

Review Article

Redefining quality of life in renal replacement therapy: a patient-centered perspective

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Received: 21 August 2025

Accepted: 06 October 2025

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ABSTRACT

Renal replacement therapy (RRT), encompassing hemodialysis (HD), peritoneal dialysis (PD) and kidney transplantation is essential for managing end stage renal disease (ESRD). As survival outcomes have improved, there is increasing recognition of the need to enhance quality of life (QoL) among patients undergoing RRT. However, widely used QoL assessment tools like ED-5D, SF-36 and KDQOL-SF often fail to capture the multifaceted psychosocial, emotional and existential dimensions of patients lived experiences. To better understand these limitations, we conducted a comprehensive review of PubMed indexed articles addressing QoL in RRT patients across different modalities. Our findings reveal that current tools inadequately reflect psychological distress, social role distribution and loss of autonomy and are inconsistently responsive across patient populations. Challenges such as fatigue, depression, physical decline and economic burden vary significantly and are often overlooked in standard metric. We propose a patient centered reframing of QoL assessment that includes domains such as purpose and identity, emotional and spiritual resilience, social integration, economic participation and digital empowerment. Incorporating these domains into clinical care and research design offers a more holistic approach to RRT, improving patient satisfaction, engagement and long term outcomes. This shift towards human centered metrics is essential for advancing patient centered nephrology care.

Keywords: Renal replacement therapy, Quality of life, Patient-centered care, End stage renal disease

INTRODUCTION

Renal replacement therapy (RRT) is a life-sustaining intervention used in patients with end-stage renal disease (ESRD) or severe acute kidney injury (AKI) when kidney function is no longer sufficient to maintain metabolic and fluid balance.¹ RRT encompasses HD, PD, continuous RRT (CRRT) for critically ill patients, and kidney transplantation, each with distinct clinical implications and challenges. The choice of modality depends on a range of clinical, logistical, and patient-centered factors, including

comorbidities, vascular access, treatment tolerance, and personal preference.²

Historically, outcomes in nephrology have centered on survival rates, biochemical control, and complication prevention. While these benchmarks remain vital, an increasing number of patients now live longer with ESRD, shifting attention towards QoL as a critical endpoint. Despite advances in dialysis technologies and transplant immunosuppression, many patients continue to experience poor QoL outcomes, including physical fatigue, emotional distress, social isolation, and diminished autonomy.^{3,4}

Conventional QoL assessment tools such as the EQ-5D, SF-36, and KDQOL-SF aim to quantify health status across domains like pain, mobility, and emotional well-being. However, emerging evidence suggests that these instruments often fail to capture the lived experience of patients on RRT. They are limited in scope, neglect cultural, psychological, and existential dimensions, and frequently lack sensitivity to detect change over time or across modalities.

This disconnect between standardized measurement and patient reality poses challenges for both clinical care and research design. This review proposes a reframing of QoL in RRT through a human-centered lens, emphasizing real-world priorities defined by patients themselves. We explore not only the challenges inherent in each RRT modality, but also the limitations of existing QoL metrics, and present innovative, multidimensional approaches that can help promote holistic well-being in this population.

CHALLENGES FACED BY PATIENTS UNDERGOING RRT

Haemodialysis

HD accounts for ~69% of RRT and 89% of dialysis cases. Though advances in technology and access have improved HD, mainly in high-income countries, global disparities in availability, cost, and outcomes remain. HD is still associated with poor QoL, high morbidity, and mortality. Despite the progress, patients on HD frequently experience a high burden of symptoms and financial challenges. Cardiovascular disease affects most HD patients and causes nearly 50% of deaths.⁵ Advanced CKD often includes undiagnosed mental disorders that worsen QoL. In HD patients, depression increases morbidity, mortality, non-compliance, and poor nutrition.⁶

Pain affects over 50% of HD patients, with up to 75% receiving inadequate treatment due to underdiagnosis.⁷ HD patients also report low energy and difficulty with daily tasks. While HD scores better in physical and emotional QoL domains, it scores lower in areas like employment, staff support, and overall satisfaction, based on KDQOL-SF 1.3 and SF-36 assessments.⁸

PD

PD and HD are dialysis options for end-stage renal disease patients in whom preemptive kidney transplantation is not possible.⁹

Patients often experience declining physical function, impairing everyday tasks. Studies show significant decreases in cardiorespiratory fitness and muscle strength, directly reducing physical capacity is a key factor in QoL. Reduced cardiorespiratory function also worsens fluid overload, further harming physical capacity.¹⁰ Many people on PD report bodily pain, often abdominal, which

limits mobility, function, and QoL. Fatigue and low energy from dialysis also reduce social engagement and negatively impact overall QoL.¹¹

Disturbed sleep due to monitoring, along with appetite loss, leads to increased fatigue and nutritional issues in many patients. Gastrointestinal symptoms like dyspepsia further impair physical health and QoL, especially in obese individuals where weight issues worsen functional decline. The daily burden of PD including strict hygiene, dietary control, and time-sensitive treatment also contributes significantly to reduced physical well-being.^{12,13}

Mental and emotional well-being is a key aspect of QoL in PD patients. They often face anxiety, depression, and fear of complications, worsened by the stress of managing their condition independently at home.^{14,15} Chronic kidney conditions requiring PD significantly affect employment and increase psychological stress, with stress levels closely linked to disease burden scores.¹⁶

Kidney transplant

Kidney transplantation is a lifesaving option for ESRD patients, offering better survival and QoL than ongoing dialysis. However, it brings new physical challenges from surgery and post-operative responses that can affect long-term health and QoL. Prolonged immunosuppressive therapy further increases infection risk. Understanding these issues can aid in developing improved rehabilitation strategies. Post-transplant patients commonly experience reduced muscle strength, fatigue, and mobility issues, which significantly impact daily functioning and overall QoL. Visual and walking impairments are also reported, contributing to increased risks of mortality and graft failure.^{17,18}

Kidney transplant patients face a higher long-term risk of cardiovascular disease, with significantly reduced cardiorespiratory fitness, studies show up to 30% lower than age-matched controls impacting functional capacity.^{19,20}

Despite physical health improvements after transplantation, many living donor recipients continue to experience anxiety, depression, and transplant-related worries, which often persist beyond the immediate post-transplant period.^{21,22}

Many patients feel unprepared for the procedure and its challenges, sometimes projecting this onto healthcare staff as perceived incompetence or neglect.

This highlights the need for thorough pre-transplant education on expected clinical courses and complications.²³ Studies show how tailored exercise regimens that combine aerobic and strength training enhance performance, longevity, and QoL.^{24,25}

Table 1: QoL challenges across RRT modalities.

Modality	Physical challenges	Mental health impact	Treatment burden	Social functioning impact	Economic burden	Autonomy and flexibility
HD	60-80% report fatigue; 40-50% have cardiovascular complication	Depression prevalence: 20-30%	3 times/week center visits, 4 hrs each; strict dietary/fluid control	65% report social role disruption	High cost of transport, job loss	Low autonomy due to fixed schedules
PD	25-35% report peritonitis or discomfort	Anxiety prevalence: ~25%	Daily home exchanges; burden on patients/caregiver	Greater flexibility but 40% still report social isolation	Moderate-supply costs at home	Moderate-high autonomy
Kidney transplant	30-50% report fatigue post transplant	Depression/Anxiety in ~15-25%	Lifelong immunosuppressants; regular monitoring	Challenges with work reintegration and identity restoration	Moderate-Med/lab costs	High- most regain independence

LIMITATIONS OF THE TRADITIONAL QOL METRICS IN RRT

The assessment of QoL in patients undergoing RRT has become a central focus in nephrology, particularly as survival outcomes improve. However, the current metrics widely used in research and clinical practice, such as EQ-5D, SF-36, and KDQOL-SF, are increasingly recognized as inadequate in capturing the multifaceted and evolving experiences of patients living with ESRD. While these tools were designed to quantify broad health dimensions such as physical functioning, pain, and mental well-being, they lack the sensitivity and specificity required to reflect the nuanced psychosocial, emotional, and existential challenges patients face on dialysis or post-transplantation.

Inadequate reflection of psychological distress

Berenguer-Martínez et al demonstrated that elevated distress symptoms, including fatigue, anxiety, and psychological exhaustion, were strongly associated with decreased QoL in HD and PD. Yet, these symptoms were only partially reflected in the KDQOL-SF subscales, suggesting an underappreciation of psychological suffering in standard metrics.²⁶ Similarly, Sawada et al found that while ED-5D-5L scores correlated reasonably with physical well-being, they poorly captured mental health concerns, highlighting a significant mismatch between instrument design and patient experience.²⁷

Poor sensitivity to social role disruption

QoL metrics often emphasize functional status while overlooking the social and occupational disruptions that patients endure. The capacity to participate in daily roles, such as employment, caregiving, or maintaining intimate relationships, is central to the patient's perception of life satisfaction. In a national cross-sectional study, Alvares et al noted that although pain and discomfort were prominently captured by EQ-5D, its five-item format

explained only 43% of patient self-reported well-being, leaving substantial variance unaccounted for, likely due to unmeasured psychosocial dimensions.²⁸ Similarly, despite clinical improvement, transplant patients often report challenges in workplace re-entry and maintaining personal relationships, which are not adequately addressed in SF-36 or KDQOL metrics.²⁹

Inconsistency across modalities and patient populations

EQ-5D and KDQOL-SF have shown variable responsiveness to clinical changes, particularly in elderly patients and those with multimorbidity. Turkmen et al found that despite adequate self-reported QoL scores, over 70% of elderly HD patients had poor sleep and 25% met criteria for depression, indicating a disparity between measured and actual well-being.³⁰ In a systematic review, Budhram et al similarly reported inconsistencies in QoL outcomes across modalities, showing that results were highly dependent on the tool used.³¹

Clinician-centric design over patient-centered priorities

QoL metrics frameworks are shaped by clinician-defined constructs, often emphasizing measurable physiological parameters over patients' subjective goals and values. Hughes et al underscore this issue by identifying a lack of validated instruments that incorporate "life participation" goals, i.e., the ability of engage in meaningful daily roles, as a key failing in current nephrology QoL assessments.³²

REFRAMING QOL: DOMAINS THAT MATTER TO PATIENTS

To address these shortcomings, it is essential to redefine QoL in RRT through a patient-centered lens. This reframing highlight underrepresented domains that shape the everyday lives of patients and should reframe future QoL frameworks.

Purpose and identity

RRT often destabilizes patients' sense of self, disrupting their roles within families and communities. Patients equate health not only with symptom relief but the capacity to feel useful and purposeful.³³

Autonomy and control

RRT often imposes strict routines and a high degree of dependency, which can erode patients' sense of control over their lives. Shared decision-making and flexible modality options are critical to restoring patients' sense of agency. Tools and care models that support treatment personalization can significantly enhance psychological well-being. The CORETH project found that patients who were meaningfully involved in modality selection, particularly those choosing PD, reported significantly higher satisfaction and psychological well-being.³⁴ Moreover, shared decision-making in outpatient settings has also been linked to improved survival outcomes after dialysis initiation.³⁵

Emotional and spiritual resilience

Mindfulness, spirituality, and existential meaning-making are powerful coping mechanisms. Qualitative studies show that spiritual engagement helps patients manage uncertainty and chronic stress.³⁶ Prayer-based interventions have enhanced spiritual coping and optimism among dialysis patients.³⁷

Social integration and relationships

Dialysis schedules, fatigue, and dietary restrictions can disrupt patients' ability to maintain social connections and fulfill relational roles, often straining marriages, parenting, and friendships. Reduced social integration has been linked to diminished QoL, while supportive social environments enhance emotional resilience and perceived well-being.³⁸⁻⁴⁰

Economic participation and routine life

Financial instability and job loss are common across all RRT modalities, significantly affecting QoL. Working age patients face significant challenges in maintaining employment and education, which in turn affect emotional and social health. Promoting employment and educational engagement among RRT patients requires proactive, patient-centered interventions. Structured pre-treatment education and shared decision-making programs have been shown to enhance psychological readiness and autonomy, thereby improving patients' capacity to maintain employment or pursue studies.^{41,42}

Digital empowerment and self-monitoring

Digital health platforms, remote monitoring, and app-based engagement tools are redefining patients' autonomy

and care personalization. Mobile apps and telehealth systems help patients track symptoms, manage medications, and communicate with health worker, leading to improved adherence and fewer complications.^{43,44} Early integration of these tools has shown promise in improving treatment adherence and emotional well-being.

CONCLUSION

As RRT becomes a lifelong reality for many patients with ESRD, improving QoL must take precedence alongside clinical outcomes. This review highlights the substantial limitations of traditional QoL metrics, which often overlook the emotional, social, and existential dimensions that truly shape patient experience. Reframing QoL through a patient-centered lens-emphasizing identity, autonomy, resilience, relationships, economic function, and digital empowerment-offers a more holistic foundation for care. Integrating these domains into clinical practice and research will not only enhance patients satisfaction but also support better adherence, engagement, and long term health outcomes.

Funding: No funding sources

Conflict of interest: None declared

Ethical approval: Not required

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Cite this article as: Sandhu MK, Goyal K, Baath SK, Sohi GS, Parikh N, Dandass JS. Redefining quality of life in renal replacement therapy: a patient-centered perspective. *Int J Res Med Sci* 2025;13:5032-7.