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The instruments for measuring QoL in hemodialysis patients: A scoping review

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Abstract

Background: Quality of life (QoL) is a crucial indicator for evaluating the well being of patients undergoing hemodialysis, encompassing physical, psychological, social, and environmental dimensions. Accurate measurement of QoL serves as a fundamental basis for clinical decision making, care planning, and the development of patient centered policies.
Purpose: To identify, synthesize, and analyze the instruments used to measure QoL in hemodialysis patients within the international literature.
Method: The PRISMA-ScR approach, employing a systematic search across four major databases: ProQuest, BMC, PubMed, Wiley, and other sources. The search yielded seven articles that met the inclusion criteria and were subsequently analyzed thematically.
Results: Seven primary instruments were identified, namely the KDQOL-SF™, KDQOL-36, QDIS-7, HARQ, WHOQOL-BREF, EQ-5D-5L, and the Caregiver Quality of Life Inventory. Each instrument demonstrated specific strengths related to construct design, contextual applicability, and target population, with adequate validity and reliability. However, variations in dimensional coverage, limited cross cultural validation, and a predominance of cross-sectional designs without longitudinal evaluation were observed.
Conclusion: The findings highlight the importance of contextual adaptation, multi-cultural validation, and integration of QoL instruments into clinical evaluation systems. They also provide a foundation for developing more responsive and culturally relevant tools to improve care quality and patient well-being.

Keywords: Hemodialysis; Measurement Instruments; Quality of Life; Scoping Review; Validity.

INTRODUCTION

Quality of Life (QoL) has become one of the key indicators in assessing the success of medical interventions, particularly in patients with chronic illnesses such as end-stage renal disease undergoing hemodialysis therapy. The concept of QoL reflects an individual's perception of their position in life, in relation to their cultural context, value systems, goals, expectations, standards, and concerns (World Health Organization, 1997). In hemodialysis patients, measuring QoL is crucial given the lengthy treatment process, intensity of care, and significant physical, psychological, and social impacts of the condition (Klarenbach & Manns, 2009). A comprehensive understanding of QoL in hemodialysis patients is essential to support clinical decision-making, care planning, and the development of patient-centered health policies (Peters Mdj, Mclnerney, Munn, Tricco, & Khalil, 2020).

QoL measurement instruments play a central role in providing valid and reliable data regarding patients' perceptions of their health and lives. Currently, various instruments have been developed and are used in both research and clinical practice, such as the Kidney Disease Quality of Life (KDQOL), the Short

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Form Health Survey (SF-36), and the WHOQOL-BREF (Peipert, Nair, Klicko, Schatell, & Hays, 2019; Abbasi-Ghahramanloo, Soltani-Kermanshahi, Mansori, Khazaei-Pool, Sohrabi, Baradaran, Talebloo, & Gholami, 2020). However, differences in instrument characteristics, domain coverage, cultural sensitivity, and psychometric quality pose challenges in selecting the most appropriate tool for the hemodialysis patient population (Joshi, Subedi, Poudel, Ghimire, Panta, & Sigdel, 2017; McIntyre, 2024). Some instruments are generic and lack specificity to the experiences of patients with kidney failure, while others are disease-specific but limited in cultural or healthcare system applicability (Khalil, Frazier, Lennie, & Sawaya, 2011). Therefore, a thorough evaluation of existing instruments is necessary to ensure accuracy, relevance, and acceptability within local clinical contexts.

On the other hand, the limited availability of comprehensive literature mapping QoL measurement instruments for hemodialysis patients remains a major issue. Most previous studies have focused on validating or translating a single instrument within one population, without synthesizing literature that compares various instruments based on domains, usage contexts, and psychometric properties (Youssef, Best, Mackay, Hagen, & Shepherd, 2020). This situation makes it difficult for practitioners and researchers to determine the optimal measurement tool, particularly for the purposes of individualized care, population-based research, and health program evaluation (Hatef, Lasser, Kharrazi, Perman, Montgomery, & Weiner, 2018; Seixas, Moore, Chung, Robbins, Grandner, Rogers, Williams, & Jean-Louis, 2020). Therefore, there is an urgent need to conduct a comprehensive literature review to identify, synthesize, and analyze QoL measurement instruments used among hemodialysis patients in various contexts.

Furthermore, preliminary literature searches through the Scopus, PubMed, and CINAHL databases indicate that no systematic literature review is currently available that comprehensively maps the types, characteristics, measured domains, and psychometric properties of QoL measurement instruments in hemodialysis patients. Existing studies are predominantly limited to individual instrument validation or reliability testing within small populations, without thoroughly addressing the strengths, limitations, and gaps among the available tools (Clarck & Watson, 2019). This highlights a research gap in the literature that requires a scoping review to provide an evidence base for advancing research and improving QoL measurement practices in the future.

A scoping review is chosen as the most appropriate methodological approach for this purpose, as it enables broad exploration of the literature, mapping of the research field, identification of key concepts, and assessment of study characteristics related to QoL measurement instruments in hemodialysis patients (Aljawadi, Babaeer, Alghamdi, Alhammad, Almuqbil, & Alonazi, 2024). Unlike a systematic review, which focuses on a narrow research question, a scoping review offers flexibility to synthesize multiple study designs and establish a foundation for future research or evidence-based policy development (Munn, Peters, Stern, Tufanaru, McArthur, & Aromataris, 2018). Using this method, it is expected that a comprehensive literature map of QoL measurement instruments will be produced, including the domains assessed, psychometric quality, contexts of use, and existing research gaps.

This scoping review aims to identify, synthesize, and analyze the instruments used to measure QoL in hemodialysis patients. Specifically, the review will map the types of instruments developed, their contexts of use, the domains they measure, and their psychometric properties such as validity, reliability, and factor structure. Consequently, the results of this scoping review are expected to provide a comprehensive overview of QoL measurement instruments for hemodialysis patients and support more accurate tool selection in both clinical practice and research.

RESEARCH METHOD

This scoping review was conducted in accordance with the Joanna Briggs Institute (JBI) methodology and followed the PRISMA (Preferred Reporting Items for Systematic Reviews) guidelines for scoping reviews. The review aimed to identify and map instruments used to measure QoL in patients undergoing hemodialysis. A scoping approach was chosen to ensure that the scope of the review remained broad while maintaining a clear focus on the main research objective, namely mapping QoL measurement instruments globally. By applying this

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framework, the review was expected to provide a comprehensive overview of the instruments, their contexts of use, and the psychometric properties reported in the literature over the past five years.

The literature search was carried out in April 2025 across four major databases ProQuest, BMC, PubMed, and Wiley selected for their broad coverage of health sciences and biomedical research. Google Scholar was also used as a supplementary source to capture gray literature such as conference proceedings and research reports not indexed in conventional databases.The search strategy was systematically developed using Boolean operators (AND, OR) with the following keyword combinations: ("hemodialysis patients" OR "patients undergoing hemodialysis") AND "quality of life" AND ("instrument" OR "questionnaire" OR "scale") AND ("validation" OR "psychometric properties" OR "reliability" OR "validity"). Terminology variations were adapted to each database's indexing system, including the use of Medical Subject Headings (MeSH) in PubMed and controlled vocabulary in Scopus or CINAHL.

To clearly define the scope of the review, the PCC (Population-Concept–Context) framework was applied. This framework guided the eligibility criteria and ensured that the review remained focused on mapping QoL instruments across diverse clinical and cultural settings.

Population: Adult patients undergoing regular hemodialysis therapy for end-stage renal failure, whether in hospitals, dialysis clinics, or other healthcare facilities. The population included patients who were the subjects of a study assessing quality of life in the context of hemodialysis therapy, regardless of gender, age over 18, or sociodemographic background.

Concept: Instruments used to measure quality of life (QoL) in hemodialysis patients include psychometric measurement tools such as questionnaires, scales, or other standardized instruments designed to assess patients' subjective perceptions of their physical, psychological, social, and environmental well-being. This concept encompasses development, validation, cross-cultural adaptation, and psychometric analysis, particularly of the reliability and validity of the instruments used.

Context: Healthcare contexts across both developed and developing countries, including outpatient dialysis services, nephrology clinics, and hospitals, were included. Studies from diverse geographic and cultural settings were included to capture global diversity in the use of QoL measurement instruments in hemodialysis patients.

Based on this framework, the inclusion criteria were defined as follows: (1) studies reporting the development, validation, or cultural adaptation of QoL instruments in adult patients undergoing hemodialysis; (2) quantitative, qualitative, or mixed-method research designs with clear methodological procedures and results; and (3) full-text articles published in English or Indonesian between January 2019 and December 2024. Studies were excluded if they were literature reviews, systematic reviews, or scoping reviews, duplicates, or articles without empirical findings relevant to QoL measurement instruments.

The study selection process followed the PRISMA framework. Initially, 962 records were retrieved from the databases. After removing duplicates, the remaining articles were screened in two stages: title and abstract screening, followed by full-text review to determine final eligibility. Screening and selection were conducted independently by two reviewers, and any disagreements were resolved through discussion or consultation with a third reviewer. Reference lists of relevant studies were also checked to identify additional eligible articles.

Data from the included studies were extracted using a standardized matrix, which captured key study characteristics (author, year, country, study objectives, sample size), instrument details (name, domains measured), study design, and psychometric properties (validity, reliability, factor structure). Data extraction was performed independently by two reviewers, with discrepancies resolved through consensus or adjudication by a third reviewer. The extracted data were synthesized descriptively and presented in both narrative and tabular formats to provide an overview of existing QoL instruments, their strengths and limitations, and research gaps requiring further investigation.

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RESEARCH RESULTS

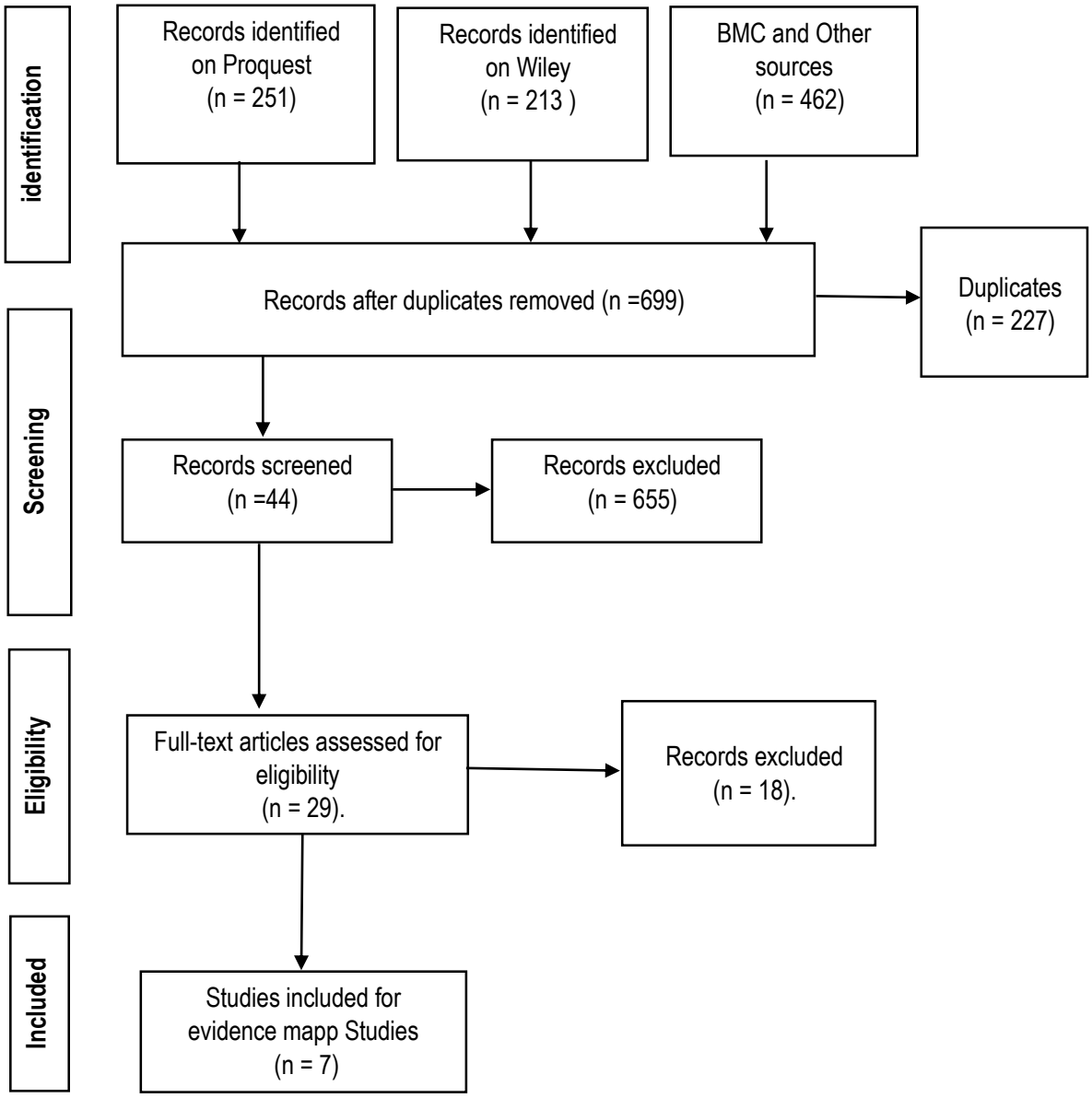


Figure Flow Prism Diagram

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Table Summary of Review Articles

(Author, Year) (Country)	Purpose	Method	Result
Fukuhara et al., 2023 (Japan)	To validate the new instrument QDIS-7 for CKD patients with hyperkalemia	A cross-sectional study	QDIS-7 more valid than SF-36 in differentiating CKD stage and PB formulation; good reliability (α = 0.86).
Manju et al., 2020 (India)	To translate and validate the KDQOL-SF™ into Malayalam for hemodialysis patients	A cross-sectional study	Malayalam KDQOL-SF™ valid and reliable (α = 0.81; scale reliability 0.71–0.92); mean health score 53.43 ± 11.48.
Rokhman et al., 2023 (Indonesia)	To evaluate the validity and reliability of the Indonesian KDQOL-36 in hemodialysis and CAPD patients	A cross-sectional study	Indonesian KDQOL-36 valid and reliable; CFA supported model; no floor/ceiling effects; good ICC in burden domain
Gebrie et al., 2022 (Ethiopia)	To translate, culturally adapt, and assess the validity and reliability of the Amharic version of KDQOL-36 in hemodialysis patients.	A cross-sectional study	Amharic KDQOL-36 was valid and reliable (α = 0.81–0.91; ICC = 0.90–0.96); CFA supported the model; strong correlations with EQ-5D-5L & VAS (0.55–0.81).
Alabdan et al., 2021 (Saudi Arabia)	To evaluate the validity and reliability of the Arabic version of KDQOL-36 in long-term dialysis patients.	A cross-sectional study	Arabic KDQOL-36 was valid and reliable (α = 0.63–0.89; ICC = 0.60–0.88); significant positive correlations with overall health score ($p < 0.01$).
Nordyke et al., 2020 (USA)	To develop the Hemodialysis Access-Related Quality of Life (HARQ) instrument for vascular access-specific QoL assessment in hemodialysis patients.	A qualitative study	HARQ was developed with 47 items across 6 domains; content validity supported by patients and clinicians.
Sajadi et al., 2020 (Iran)	To design and validate a quality of life inventory for family caregivers of hemodialysis patients.	A mixed-method study	34-item inventory was valid and reliable (α > 0.7; good ICC), with 5 factors: care burden, conflict, positive perception, self-actualization, and worry.

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DISCUSSION

Based on the results of a systematic review of seven studies that met the inclusion criteria, several important insights can be discussed comprehensively regarding QoL measurement instruments in hemodialysis patients. The Kidney Disease Quality of Life family of instruments, particularly KDQOL-SF and KDQOL-36, consistently emerged as the most widely used and validated tools across various cultural contexts. Studies in India, Indonesia, and Ethiopia confirmed high construct validity and internal consistency (Cronbach's α ranging from 0.81 to 0.91), with confirmatory factor analyses supporting their structural validity and showing no significant floor or ceiling effects (Manju, Joseph & Beevi, 2020; Rokhman, Wardhani, Partiningrum, Purwanto, Hidayati, Idha, Thobari, Postma, Boersma & van der Schans, 2023; Gebrie, Asfaw, Bilchut, Lindgren, & Wettergren, 2022). These findings demonstrate that KDQOL-36 is a reliable instrument for measuring both generic dimensions of health such as physical and mental well-being, and kidney-specific aspects such as burden of kidney disease, symptoms, and treatment effects, thereby providing a comprehensive framework for assessing QoL among hemodialysis patients.

Beyond the KDQOL instruments, several tools were developed to address more specific clinical contexts and contributed unique perspectives to QoL measurement. The Hemodialysis Access-Related Quality of Life (HARQ) was designed specifically to capture the impact of vascular access on patient QoL (Nordyke, Nicholson, Gage, Lithgow, Himmelfarb, Rivara, Hays, Woo, & Peipert, 2020). This instrument consists of 47 items distributed across six domains, including symptoms, physical functioning, emotional impact, social and role functioning, sleep, and treatment burden. Its development incorporated patient and clinician input through focus groups, interviews, and cognitive testing, ensuring strong content validity and clinical relevance in distinguishing the effects of different vascular access types such as fistulas, grafts, and catheters. Similarly, the scope of QoL assessment was broadened by the design and validation a 34-item inventory for family caregivers of hemodialysis patients (Sajadi, Ebadi, Moradian, & Akbari, 2020). This tool covered five main factors care burden, conflict, positive perception, self-actualization, and concern and demonstrated good reliability (Cronbach's α > 0.70, acceptable ICC values). The inclusion of caregiver perspectives highlights the importance of family roles in chronic disease management and emphasizes that QoL evaluation should extend beyond patients to their support systems. From Another Perspective, the QDIS-7 was introduced as disease specific instrument for chronic kidney disease patients with hyperkalemia (Fukuhara, Yamazaki, Wakita, Ware, Wang, Onishi, Yajima, Sada, Yamamoto, & Shibagaki, 2023). Compared to SF-36, QDIS-7 showed superior discriminative validity in differentiating CKD stages and phosphate binder treatments, with good reliability (Cronbach's α = 0.86). This finding indicates that QDIS-7 has strong potential for targeted application in hemodialysis populations with comorbidities.

From a methodological perspective, most studies employed cross-sectional designs, which allowed assessment of reliability and validity at a single time point but limited conclusions regarding responsiveness to long-term changes. Only a few studies, included test retest reliability, while multicenter longitudinal studies remain scarce (Rokhman et al., 2023; Daderman, Persson, Ahlstrand, Hallgren, Larsson, Larsson, Sundler, Heden, Nunstedt, Ekmani Lood, Hammar, & Pennbrant, 2025). Another critical issue is cultural and linguistic adaptation. Although instruments were translated and validated in multiple settings,including Malayalam in India, Indonesian, Amharic in Ethiopia, and Arabic in Saudi Arabia. However, comprehensive cross-cultural validation was often absent. For example, strong correlations between the Amharic version of KDQOL-36 and EQ-5D-5L and VAS scores (r = 0.55–0.81) were reported (Gebrie et al., 2022), while positive correlations with overall health scores were demonstrated for the Arabic version (Alabdan, Al-Sayyari, AlHejaili, Alrajhi, Adnan, Aldelhm, Hakami, Rayan, & Vasudevan, 2021). However, both instruments have not yet been routinely integrated into clinical practice, highlighting a gap between validation studies and real-world application.

Taken together, the findings of this review suggest that no single QoL instrument can be universally applied across all hemodialysis populations. KDQOL-36 may serve as a robust standard for general assessment, but specialized instruments such as HARQ, caregiver inventories, and QDIS-7 provide

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complementary insights into specific clinical or familial dimensions. The selection of an appropriate instrument should therefore consider cultural appropriateness, clinical objectives, and patient-specific needs. The implications of these findings are highly relevant for clinicians, researchers, and policymakers, as integrating QoL instruments into healthcare systems requires not only psychometric soundness but also cultural adaptability and feasibility in daily practice. Future research should prioritize broader cross-cultural validation, conduct longitudinal studies to test instrument responsiveness, and develop strategies to embed QoL measurement into healthcare policy and quality improvement initiatives. Strengthening these areas will enhance evidence-based practice, improve patient-centered care, and support the sustainability of hemodialysis services across diverse global contexts.

CONCLUSION

instruments for measuring QoL in hemodialysis patients have evolved in various forms, reflecting diverse conceptual approaches tailored to clinical contexts and local cultures. Instruments such as the KDQOL-36 and HARQ have demonstrated high validity and reliability, covering dimensions including physical and mental health, kidney disease symptoms, treatment burden, and emotional and social impacts. Furthermore, the development of instruments for caregivers expands the scope of QoL assessment by incorporating the family's perspective as an integral part of patient care support (Sajadi et al., 2020). However, this analysis also reveals several systemic limitations, including the lack of consistent theoretical consensus regarding the definition and scope of measured dimensions; the predominance of cross-sectional study designs without testing the instruments' sensitivity to long-term changes; and the limited formal efforts toward cross-cultural validation. In addition, evidence regarding the integration of these instruments into hospital policies or quality management systems in healthcare remains scarce. Therefore, while these instruments hold significant potential for monitoring the QoL of hemodialysis patients, their implementation in real-world clinical practice remains suboptimal. Further efforts are needed to expand cross-cultural validation, conduct longitudinal validity testing, and integrate these instruments into kidney healthcare quality evaluation systems.

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