substantiated by detailed patient-reported outcomes. While a considerable portion of patients rated their general health as "good" (48%) or "fair" (32%), as seen in Table 2**,** their functional capacity was significantly impaired. A combined 78% of individuals reported that moderate physical activities were "limited a little" or "limited a lot", and this limitation was more pronounced in more demanding tasks, with 46% stating their ability to climb several flights of stairs was "limited a lot". Consequently, a vast majority (74%) acknowledged accomplishing less than they desired due to their physical health. In contrast to these functional limitations, bodily pain was a less pervasive issue, as 50% of the cohort reported that pain did not interfere with their normal work "at all".

In addition to the extensive physical limitations reported, the mental and emotional domains were found to be substantially impacted, consistent with the SF-12 MCS score. Two-thirds of the patients (66%) reported that emotional problems, such as feeling depressed or anxious, led them to accomplish less with their work or other regular activities. Analysis of emotional well-being revealed a significant negative balance; for instance, 34% felt "downhearted and blue" some of the time and 22% felt this way most of the time. This emotional distress was coupled with diminished energy levels, with only 10% reporting they had energy "all the time". Social functioning was also broadly affected, with patient responses distributed across the spectrum from being impacted "none of the time" to "all the time" (Table 3).

The most striking findings emerged from the disease-specific domains of the KDQOL. The extremely low mean score for the "burden of kidney disease" was elucidated by specific responses where patients overwhelmingly felt the disease dominated their lives. A combined 88% reported it was "definitely true" or "mostly true" that their kidney disease interfered with their life. Similarly, 86% felt that too much of their time was spent dealing with their condition, and 86% expressed frustration in coping with it. This sentiment extended to their social context, with 74% feeling like a significant burden on their family (Table 4). Regarding the "symptom/ problem list", dermatological issues were highly prevalent, with a majority reporting being at least "somewhat bothered" by itchy skin (76%) and dry skin (74%). Other common complaints included feeling washed out or drained (70%) and cramps (66%). In contrast, severe somatic symptoms were less frequent, as 78% were "not at all bothered" by chest pain and 70% were not bothered by faintness or dizziness (Table 5).

Finally, the effects of the disease and its treatment permeated nearly every aspect of daily functioning and lifestyle. Treatment mandated restrictions were a major source of distress; 94% of patients were bothered by fluid restrictions and 88% by dietary restrictions, with a majority in both groups finding them moderately to extremely bothersome. This directly impacted lifestyle activities, with 82% reporting their ability to work around the house was compromised and 90% reporting their ability to travel was limited. A profound sense of dependence was evident, as 98% of participants felt bothered by their reliance on doctors and medical staff, which culminated in significant psychological stress. The impact extended to personal life, with 62% of participants expressing some level of dissatisfaction with their sex life (especially in patients younger than 60 years), and 64% were dissatisfied with their personal appearance, an issue more prevalent among females.

Table 1: Demographic characteristics distribution.

Variables	N (%)	Mean±SD	Median (25th-75th percentile)	Range
Age (in years)				
21 to 30	4 (4.00)	58.08±12.3	59.5 (52-68)	21-74
31 to 40	4 (4.00)			
41 to 50	14 (14.00)			
51 to 60	30 (30.00)			
61 to 70	30 (30.00)			
>70	18 (18.00)			

Continued.

Variables	N (%)	Mean±SD	Median (25th-75th percentile)	Range
Gender				
Female	34 (34.00)	-	-	-
Male	66 (66.00)			

Table 2: Status of health distribution.

Status of health	N	Percentage (%)
Very good	14	14.00
Good	48	48.00
Fair	32	32.00
Poor	6	6.00

Table 3: Social functioning distribution.

Social functioning	N	Percentage (%)
All of the time	24	24.00
Most of the time	20	20.00
Some of the time	22	22.00
A little of the time	22	22.00
None of the time	12	12.00

Table 4: Burden of kidney disease distribution.

Burden of kidney disease	Definitely true (%)	Mostly true (%)	Don't know (%)	Mostly false (%)	Definitely false (%)
Kidney disease interference with life	44 (44.00)	44 (44.00)	2 (2.00)	8 (8.00)	2 (2.00)
Time spent managing kidney disease	32 (32.00)	54 (54.00)	2 (2.00)	8 (8.00)	4 (4.00)
Frustration with dealing with kidney disease	46 (46.00)	40 (40.00)	4 (4.00)	8 (8.00)	2 (2.00)
Feeling like burden on family	42 (42.00)	32 (32.00)	2 (2.00)	6 (6.00)	18 (18.00)

Table 5: Symptoms/problems distribution.

Symptoms/problems	Not at all bothered (%)	Somewhat bothered (%)	Moderately bothered (%)	Very much bothered (%)	Extremely bothered (%)
Extent of soreness in muscles	54 (54.00)	32 (32.00)	10 (10.00)	2 (2.00)	2 (2.00)
Extent of chest pain	78 (78.00)	14 (14.00)	4 (4.00)	4 (4.00)	0 (0.00)
Extent of cramps	34 (34.00)	38 (38.00)	12 (12.00)	6 (6.00)	10 (10.00)
Extent of itchy skin	24 (24.00)	52 (52.00)	14 (14.00)	4 (4.00)	6 (6.00)
Extent of dry skin	26 (26.00)	40 (40.00)	16 (16.00)	10 (10.00)	8 (8.00)
Extent of shortness of breath	44 (44.00)	24 (24.00)	22 (22.00)	10 (10.00)	0 (0.00)
Extent of faintness or dizziness	70 (70.00)	22 (22.00)	6 (6.00)	0 (0.00)	2 (2.00)
Extent of lack of appetite	32 (32.00)	28 (28.00)	24 (24.00)	10 (10.00)	6 (6.00)
Extent of feeling washed out/drained	30 (30.00)	38 (38.00)	18 (18.00)	14 (14.00)	0 (0.00)
Extent of numbness in hands or feet	70 (70.00)	22 (22.00)	4 (4.00)	4 (4.00)	0 (0.00)
Extent of nausea or upset stomach	46 (46.00)	32 (32.00)	14 (14.00)	6 (6.00)	2 (2.00)
Problems with access/catheter site	60 (60.00)	16 (16.00)	8 (8.00)	12 (12.00)	4 (4.00)
Fluid restriction	6 (6.00)	30 (30.00)	28 (28.00)	24 (24.00)	12 (12.00)
Dietary restriction	12 (12.00)	36 (36.00)	32 (32.00)	10 (10.00)	10 (10.00)
Ability to work around the house	18 (18.00)	36 (36.00)	20 (20.00)	12 (12.00)	14 (14.00)
Ability to travel	10 (10.00)	34 (34.00)	38 (38.00)	12 (12.00)	6 (6.00)
Dependency on doctors and medical staff	2 (2.00)	30 (30.00)	44 (44.00)	10 (10.00)	14 (14.00)
Stress or worries caused by kidney disease	6 (6.00)	8 (8.00)	32 (32.00)	38 (38.00)	16 (16.00)
Satisfaction with sex life	38 (38.00)	22 (22.00)	28 (28.00)	10 (10.00)	2 (2.00)
Satisfaction with personal appearance	36 (36.00)	34 (34.00)	20 (20.00)	8 (8.00)	2 (2.00)

DISCUSSION

The imperative to evaluate QOL in patients with ESRD is gaining recognition, as QOL scores are not only a measure of patient well-being but are also associated with clinical outcomes such as mortality.[7] Our study, conducted in a North Indian setting, aims to assess the QOL of HD patients using the KDQOL-36 instrument and explore the factors influencing it. The findings reveal significant impairment across multiple domains underscoring the profound challenges faced by this patient population in a developing country context.

The mean scores for the PCS and MCS in our study were 41.19 and 42.52, respectively. These scores indicate a considerable impact on both physical and mental health. Our results for the PCS are lower than those reported in a study in Saudi Arabia by Ajeebi et al (49.4) but higher than those in a large study in the USA by Cohen et al (36.6).[7,9] Conversely, our MCS score is slightly higher than that of the study by Ajeebi et al (38.8) but lower than that of the study of Cohen et al (49.0).[9]

In our cohort, the mental component score was slightly higher than the physical component score. This finding aligns with the study by Tasnim et al and several other studies, which suggest that while patients with chronic diseases experience significant physical limitations, they may develop psychological adaptation over time, resulting in a relatively more stable mental status, even as their physical health deteriorates.[10-14]

The low PCS score is substantiated by the fact that 78% of our patients reported limitations in moderate physical activities and 74% accomplished less than they desired due to their physical health. As other studies have noted, such low physical health score clearly demonstrate that the daily lives of ESRD patients are disturbed due to their dependence on RRT for survival.[2] Interestingly, while a large portion of our patients rated their health as “good”, their functional capacity was markedly impaired. This contrasts with the findings of Cohen et al where patient perception of general health was not correlated with the PCS, suggesting that cultural or individual expectations may influence self-rated health, which may not always align with objective functional status.[9]

However, the psychological adaptation in our cohort appears incomplete. The mental and emotional well-being of our patients was also significantly compromised, with two-thirds (66%) reporting that emotional problems interfered with their work and daily activities, leading them to accomplish less. Feelings of being “downhearted and blue” were common, and social functioning was broadly affected. This psychological distress is a well-documented consequence of living with a chronic, life-altering illness, where constant stress, anxiety about the future and feelings of being a burden contribute to lower scores in the psychological domain.[15] This suggests that despite some adaptation, the mental role remains a significant challenge.

A key finding of our study was in the burden of kidney disease domain, which had a mean score of 24.00, indicating that the perceived impact of the illness is a primary concern for our patients. This score is drastically lower than that of 52.6 and 51.3 reported in Saudi and US populations, respectively, highlighting the overwhelming extent to which the disease dominates the life of our patients in the Indian context.[7,9] This finding is consistent with research by Tasnim et al which also identified the burden of kidney disease as having the lowest mean score, reflecting the immense pressure the disease places on patients’ lives.[10] This finding is underscored by specific patient-reported outcomes, as a staggering 88% felt that the disease interfered with their life, 86% were consumed by the time spent dealing with their condition, and 74% perceived themselves to be a burden on their families. Time-intensive nature of dialysis, coupled with the constant need to manage their condition, contributes heavily to this sentiment.[2,15]

In symptom/problem list domain, our findings are similar to those in other studies. Dermatological issues like itchy and dry skin, along with feeling washed out or drained were highly prevalent in our patient population. The study by Cohen et al noted that while some symptoms have become less bothersome overtime due to advancements in care, these symptoms persist as common complaints.[9] The high prevalence of these symptoms underscores the need for better symptomatic management in dialysis population.

The effects of kidney disease domain highlighted the pervasive impact of treatment on daily life. Fluid and dietary restrictions were a major source of distress for 90% of our patients. Furthermore, the ability to travel and work around the house was severely limited, and an overwhelming 98% felt bothered by their dependence on doctors and medical staff. These findings echo the challenges reported by Sathvik et al where patients’ lives are heavily structured around their treatment, leading to a loss of personal freedom and autonomy.[2]

It is crucial to consider these findings within the Indian context. The immense burden is likely amplified by specific socioeconomic challenges, such as economic constraints that often lead to reduced dialysis frequency, and limited access to supportive therapies like erythropoietin, which can directly impact QOL. While our study did not deeply analyze socioeconomic predictors, the literature consistently shows factors like employment and income to be strong predictors of QOL.[10,16] The high percentage of patients feeling like a family burden point towards the financial and emotional dependency, which is known to deteriorate QOL.[17,18]

These findings have significant implications, underscoring the necessity for renal healthcare teams in India to move beyond traditional morbidity and mortality indicators and integrate routine QOL assessments into patient care. The extremely low burden of kidney disease score signals an urgent need for targeted psychosocial interventions, including counselling and family support systems, to help patients and their families cope with the immense strain of the disease. Furthermore, addressing the socioeconomic barriers that prevent optimal care is critical to alleviating the financial burden of ESRD treatment in India.

This study has several limitations. As a single center, cross-sectional study with the sample size of 100, the findings may not be generalizable to the entire Indian HD population. The self-reported nature of the questionnaire is also subject to potential response bias; specifically, conducting the study at our own institution could have introduced a social desirability bias, where patients might provide more positive answers. Furthermore, we did not collect data on key biochemical parameters, such as hemoglobin and albumin levels, nor on comorbidities or economic status, all of which are known to be important predictors of QOL.

Despite these limitations, the study provides crucial, context-specific data on a significantly under-researched population. It highlights that while the symptomatology of ESRD may be universal, its burden and effect on life are intensely modulated by local socioeconomic and healthcare system realities.

CONCLUSION

The study highlights the profound and multifaceted impairment of QOL across physical, mental, and disease-specific domains among HD patients in a North Indian setting. The most critical finding is the exceptionally low score in the ‘burden of kidney disease’ domain, suggesting the perceived weight of the illness is a more significant challenge in our cohort compared to reports from other regions. These results underscore the urgent need for Indian renal healthcare systems to integrate routine QOL assessments into standard patient care. This would enable a shift beyond mere survival-based metrics to a more holistic approach, facilitating targeted psychosocial interventions aimed at alleviating the immense disease burden and improving overall patient well-being. While larger, multicentre studies are warranted, our research provides crucial evidence for prioritizing patient-reported outcomes in the management of ESRD in India.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

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Cite this article as: Goyal A, Sharma A, Sharma P, Bagal T. Assessment of quality of life in patients undergoing maintenance hemodialysis in a tertiary care hospital. Int J Res Med Sci 2025;13:4634-40.