

Review

Supportive Care Needs and Patient Preferences Among Hemodialysis Patients with Chronic Kidney Disease: A Scoping Review of Evidence for Patient-Centered Kidney Supportive Care



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ABSTRACT

Background: Patients with Chronic Kidney Disease (CKD) undergoing maintenance Hemodialysis (HD) face physical, psychological, social, and spiritual challenges that reduce quality of life. This scoping review mapped and synthesised evidence on supportive care needs and patient preferences to inform the development of holistic, person-centred, and culturally responsive Kidney Supportive Care (KSC) models for adults receiving maintenance HD.

Methods: This scoping review followed the PRISMA-ScR guidelines and the Arksey and O'Malley methodological framework, guided by the Population–Concept–Context (PCC) approach. Literature searches were conducted on May 25, 2026, across PubMed, Scopus, ScienceDirect, and EBSCOhost. Eligible studies included English- and Indonesian-language publications from 2021–2026 involving adults with CKD receiving maintenance HD. Qualitative, quantitative, and mixed-methods studies, as well as systematic reviews, were included. Study selection, data charting, thematic synthesis, and methodological quality appraisal were conducted using predefined criteria and Joanna Briggs Institute (JBI) critical appraisal tools.

Results: Twelve studies met the inclusion criteria. Four overarching themes were identified: (1) multidimensional supportive care needs, including physical symptom management, psychological support, social and financial assistance, spiritual care, and informational needs; (2) patient preferences for patient-centered care, emphasizing effective communication, shared decision-making, family involvement, and respect for spiritual values; (3) barriers to KSC implementation, including workforce limitations, inadequate psychosocial resources, financial burdens, insufficient professional training, and organizational constraints; and (4) strategies to strengthen KSC through interdisciplinary collaboration, Patient-Reported Outcome Measures (PROMs), family engagement, and integrated palliative care approaches. The review also identified evidence gaps regarding culturally adapted supportive care models, caregiver-support interventions, and implementation strategies in resource-limited settings.

Conclusion: Cultural beliefs are crucial in shaping treatment choices for ENT conditions. Public awareness campaigns by the Ministry of Health and local health authorities are recommended to educate communities on the benefits and risks of traditional medicine while promoting evidence-based healthcare practices.

Keywords: Chronic Kidney Disease; Hemodialysis; Kidney Supportive Care; Supportive Care Needs; Patient Preferences; Person-Centered Care; Palliative Care.

Implications for Practice:

- Routine assessment of multidimensional supportive care needs using validated patient-reported outcome measures (e.g., IPOS-Renal) should be integrated into HD services to improve symptom management, quality of life, and patient-centred care.
- KSC should be delivered through interdisciplinary collaboration involving nurses, nephrologists, psychologists, dietitians, social workers, and spiritual care providers to address the physical, psychological, social, and spiritual needs of patients comprehensively.
- Family-centered and culturally responsive supportive care approaches, including shared decision-making, spiritual support, and clear communication, should be incorporated into routine HD practice to strengthen patient autonomy, caregiver support, and overall well-being.

Introduction

CKD has now become a significant global public health crisis, with the latest estimates indicating that approximately 788 million adults will be living with this condition by 2023, representing an age-standardized prevalence of approximately 14.7% (Mark et al., 2025). (Mark et al., 2025). This global burden is reinforced by various other analyses estimating that CKD prevalence accounts for approximately 9% to 13% of the world's population, or the equivalent of 700 to 800 million people (Bikbov et al., 2020; Carney, 2020; Qin et al., 2024; Xie et al., 2025). This increase in cases has been sharp, with incidence and prevalence rates reported to have nearly doubled between 1990 and 2021—a phenomenon driven by rapid population growth and global aging (Deng et al., 2025; Qin et al., 2024; Ying et al., 2024). Given the ongoing escalation in the number of patients, a deep understanding of supportive care needs and patient preferences has become crucial, particularly for those undergoing

maintenance HD, to ensure optimal quality of life. Identifying these needs and preferences is an essential first step in developing more responsive, patient-centered healthcare services amid this growing epidemiological burden.

CKD is currently the ninth leading cause of death globally in 2023, with an estimated 1.48 million deaths, and ranks as the 12th leading cause of Disability-Adjusted Life Years (DALYs) worldwide (Mark et al., 2025). This high mortality rate is estimated to have reached 1.2 to 1.7 million deaths in 2017 when accounting for cardiovascular deaths closely associated with impaired kidney function (Bikbov et al., 2020; Fletcher et al., 2022; Ying et al., 2024). The burden of this disease continues to escalate at an alarming rate, with DALYs due to CKD rising to over 40 million years of life lost in 2019 (Qin et al., 2024; Ying et al., 2024). This situation is further exacerbated by the fact that CKD is a very strong risk factor for cardiovascular disease, with impaired kidney function accounting for approximately 7% to 12% of total global cardiovascular deaths (Jadoul et al., 2024; Mark et al., 2025). Given the significant clinical impact and the burden on patients' lives, understanding their needs for supportive care and their preferences is crucial, particularly for those undergoing maintenance HD, to ensure a better quality of life.

A comprehensive global review encompassing 449 studies involving 199,147 patients across 62 countries revealed a substantial burden of symptoms and a significant decline in health-related quality of life (HRQOL) across all stages of CKD (Fletcher et al., 2022). Among the various complaints reported, fatigue is a very common symptom, affecting approximately 70% of patients in both the non-dialysis and dialysis groups. Additionally, patients consistently report various other health issues, including

depression, itching, sleep disturbances, mobility impairments, and dry mouth ([Deng et al., 2025](#); [Fletcher et al., 2022](#); [Supriatin et al., 2025](#)). Specifically, patients undergoing dialysis exhibit the lowest physical and mental quality of life scores, which are even worse compared to non-dialysis CKD patients and post-transplant patients. This situation is also reflected in a review from Indonesia, which confirms that the quality of life of patients with CKD is influenced multidimensionally by physical, psychological, social, and economic factors, all of which are closely related to the patients' clinical condition and the level of psychological distress they experience ([Fletcher et al., 2022](#); [Supriatin et al., 2025](#)). The complexity of the symptom burden and the low quality of life necessitate a care approach that focuses not only on technical medical interventions but also on more holistic support.

The global burden of CKD reveals significant disparities, with the highest burden concentrated in countries with low to medium Socio-Demographic Indices (SDI) ([Fletcher et al., 2022](#); [Jadoul et al., 2024](#)). Countries in this SDI category face significantly higher mortality rates and DALYs compared to developed countries, a situation exacerbated by severely limited access to essential therapies such as dialysis, kidney transplantation, and routine medications. Consequently, many patients in low-income countries die upon reaching end-stage kidney disease due to the absence or limited access to adequate renal replacement therapy ([Francis et al., 2024](#); [Hill et al., 2016](#); [Jadoul et al., 2024](#)). To address this crisis, international consensus has emphasized the urgency of early detection, prevention, and the development of financially accessible healthcare models to stem the rapidly rising global burden of CKD ([Francis et al., 2024](#)). Amid these challenges of accessibility and limited medical resources, a deep understanding of

how patients undergo therapy and what they need is crucial to ensuring that their quality of life is maintained during chronic treatment.

In the ASEAN region, the burden of CKD has also shown a significant increase, reflecting broader epidemiological shifts related to population aging, urbanization, diabetes, and hypertension. Countries such as Thailand, Malaysia, Singapore, Vietnam, and the Philippines have reported an increase in the number of CKD patients requiring renal replacement therapy, particularly HD ([Makmun et al., 2025](#); [Satirapoj et al., 2025](#); [Thurlow et al., 2021](#)). Despite differences in healthcare financing systems and access to kidney care, CKD remains a major contributor to morbidity, mortality, and healthcare expenditures across Southeast Asia. Compared to some neighboring ASEAN countries that have expanded dialysis coverage and supportive care programs, many low- and middle-resource regions in the region continue to face challenges related to equitable access, financial burden, and the integration of supportive and palliative care services ([Gurung & Devkota, 2025](#); [Makmun et al., 2025](#); [Marsh et al., 2024](#)). These regional similarities and disparities underscore the importance of understanding patients' supportive care needs and preferences within the ASEAN context, particularly in Indonesia, where the growing burden of CKD poses significant challenges to the delivery of patient-centered care.

In Indonesia, the burden of CKD has increased substantially over the past decade. Data from the National Basic Health Survey (Riskesdas) showed that the prevalence rose from 0.2% in 2013 to 3.8 per 1,000 population in 2018, affecting an estimated 713,000–739,000 individuals nationwide ([Amaludin et al., 2025](#); [Kasih Maharani et al., 2025](#); [Utami et al., 2020](#)). This escalation in the disease burden aligns with Pernefri's estimates, which predict

approximately 70,000 CKD patients with an annual case growth rate of 10% ([Baroleh et al.](#), 2019). Although the 2023 Riskesdas report indicates a prevalence rate of 0.18% or approximately 382,646 people, the distribution of the disease is uneven, with provinces such as Gorontalo and North Sulawesi ranking highest nationally ([Badan Kebijakan Pembangunan Kesehatan](#), 2023). This situation poses a significant challenge to the healthcare system, given that only about 60% of CKD patients in Indonesia have access to dialysis therapy ([Utami et al.](#), 2020). In addition to limited access, CKD is also associated with the risk of severe complications such as anemia, hypertension, and electrolyte imbalances, which entail very high treatment costs for patients and their families ([Irawati et al.](#), 2024; [Pondaag et al.](#), 2024). This issue is compounded by the low level of awareness among individuals with hypertension and diabetes regarding CKD, which directly risks accelerating disease progression toward end-stage kidney failure ([Imran Pashar et al.](#), 2023; [Indrayani & Utami](#), 2022).

HD is currently the most prevalent form of kidney replacement therapy (KRT) worldwide, accounting for approximately 69% of all KRT and 89% of all dialysis procedures ([Bello et al.](#), 2022). The dominance of this method is evident in many countries, where at least 80% or more of chronic dialysis patients undergo HD procedures routinely at healthcare centers or in-center HD ([Thurlow et al.](#), 2021). Based on a 2018 global survey conducted in 182 countries, HD was officially reported as the “primary life-support therapy” for patients with kidney failure, with a median usage rate of 298 per million population ([Htay et al.](#), 2021). Given HD’s vital role as a life-saving technology for millions of people worldwide, patients’ long-term dependence on this therapy often presents various physical and psychosocial challenges. The

high rate of HD use in healthcare centers underscores the importance of understanding patients’ daily experiences and ensuring that the services provided focus not only on technical medical aspects but also on patients’ overall well-being.

The management of CKD has long been dominated by the achievement of physiological targets such as blood pressure control, glycemic control, the use of renoprotective medications, and dialysis procedures; however, recent research indicates that this model is often insufficient to address the emotional distress, reduced quality of life, and long-term treatment burden experienced by patients. Although models focused on the disease and renal replacement therapy have successfully improved biomedical parameters and survival rates, this approach does not automatically improve patients’ quality of life because it fails to integrate psychosocial, ethical, affective, emotional, and spiritual aspects ([Zuñiga-San Martin](#), 2021). This gap is particularly evident in many low- to middle-income countries, where both conservative care and dialysis services remain heavily focused on life-prolongation efforts alone, while other supportive needs are often neglected ([Akpakli Addo & Senoo-Dogbey](#), 2025). Consequently, CKD patients undergoing dialysis continue to bear the burden of severe symptoms and complex emotional distress, including chronic fatigue, pain, sleep disturbances, anxiety, depression, fear of the future, loss of independence, and crushing financial impacts ([Gurung & Devkota](#), 2025; [Kalantar-Zadeh et al.](#), 2022; [Winner et al.](#), 2025). This clinical reality underscores the urgency of shifting toward a more holistic, patient-centered care model to bridge the gap between medical technical success and patients’ psychosocial well-being.

The implementation of structured palliative care interventions in patients with CKD has been shown to significantly

reduce the burden of symptoms such as pain, fatigue, depression, and anxiety, while also meaningfully improving patients' physical, cognitive, and emotional functioning ([Mark et al., 2025](#)). The success of these interventions is closely linked to the integration of psychosocial and spiritual support, which plays an explicit role in addressing emotional distress, meeting family needs, and assisting with end-of-life planning ([Kalantar-Zadeh et al., 2022](#); [Marsh et al., 2024](#)). Various phenomenological studies have also found that patients have a significant need for psychological, social, and spiritual support from healthcare providers and family members as a form of "holistic support" that is essential during therapy ([Shahgholian & Yousefi, 2015](#)). Furthermore, the availability of social support and family resilience have been shown to be positively associated with the psychological resilience of HD patients over time, which directly strengthens their mental health in coping with a chronic disease trajectory ([Y. Wang et al., 2024](#)). Therefore, understanding how these support elements can be integrated based on patients' specific preferences is crucial for improving the quality of healthcare services provided.

Family and spirituality play a crucial role as the primary foundation for maintaining the psychological well-being and adaptive capacity of patients undergoing maintenance HD. The family functions as the primary "emotional support system" that directly influences quality of life, motivation to undergo HD, and patients' self-care abilities, with strong family support proven to significantly improve self-care management. Findings from various studies in Indonesia further underscore the urgency of implementing a family-centered caregiving model in HD units, alongside the provision of structured counseling services for caregivers to ensure the continuity of care ([Kristian et al., 2025](#);

[Lianti & Rosyid, 2024](#)). In line with this social support, the aspect of spirituality emerges as a fundamental need for HD patients who require strengthening of their faith and assistance in resolving spiritual conflicts to achieve a sense of peace and better disease adaptation ([Shahgholian & Yousefi, 2015](#)). Interventions involving spiritual support, such as religious activities, education, or spiritual counseling, have been clinically proven to reduce anxiety levels without reported side effects ([Maisyaroh et al., 2024](#)). Furthermore, mature spirituality is positively correlated with lower anxiety and greater psychological resilience in patients undergoing long-term dialysis therapy ([Sanli et al., 2023](#)).

Globally, there is widespread recognition of the importance of transforming healthcare services toward a more integrated model to address the complex challenges faced by patients with advanced CKD. The Kidney Disease: Improving Global Outcomes (KDIGO) Conference on Supportive Care has explicitly highlighted the "critical global need" to provide integrated supportive care for all patients with advanced CKD through universal access, integrated service models, and enhanced training for healthcare professionals in psychosocial and palliative care. In line with this vision, the International Society of Nephrology's working group now positions KSC (KSC) and conservative kidney management as core components of integrated care, and advocates for the development of national policies that include standard definitions, core elements, and international quality indicators to strengthen palliative care as an integral part of the care continuum ([Davison et al., 2024](#)). Various other global documents also emphasize that supportive care is an integral part of End-Stage Kidney Disease (ESKD) services that must be available in countries at all income levels,

with a focus on providing clear prognostic information, developing context-appropriate evidence, and robust integration into existing health infrastructure (Hole et al., 2020). The adoption of these international standards requires a better understanding of how patients' needs and expectations can be aligned with this global policy framework.

There is a significant gap between routine clinical care and unmet palliative care needs among patients undergoing maintenance HD in various parts of the world. Evidence from various studies in China indicates that nearly 50% of maintenance HD patients fall into the moderate-to-severe palliative care needs category, where these needs are heavily influenced by symptom burden, low functional status, financial stress, depression, and a lack of social support (Y. Wang et al., 2024). Another study in the same population also found a high symptom burden with moderate palliative care needs, particularly related to family anxiety and an urgent need for information and support (Htay et al., 2021). More broadly, the spectrum of patient needs encompasses pain management, fatigue, depression, anxiety, as well as practical issues and spiritual-psychosocial support; however, nearly half of patients consistently report that their palliative care needs remain unmet (Axelsson et al., 2019). This phenomenon is exacerbated by the fact that CKD/ESKD patients often have poor knowledge of palliative options and their disease trajectory, a lack of discussion regarding end-of-life planning, and a very high reliance on the nephrology team for symptom management and psychosocial-spiritual support, which is not yet systematically structured (Axelsson et al., 2019; Davison et al., 2024).

The global implementation of end-of-life care still faces significant challenges rooted in knowledge, systemic, and

communication barriers at various levels of the healthcare system. In Ghana, nurses reportedly have only partial awareness of PSC, where clinical practice remains dominated by life-prolonging efforts while psychological support remains informal without structured guidance, a situation exacerbated by resource constraints and limited interdisciplinary collaboration (Akpakli Addo & Senoo-Dogbey, 2025). This situation is reinforced by meta-synthesis findings highlighting gaps in institutional frameworks, a lack of palliative care infrastructure, and time pressures that make it difficult to integrate palliative care into routine practice (Li et al., 2025). A similar phenomenon was observed in China, where nephrology staff actually hold positive attitudes toward renal palliative care but exhibit very low levels of confidence and knowledge, leading them to view formal training and practice guidelines as urgent needs (Zhang et al., 2023). Furthermore, a survey in Europe confirms that while specialized education is a key enabler, a lack of role-specific experience in palliative care, as well as cultural and religious differences, remain major barriers to optimizing such services (de Barbieri et al., 2022, 2024). The complexity of these barriers indicates that patient-centered care cannot be achieved without systemic reforms and structured improvements in healthcare professionals' competencies.

It is important to clarify that, in the context of HD, "patient preferences" refer to conscious choices, personal values, and individual expectations regarding how their healthcare should be provided. This goes beyond merely meeting clinical needs and encompasses specific aspects such as communication preferences, where patients may prefer the use of their native language or simple, everyday language to ensure a deep understanding without being hindered by technical terms (Beckwith et al., 2022; Schneider et al., 2023; Wong et al.,

2024). Furthermore, these preferences include active involvement in shared decision-making regarding treatment plans and end-of-life care choices, where patients often prioritize comfort over aggressive medical interventions, including the autonomy to choose to die at home rather than in a hospital ([González-Bedat et al., 2023](#); [van der Horst et al., 2023](#)). This operational definition also addresses care delivery methods, such as the desire for in-person psychosocial support within the dialysis unit to facilitate peer support, the integration of spiritual beliefs into routine care, and respect for the privacy of sensitive health data ([X. Wang et al., 2022](#)).

Cultural context plays a significant role in shaping supportive care preferences among patients undergoing maintenance HD. In Indonesia, healthcare decision-making is strongly influenced by collectivist values, where families are often deeply involved in treatment discussions, caregiving responsibilities, emotional support, and decisions regarding future care ([Cipta et al., 2024](#); [Kristanti et al., 2021](#); [Martina et al., 2022](#)). Family members frequently act as advocates, caregivers, and key partners in managing chronic illness, reflecting a family-centered model of care ([Krisdianto et al., 2024](#)). This contrasts with many Western healthcare systems, which are predominantly guided by the principle of individual autonomy and emphasize patients' independent decision-making, informed consent, and personal control over treatment choices. While Western models prioritize the individual patient's preferences as the primary determinant of care planning, Indonesian patients often view healthcare decisions as a shared responsibility involving family members and close relatives ([Cipta et al., 2024](#); [Harrington et al., 2026](#); [Martina et al., 2022](#); [Saleem, 2026](#)). Furthermore, spiritual and religious beliefs are commonly integrated into family discussions and coping

strategies in Indonesia, whereas Western supportive care models tend to rely more heavily on formal psychosocial services and structured advance care planning. These cultural differences suggest that supportive care interventions developed in Western settings may require adaptation to align with the family-oriented values, collective decision-making processes, and spiritual needs that characterize the Indonesian context.

Despite growing attention to patients' quality of life, evidence regarding the types of supportive care needs and patient preferences among individuals undergoing HD remains fragmented across regions and has not yet been comprehensively mapped within a single integrated review. Existing literature gaps indicate the absence of a review that explicitly synthesizes evidence on how patient preferences can effectively inform the development of person-centered care models in HD settings. This lack of an integrated evidence synthesis hinders a comprehensive understanding of the interplay between patients' clinical needs and personal expectations across diverse cultural contexts. By mapping the available evidence, healthcare providers can gain the insights necessary to design care strategies that not only focus on survival and clinical outcomes but also respect patient autonomy and individual values. Such efforts are essential to bridging the gap between standard medical practice and the psychosocial and spiritual support needs that are often overlooked in routine dialysis care.

Although several previous reviews have examined symptom burden, palliative care needs, and quality of life among patients with CKD undergoing HD, most have focused on specific domains such as physical symptoms, psychological distress, or the effectiveness of palliative care interventions ([Almutary et al., 2013](#); [Fletcher et al., 2022](#); [Lu et al., 2024](#); [Zheng](#)

[et al.](#), 2025a). Existing reviews have also primarily synthesized evidence regarding symptom prevalence and clinical outcomes, with limited attention to patients' preferences for care delivery, communication, shared decision-making, family involvement, and spiritual support. Furthermore, many reviews were conducted using systematic review methodologies that addressed narrowly defined clinical questions and did not comprehensively map the breadth of evidence across diverse study designs and healthcare contexts. Given the increasing emphasis on person-centered and KSC approaches, a broader synthesis is needed to integrate both supportive care needs and patient preferences within a single framework. Therefore, this scoping review was undertaken to systematically map the available evidence, identify key themes and knowledge gaps, and provide a comprehensive understanding of how supportive care services can be aligned with the values, expectations, and lived experiences of patients receiving maintenance HD.

The present review is informed by several complementary theoretical frameworks that underpin supportive care for patients with CKD. First, the Person-Centered Care Framework emphasizes the delivery of care that respects patients' values, preferences, and individual goals while promoting active participation in healthcare decisions ([Saeed et al.](#), 2025; [Zisman-Ilani et al.](#), 2026). Second, the Supportive Care Needs Framework recognizes that patients with chronic illness experience multidimensional needs encompassing physical, psychological, social, spiritual, informational, and practical domains that require comprehensive assessment and intervention ([Akpakli Addo & Senoo-Dogbey](#), 2025; [Bulathwatta et al.](#), 2024; [Chao et al.](#), 2025). Third, the Total Pain Theory highlights that suffering in

chronic and life-limiting illnesses extends beyond physical symptoms and includes emotional, social, and spiritual distress. In addition, the Shared Decision-Making Model provides a foundation for collaborative treatment planning between patients, families, and healthcare professionals, ensuring that care aligns with patients' priorities and preferences ([Buur et al.](#), 2024; [Corman et al.](#), 2025; [Lanini et al.](#), 2022). Finally, the Capability–Opportunity–Motivation–Behavior (COM-B) Framework offers a useful lens for understanding how patients' knowledge, environmental resources, and motivational factors influence engagement in self-management and supportive care ([Ahn et al.](#), 2022; [Baay et al.](#), 2019; [Diaz-Martinez et al.](#), 2026). Collectively, these frameworks support a holistic understanding of supportive care needs and patient preferences among individuals undergoing maintenance HD and provide a conceptual foundation for mapping the available evidence in this review.

Conceptually, supportive care needs, patient preferences, quality of life, and KSC outcomes are closely interconnected within a person-centered care continuum. Patients undergoing maintenance HD frequently experience multidimensional supportive care needs, including physical symptoms, psychological distress, social challenges, spiritual concerns, and informational needs ([Matthews et al.](#), 2024; [Zheng et al.](#), 2025b). The extent to which these needs are recognized and addressed is influenced by patients' individual preferences regarding communication, family involvement, spiritual support, care delivery, and participation in shared decision-making. When healthcare services are aligned with both patients' supportive care needs and personal preferences, the implementation of KSC becomes more responsive and patient-centered, leading to improved symptom control, greater treatment

satisfaction, enhanced psychological well-being, and better quality of life ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Zheng et al., 2025b](#)). Conversely, unmet supportive care needs and care that does not reflect patient preferences may contribute to increased symptom burden, emotional distress, reduced treatment adherence, and poorer health outcomes. Therefore, understanding the dynamic relationship between supportive care needs and patient preferences is essential for optimizing KSC interventions and achieving meaningful patient-centered outcomes in individuals receiving maintenance HD.

In Indonesia, the need to systematically map supportive care needs and patient preferences is particularly urgent given the limited availability of formal palliative and supportive care services, alongside the strong influence of collectivist cultural values that shape healthcare decision-making. Within this context, families frequently serve as the primary source of emotional, practical, and spiritual support while simultaneously assuming substantial caregiving responsibilities in the absence of structured clinical guidance. A comprehensive understanding of these multidimensional needs and preferences is essential not only for improving patient outcomes but also for informing the development of nephrology nursing protocols that incorporate routine assessment of physical, psychological, social, spiritual, and informational needs. Furthermore, such evidence can support policy development aimed at integrating KSC into standard nephrology services and guide the redesign of dialysis care models toward more holistic, family-centered, and person-centered approaches. To ensure a systematic exploration of this broad and complex body of evidence, this scoping review is guided by the Population-Concept-Context (PCC) framework, in which the population comprises individuals

with CKD undergoing maintenance HD, the concept focuses on supportive care needs and patient preferences, and the context encompasses diverse dialysis care settings. Therefore, this review aims to map and synthesize the available evidence on supportive care needs and patient preferences to inform the development of holistic, patient-centered, and culturally responsive supportive care models for individuals receiving maintenance HD, with the ultimate goal of informing culturally appropriate, evidence-based, and patient-centered supportive care strategies, particularly in resource-limited settings such as Indonesia.

Methods

Design

This scoping review was conducted using the methodological framework developed by Arksey and O'Malley in 2005 ([Buus et al., 2022](#)), which has been further refined by the Joanna Briggs Institute (JBI) ([Aromataris et al., 2022](#)), and reported in accordance with the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) ([Manuilova et al., 2024](#)). This review followed five core steps: (1) identifying the research question, (2) identifying relevant studies through a comprehensive and structured search, (3) selecting studies using predefined inclusion and exclusion criteria, (4) charting, categorizing, and organizing data, and (5) synthesizing, summarizing, and reporting findings. The study selection process is presented both narratively and via a PRISMA-ScR flowchart to ensure transparency and reproducibility from the identification, screening, and eligibility assessment stages through to final inclusion ([Manuilova et al., 2024](#)).

This review employs a scoping review approach rather than a systematic review because its primary objective is to map the

scope and synthesize scientific evidence regarding supportive care needs and patient preferences in the CKD population undergoing maintenance HD, clarify these multidimensional concepts, and identify research gaps, rather than merely producing estimates of intervention effects. A scoping review is considered highly appropriate because the literature on supportive care in this population is heterogeneous, encompassing physical, psychological, social, and spiritual domains, and is methodologically diverse, involving qualitative, quantitative, and mixed-methods studies that have not yet been comprehensively synthesized ([Manuilova et al., 2024](#); [Sher et al., 2025](#)). This approach allows for the inclusion of various study designs and types of evidence from diverse healthcare settings, supporting the exploration of broad questions regarding priorities and patients' real-world experiences. Additionally, this review can provide important information regarding the feasibility of conducting a systematic review in the future and highlight where critical evidence gaps still exist in efforts to strengthen patient-centered care in HD units.

The review questions were developed using the PCC framework recommended by the Joanna Briggs Institute for scoping reviews. The population (P) comprised adults with CKD undergoing maintenance HD; the concept (C) focused on supportive care needs and patient preferences; and the context (C) encompassed HD care settings across different healthcare systems and sociocultural environments. This scoping review aims to map and synthesize the scientific evidence regarding supportive care needs and patient preferences among patients with CKD undergoing maintenance HD. Specifically, this review is designed to address the following research questions:

1. To what extent do the scope and characteristics of existing scientific

evidence regarding supportive care needs and patient preferences apply to CKD patients undergoing maintenance HD?

2. What specific supportive care needs (physical, psychological, social, and spiritual) and care preferences (related to treatment, care delivery, and shared decision-making) are reported by patients?
3. How do these supportive care needs and patient preferences vary across different healthcare settings and socio-demographic contexts, such as financial status and level of social support?

Collectively, these questions were designed to explore the multidimensional aspects of patients' needs and the alignment of healthcare services with their personal values, thereby providing a comprehensive understanding of the role of integrated supportive care in improving quality of life through a holistic and patient-centered approach. Consistent with the PCC framework, this review sought to map the available evidence concerning supportive care needs and patient preferences among adults receiving maintenance HD and to identify how these needs and preferences are influenced by different care contexts.

A review protocol was developed prior to study commencement to guide the review process; however, it was not formally registered in the Open Science Framework or another public repository. The protocol specified the review objectives, eligibility criteria, search strategy, and data charting procedures before the literature search was undertaken.

Eligibility Criteria

The eligibility criteria for articles included (1) studies involving adult patients with CKD who were currently undergoing maintenance HD; (2) eligible study designs included randomized controlled trials

(RCTs), experimental studies, qualitative studies, cross-sectional studies, cohort studies, systematic reviews, and meta-analyses. This approach is consistent with the purpose of a scoping review, which aims to comprehensively map the extent, range, and nature of available evidence rather than evaluate the effectiveness of a specific intervention. Including diverse study designs enabled the review to capture both quantitative evidence regarding supportive care needs and qualitative insights into patients' experiences, values, and preferences, thereby providing a more comprehensive understanding of patient-centered supportive care among individuals receiving maintenance HD; (3) search results limited to Indonesian and English, with a publication period between 2021 and 2026. This decision was made because the research team is fluent only in those two languages, to ensure that quality assessment and data extraction could be conducted reliably. Methodologically, language restriction is an acceptable approach to ensure the accuracy and consistency of the evidence synthesis given available resources ([Dobrescu et al., 2021](#)). Additionally, the time restriction aims to identify results relevant to current clinical conditions and contemporary healthcare infrastructure, such as recent developments in CKD, so that the findings are more applicable in clinical practice. Exclusion criteria for this review include (1) patients undergoing peritoneal dialysis only; (2) kidney transplant recipients not undergoing HD, or patients with acute kidney injury; (3) studies focusing solely on clinical outcomes (e.g., biomedical parameters) without assessing the need for supportive care or patient preferences; and (4) gray literature. Gray literature may be included, particularly if the academic discussion is well-developed, there are clear quality standards for journal sources, and it has undergone a peer-review process,

thereby making it more credible ([Nair & Borkar, 2023](#)). Therefore, gray literature was excluded because its methodological quality and reporting standards often vary and are difficult to evaluate consistently. By limiting this review to peer-reviewed publications, a more rigorous and transparent synthesis of the evidence regarding supportive care needs and patient preferences among patients undergoing maintenance HD can be conducted.

The inclusion and exclusion criteria in this review were designed to ensure that the evidence gathered is truly relevant and reliable for the target population. Limiting the articles to patients undergoing routine HD ensures that the findings specifically describe the physical, psychological, social, and spiritual needs within that care setting. The restriction on publication year is intended to yield up-to-date results aligned with the global shift toward patient-centered care and holistic management in nephrology. The exclusion of studies focusing solely on clinical parameters aims to keep the synthesis centered on the human experience, including emotional distress and treatment preferences, which are often overlooked in traditional disease-centered models. By including various study designs, including qualitative, quantitative, and mixed-methods approaches, this review provides a comprehensive mapping of the evidence while maintaining high standards of credibility through peer-reviewed scientific journals.

Information Sources

The literature search for this scoping review was conducted systematically across four major electronic databases: PubMed, Scopus, ScienceDirect, and EBSCOhost. These databases were selected because they provide extensive coverage of biomedical, nursing, allied health, and multidisciplinary literature relevant to CKD,

HD, supportive care, and patient-centered healthcare. In addition, the reference lists of all included studies were manually screened through backward citation tracking to identify potentially relevant articles that were not retrieved through the electronic searches. The database search was initially conducted on May 25, 2026. Web of Science, CINAHL, and ProQuest were not searched because substantial overlap exists between these databases and the selected sources, particularly regarding peer-reviewed literature in nephrology, nursing, and health sciences. EBSCOhost was included as a multidisciplinary platform providing access to several health-related databases, thereby broadening the scope of retrieval while minimizing duplication. Given the exploratory nature of this scoping review and resource considerations, the selected databases were considered sufficient to capture the breadth of evidence relevant to the review objectives. Gray literature, including theses, dissertations, conference proceedings, policy documents, and unpublished reports, was excluded because these sources often demonstrate heterogeneous methodological quality, limited peer-review processes, and inconsistent reporting standards. Restricting the review to peer-reviewed publications enhanced the rigor, transparency, reproducibility, and credibility of the evidence synthesis. Furthermore, the review aimed to synthesize evidence from studies with clearly reported methodologies to support the development of evidence-based recommendations regarding supportive care needs and patient preferences among patients receiving maintenance HD.

Search Strategy

The search strategy was developed using the PCC framework recommended for scoping reviews to ensure alignment between the review objectives, eligibility

criteria, and search terms. In this review, the Population comprised adults with CKD receiving maintenance HD; the Concept focused on supportive care needs and patient preferences, including physical, psychological, social, spiritual, informational, and practical dimensions; and the Context encompassed diverse HD care settings. Prior to the formal search, a pilot search was conducted in PubMed to identify relevant keywords, Medical Subject Headings (MeSH), and index terms used in the literature. The search terms were subsequently refined through iterative discussions among the review team to improve the sensitivity and specificity of the search strategy. A comprehensive literature search was then performed in PubMed, Scopus, ScienceDirect, and EBSCOhost. Search terms were combined using Boolean operators (AND, OR), truncation symbols, and database-specific subject headings where applicable. To maximize retrieval of relevant studies, search strategies were adapted to the indexing systems and search functionalities of each database while maintaining conceptual consistency across sources. All search strings, filters, limits, and database-specific adaptations were predefined and applied systematically.

To ensure transparency and reproducibility, the complete search strategies for all databases, including the full search strings, Boolean operators, field restrictions, and search limits, are provided in Supplementary File S1. These supplementary materials enable replication of the search process and facilitate methodological appraisal of the review. Search keywords and terms are tailored to each database and combined using Boolean operators. The terms used include:

(CKD OR chronic kidney disease OR renal disease OR renal failure OR kidney disease OR kidney failure) AND (psychological OR mental health OR psychological well-being OR emotional)

AND (spirituality OR spiritual care OR spiritual needs).

Similar search terms were adapted for ScienceDirect using appropriate column tags and syntax, namely:

(chronic kidney disease OR renal failure) AND (psychological) AND (spirituality)

Additionally, the search was tailored to include all source types to enhance search results. This strategy aims to ensure that the identified literature covers a wide range of supportive care needs and patient preferences for those undergoing HD, using a holistic and patient-centered care approach.

Selection Process

The literature search for this study was conducted systematically and comprehensively using four electronic databases: PubMed, ScienceDirect, Scopus, and EBSCOhost. The initial search identified 1,454 records, including 210 from PubMed, 257 from ScienceDirect, 729 from Scopus, and 258 from EBSCOhost. All retrieved records were exported to reference management software, and duplicate records were removed prior to screening. A total of 307 duplicates were identified and excluded, leaving 1,147 records for title and abstract screening. The screening and study selection process was conducted by the review team using predefined inclusion and exclusion criteria. During the title and abstract screening stage, 608 records published before 2021 were excluded. The remaining 539 articles underwent full-text assessment for eligibility. Any uncertainties regarding study eligibility were discussed among the review team until consensus was reached. Following full-text review, 523 articles were excluded because they did not meet the review objectives or eligibility criteria, including 78 studies unrelated to CKD and 445 studies that did not address supportive care needs or patient

preferences. Ultimately, 12 studies met all eligibility criteria and were included in the final review. These studies subsequently underwent methodological quality appraisal using the JBI critical appraisal tools. The study selection process is presented in the PRISMA flow diagram (see Figure 1) to ensure transparency and reproducibility of the review process.

Data Collection Process

The initial literature search was conducted by the first author using four electronic databases (PubMed, ScienceDirect, Scopus, and EBSCOhost). The retrieved records were managed using reference management software (Mendeley and EndNote), and duplicate records were identified and removed prior to the screening process. After removing duplicates, titles and abstracts were screened based on predefined eligibility criteria, thereby excluding studies published before 2021 and those clearly irrelevant to the review's objectives. A structured data extraction form was developed by the review team based on the review's objectives, the PCC framework, and key variables of focus, including study characteristics, population, supportive care needs, patient preferences, context, methodology, and key findings. Formal inter-rater reliability statistics were not calculated; however, consistency was enhanced through cross-checking and consensus discussions among the review team. Full-text screening and data extraction were then conducted by the review team using a standardized extraction template. To improve consistency and reduce potential bias, the extracted data were reviewed through cross-checking among team members. Any discrepancies regarding study eligibility, data interpretation, or extracted information were resolved through discussion and consensus among the

authors. The final dataset was verified prior to synthesis to ensure completeness, accuracy, and alignment with the review's objectives. Studies meeting the eligibility criteria then underwent methodological quality assessment using the JBI Critical Appraisal Tool.

Data Charting Process

A systematic data charting process was undertaken in accordance with the Arksey and O'Malley scoping review framework, the JBI methodology, and the PRISMA-ScR reporting guidelines. Following study identification, screening, eligibility assessment, and inclusion, data from the 12 eligible studies were extracted into a structured charting table developed by the review team. The charting framework was informed by the PCC framework and included study characteristics (author, year, country, and study design), population characteristics, supportive care needs, patient preferences, healthcare context, methods, and key findings relevant to the review objectives. To enhance consistency during data charting, the extracted information and categorization process were reviewed and discussed among all authors. Any uncertainties regarding study classification, interpretation of findings, or assignment of evidence to thematic categories were resolved through team discussion and consensus. The final charted data were subsequently used to support descriptive synthesis, thematic mapping, and methodological appraisal using the JBI critical appraisal tools. To improve transparency and reproducibility, the data-charting framework used in this review is presented in Supplementary File S2.

The synthesis of results was conducted using a thematic synthesis approach to identify patterns and recurring concepts across the included studies. Following data charting, findings related to supportive care needs, patient preferences, implementation

barriers, and supportive care strategies were extracted from each study and reviewed repeatedly by the research team. Initial codes were generated inductively from the reported findings and grouped according to conceptual similarities. Examples of initial codes included fatigue, pain, pruritus, anxiety, depression, family support, spiritual support, communication preferences, shared decision-making, financial burden, and healthcare resource limitations. The codes were subsequently compared and organized into broader categories representing related concepts. For example, fatigue, pain, sleep disturbance, and pruritus were categorized as physical supportive care needs, whereas anxiety, depression, and emotional distress were categorized as psychological supportive care needs. Through an iterative process of comparison, refinement, and discussion among the author's, related categories were merged into higher-order themes that reflected the overall patterns within the evidence base. Any uncertainties regarding coding, category assignment, or theme development were resolved through consensus discussions among the review team (Supplementary File S4).

This process resulted in four overarching themes: (1) multidimensional supportive care needs, (2) patient preferences for patient-centered care, (3) barriers to supportive care implementation, and (4) strategies to strengthen KSC. These themes were used to organize the narrative synthesis and evidence mapping presented in the Results section.

Data Items

Data items were selected and operationally defined according to the PCC framework to ensure alignment with the review objectives and research questions. The selected variables were intended to comprehensively map the characteristics of the available evidence, identify the

multidimensional supportive care needs of patients receiving maintenance HD, and explore patient preferences regarding healthcare delivery. For the Population component, data extracted included publication year (2021–2026), country of study, study design, sample characteristics, and the target population of adult patients with CKD receiving maintenance HD. These variables were collected to describe the scope, geographical distribution, and methodological characteristics of the existing evidence. For the Concept component, data were extracted on supportive care needs and patient preferences, which constituted the primary phenomena of interest in this review. Supportive care needs were operationally defined as physical, psychological, emotional, social, spiritual, informational, practical, and financial needs reported by patients undergoing maintenance HD. Patient preferences were defined as patients' expressed values, expectations, and choices regarding treatment, communication, care delivery, family involvement, shared decision-making, and end-of-life care. Data were also collected on measurement instruments used to assess these concepts, including the EQ-5D-5L (questionnaire designed to measure a person's health-related quality of life), EQ-5D-3L (descriptive system comprises the following five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression), KDQOL-SF (disease-targeted items focus on particular health-related concerns of individuals with kidney disease and on dialysis), IPOS & IPOS-Renal (questionnaire the most common symptoms experienced by patients with kidney failure), KPS (11-point, percentage-based tool used to measure the functional impairment, functional status, and overall quality of life in CKD and End-Stage Renal Disease patients) and COM-B framework, as well as the analytical approaches employed

by each study. These variables were selected because they provide important information regarding the assessment, reporting, and interpretation of supportive care needs and patient preferences. For the Context component, data extraction focused on healthcare settings and contextual factors that may influence supportive care experiences and preferences. These variables included symptom burden (e.g., fatigue, pain, depression, anxiety), quality-of-life outcomes, implementation of KSC, financial burden, social support, caregiver involvement, healthcare infrastructure, and barriers and facilitators to supportive care delivery. These contextual variables were included because previous evidence suggests that supportive care needs and patient preferences are shaped by both individual and healthcare-system factors. Collectively, the selected data items enabled a comprehensive mapping of evidence related to supportive care needs and patient preferences among patients receiving maintenance HD.

Critical Appraisal of Individual Sources of Evidence

Critical appraisal was undertaken to provide an assessment of the methodological rigor and potential limitations of the included evidence. Given the heterogeneity of the literature on supportive care needs and patient preferences among patients receiving maintenance HD, methodological quality was evaluated using the Joanna Briggs Institute (JBI) Critical Appraisal Tools appropriate to each study design. Specifically, the JBI Checklist for Qualitative Research was applied to qualitative studies, the JBI Checklist for Analytical Cross-Sectional Studies was applied to cross-sectional studies, and the JBI Checklist for Systematic Reviews and Research Syntheses was applied to systematic reviews. Each checklist item was assessed

as “Yes,” “No,” “Unclear,” or “Not Applicable” according to JBI guidance. The appraisal process focused on evaluating methodological transparency, participant selection, data collection procedures, measurement validity, analytical rigor, and the credibility of study findings. Rather than using appraisal results as exclusion criteria, methodological quality assessment was conducted to support interpretation of the evidence and to identify potential strengths and limitations across the included studies. The appraisal findings were incorporated into the narrative synthesis and evidence mapping process. Studies with methodological limitations were retained because the objective of a scoping review is to map the breadth of available evidence rather than exclude studies solely on the basis of quality. However, the identified methodological strengths and weaknesses were considered when interpreting findings, identifying evidence gaps, and formulating recommendations for future research. The detailed appraisal results for each study are presented in Figure 3 and Supplementary File S3.

Consultation to Expert

In the process of identifying gaps and providing context for the mapped literature on supportive care needs and patient preferences among patients with CKD undergoing maintenance HD, we evaluated the methodological quality and relevance of the included studies using the JBI critical appraisal tools (Aromataris et al., 2022). In accordance with the Arksey and O'Malley scoping review framework, consultation with experts and stakeholders is considered an optional stage that may complement the literature review process (Buus et al., 2022). Therefore, this component was not undertaken in the present review. The decision not to conduct expert or stakeholder consultation was made to maintain a transparent and reproducible

evidence-mapping process based solely on published literature and predefined eligibility criteria. Consistent with JBI and PRISMA-ScR guidance, the review prioritized systematic identification, selection, appraisal, and synthesis of available evidence (Thijssen et al., 2024; Wolfenden et al., 2022). Consequently, assessments of study relevance and quality were conducted through team-based review and consensus rather than external expert input. However, the absence of a consultation phase may have limited the contextual interpretation and practical application of the findings. Expert clinicians, patients, caregivers, and other stakeholders may have provided additional insights regarding local implementation challenges, cultural considerations, service delivery priorities, and emerging supportive care needs that are not fully represented in the published literature. As a result, some context-specific knowledge relevant to the translation of evidence into clinical practice may not have been captured. Nevertheless, the inclusion of studies from diverse countries, healthcare settings, and methodological approaches allowed the review to provide a broad overview of supportive care needs and patient preferences among individuals receiving maintenance HD while identifying areas that may benefit from future stakeholder engagement and knowledge translation activities.

Synthesis of Results

The synthesis of results was conducted using a thematic synthesis approach to summarize and organize the charted data from the included studies. Findings related to supportive care needs, patient preferences, implementation barriers, and supportive care strategies were extracted and reviewed repeatedly by the research team. Initial codes were generated inductively from the study findings and

grouped based on conceptual similarities. Related codes were then categorized into broader domains and refined through an iterative process of comparison and discussion among the authors. Any discrepancies were resolved through consensus. This process resulted in four overarching themes: (1) multidimensional supportive care needs, (2) patient preferences for patient-centered care, (3) barriers to Kidney Supportive Care implementation, and (4) strategies to strengthen Kidney Supportive Care, which formed the basis of the narrative synthesis and evidence mapping.

Results

Selection of Sources of Evidence

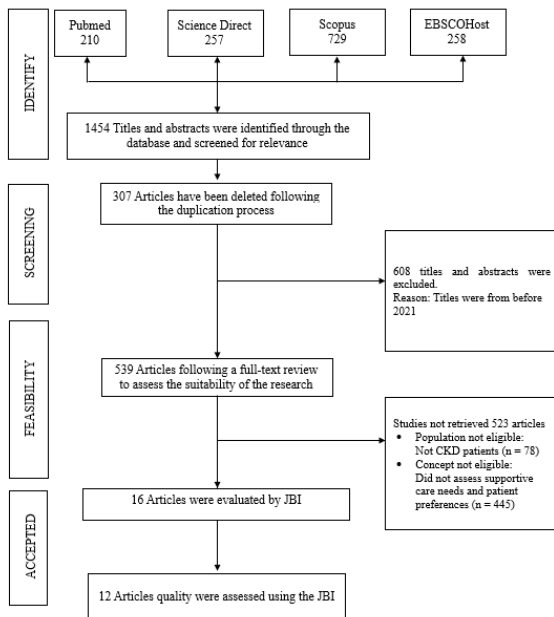


Figure 1. Illustrates the PRISMA-ScR screening process.

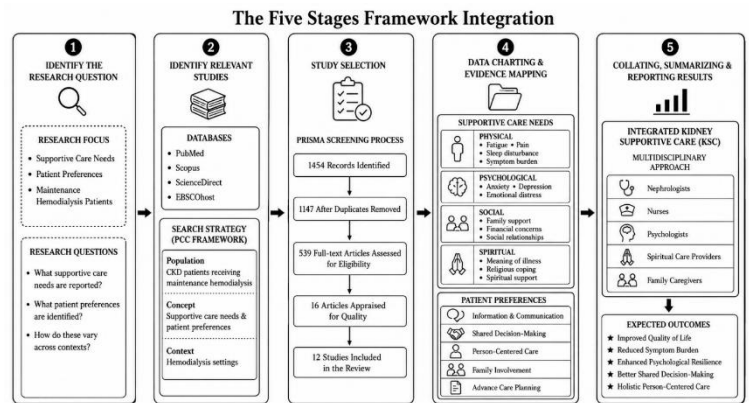


Figure 2. Illustrate The Five Stages Framework Integration

The conduct of this scoping review followed the five core stages of the methodological framework established by Arksey and O'Malley and further refined by JBI. These stages include identifying the research question, conducting a comprehensive search for relevant studies, selecting evidence based on predefined inclusion and exclusion criteria, charting and categorizing data, and synthesizing and reporting the findings. To ensure the study remains focused and structured, the PCC (Population, Concept, Context) framework was used to operationally define key variables: population (CKD patients undergoing HD), concept (needs for supportive care and patient preferences), and context (various HD service settings). Adherence to the PRISMA-ScR guidelines ensures that the entire process is conducted transparently, is replicable, and is clearly documented through flowcharts. This methodological approach was chosen for its strength in mapping the scope of heterogeneous literature and identifying research gaps, making it more suitable for exploring broad questions regarding multidimensional supportive care needs (physical, psychological, social, and spiritual) than a narrow systematic review. Although the Arksey and O'Malley framework includes an expert consultation

stage, the implementation of this review prioritized a transparent and traceable literature mapping phase in accordance with JBI and PRISMA-ScR standards. Therefore, it was decided to omit the consultation component to focus entirely on synthesizing the available literature evidence (**Figure 1** and **Figure 2**).

Characteristics of Sources of Evidence

The reviewed literature encompasses a variety of research designs employing rigorous methodologies, ranging from qualitative studies (exploratory-descriptive and interpretive phenomenological) and quantitative studies (cross-sectional, longitudinal, and retrospective) to systematic reviews that provide a global synthesis of the evidence. Geographically, these sources have a broad international scope, covering research in Asia (China, Indonesia, Sri Lanka, Jordan, and India), Europe (England and Northern Ireland),

North America (Canada), and Africa (Ghana). The primary focus of this literature is on supportive care needs, encompassing physical, psychological, social, and spiritual dimensions, as well as the management of symptom burdens such as fatigue, pain, itching, and dry mouth. Additionally, this literature strongly emphasizes the role of multidisciplinary care teams (including nurses, nephrologists, psychologists, and dietitians) as well as the empowerment of family caregivers (informal caregivers) through adaptive strategies and emotional support to overcome barriers in long-term care. The target population generally consists of adult and elderly patients with CKD undergoing HD, including those with comorbidities such as diabetes and hypertension. The shared ultimate goal of this entire literature is to optimize symptom management, improve quality of life, and ensure the delivery of healthcare that aligns with patients' personal preferences and values (**Table 1** and **Table 2**).

Critical Appraisal Within Sources of Evidence

Table 1. Illustrates the JBI Appraisal Findings: Supportive Care Needs and Patient Preferences Among CKD Patients

Title & Source (Author, Year)	Study (Design)	Sampling & Comparability	Measurement & Outcomes	Confounding Management	Risk of Bias Interpretation	Quality Category	Assessment Result (Yes, No, Unclear, NA)	Overall Internal Validity	Applicability
Exploring Nurses' Supportive Care Practices for Managing Patients with Chronic Kidney Disease (CKD) in a Tertiary Care Facility in Ghana (Akpakli Addo & Senoo-Dogbey, 2025)	Qualitative (Exploratory descriptive)	Purposive sampling of 18 nurses from a tertiary dialysis unit in Ghana.	Semi-structured interviews exploring Kidney Supportive Care (KSC) awareness.	Data triangulation, reflexivity, and attainment of data saturation.	Low Risk: Followed Lincoln & Guba's criteria for trustworthiness with data saturation.	High Quality	Yes: 10, No: 0, Unclear: 0, NA: 0	High; followed Lincoln & Guba's criteria for trustworthiness.	Highly relevant for understanding barriers to psychosocial care in African clinical settings.
Level of Depression and Anxiety on Quality of Life Among Patients Undergoing Hemodialysis (Alshelleh et al., 2023)	Quantitative (Cross-sectional)	Convenience sample of 66 patients from one dialysis unit in Jordan.	Used PHQ9, GAD7, and WHOQOL-BREF instruments.	Statistical analysis comparing various socio-demographic variables.	Moderate Risk: Limited by small sample size and single-center design.	Moderate Quality	Yes: 8, No: 0, Unclear: 0, NA: 0	Moderate; limited by small sample size and single-center design.	Essential for routine mental health screening protocols in hemodialysis patients.
"You need a team": perspectives on interdisciplinary symptom management using patient-reported outcome measures in hemodialysis care—a	Qualitative (Descriptive approach)	Purposive sampling with maximum variation (patients, clinicians, caregivers).	In-depth interviews and field observations related to PROM usage.	Double team coding, iterative discussion, and reflexive thematic analysis.	Low Risk: Rigorous qualitative methodology with double team coding and reflexivity.	High Quality	Yes: 10, No: 0, Unclear: 0, NA: 0	High; part of a large RCT with rigorous qualitative methodology.	Highly applicable for integrating interdisciplinary symptom management in HD units.



qualitative study (Baragar et al., 2023)									
Depression and anxiety in people with kidney disease: understanding symptom variability, patient experience and preferences for mental health support (Chilcot et al., 2025)	Quantitative (Cross-sectional online survey)	458 participants from 56 UK kidney services and social media.	Depression (PHQ-8), anxiety (GAD-7) screening, and COM-B framework.	Case-mix adjusted linear mixed regression models.	Low Risk: Large sample size with robust multi-center statistical analysis.	High Quality	Yes: 8, No: 0, Unclear: 0, NA: 0	High; large sample with robust statistical and multi-center analysis.	Very relevant for designing integrated psychosocial support services.
Profiling mortality patterns and place of death in patients on maintenance hemodialysis: a retrospective study in a tertiary care academic hospital in India (Gayathri M et al., 2025)	Quantitative (Retrospective study)	280 patient medical records in an Indian academic hospital.	IPOS evaluation, mortality patterns, and out-of-pocket financial burden.	Statistical comparison between home vs. hospital deaths.	Moderate Risk: Retrospective design with potential data gaps on home deaths.	Moderate Quality	Yes: 7, No: 0, Unclear: 1, NA: 0	Moderate; retrospective design with potential data gaps on home deaths.	Relevant for strengthening end-of-life care protocols and ACP.
Factors Associated with Symptom Burden in Adults with Chronic Kidney Disease Undergoing Hemodialysis: A Prospective Study (Gunarathne et al., 2022)	Quantitative (Cross-sectional & longitudinal)	118 patients at baseline and 102 at 6-month follow-up in Sri Lanka.	CKDSI-SL, PSS-10, BIPQ, and social support (SSQ6) scales.	Multiple linear regression to determine symptom burden determinants.	Low Risk: Prospective design using culturally validated instruments.	High Quality	Yes: 8, No: 0, Unclear: 0, NA: 0	High; prospective design with culturally validated instruments.	Crucial for identifying stress and illness perception as symptom triggers.
Palliative Care Needs and Symptom Burden in Patients Undergoing Maintenance Hemodialysis: A Systematic Review (Haneef & Abdullah, 2024)	Systematic Review	Synthesis of 9 selected studies via PubMed and ScienceDirect searches.	Quality assessment using the Newcastle-Ottawa Scale (NOS).	Screening and data extraction performed by two independent researchers.	Low Risk: Systematic methodology with independent extraction and NOS assessment.	High Quality	Yes: 11, No: 0, Unclear: 0, NA: 0	High; systematic methodology with transparent finding validation.	Provides a strong basis for the importance of early palliative care for HD patients.
Emotional Support and Family Strategies for Patients with Chronic Kidney Disease Undergoing Hemodialysis (Kristian et al., 2025)	Qualitative (Interpretative phenomenological)	Purposive sampling of 12 family members at a hospital in Indonesia.	Semi-structured in-depth interviews and IPA analysis.	Data triangulation, member checking, and rich narrative description.	Low Risk: High credibility through data triangulation and member checking.	High Quality	Yes: 10, No: 0, Unclear: 0, NA: 0	High; ensures credibility and authenticity of family subjective experiences.	Highly relevant for developing family-centered care models in Indonesia.
Mental health status and quality of life in patients with end-stage renal disease undergoing maintenance hemodialysis (Ma et al., 2021)	Quantitative (Observational, cross-sectional)	190 patients from one hemodialysis center in Shanghai, China.	Mandarin versions of SCL-90 and KDQOL-SF questionnaires.	Stepwise linear regression to control for clinical and laboratory variables.	Low Risk: High internal validity with statistical control for clinical variables.	High Quality	Yes: 8, No: 0, Unclear: 0, NA: 0	High; face-to-face interviews with detailed clinical data collection.	Useful for clinicians in adopting early interventions to improve QOL.
Exploring the unmet needs and experiences of informal caregivers of patients with end-stage kidney disease (ESKD) receiving haemodialysis – a qualitative study (Matthews et al., 2024)	Qualitative study (Semi-structured interviews)	Purposive sampling of 24 informal caregivers in Northern Ireland.	In-depth interviews, thematic analysis, and NVIVO usage.	Researcher reflexivity and audit trail for process transparency.	Low Risk: Strong transparency with audit trail and researcher reflexivity.	High Quality	Yes: 10, No: 0, Unclear: 0, NA: 0	High; provides deep understanding of neglected caregiver needs.	Vital for designing supportive interventions for families of ESKD patients.
Palliative care needs and symptom	Quantitative (Cross-sectional)	236 patients (divided by younger vs.	POS, DSI, and EQ-5D-3L instruments.	Inter-group age comparisons	Low Risk: Good instrument reliability and	High Quality	Yes: 8, No: 0, Unclear: 0, NA: 0	High; good instrument reliability and	Highlights higher priority of palliative

burden in younger and older patients with end-stage renal disease undergoing maintenance hemodialysis: A cross-sectional study (X. Wang et al., 2022)	Quantitative (Cross-sectional)	305 participants from two hemodialysis centers in China.	Latent Profile Analysis (LPA) on the POS instrument.	Multinomial logistic regression to identify unmet needs risk factors.	Low Risk: Advanced statistical methods (LPA) to address heterogeneity.	High Quality	Yes: 8, No: 0, Unclear: 0, NA: 0	High; use of advanced statistics to address population heterogeneity.	needs in elderly patients. Excellent for identifying priority groups requiring palliative care.
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Results of Individual Sources of Evidence

Table 2. Summarizes Characteristics of Included Studies.

Title & Source (Author, Year)	Country	Study Design	Sample Size	Main Findings	Theme 1 Needs	Theme 2 Preferences	Theme 3 Barriers	Theme 4 Strategies
Exploring Nurses' Supportive Care Practices for Managing Patients with Chronic Kidney Disease (CKD) in a Tertiary Care Facility in Ghana (Akpakli Addo & Senoo-Dogbey, 2025)	Ghana	Qualitative (Descriptive Exploratory)	18 participants	Nurses are aware of supportive care, but practice still focuses on life extension; psychosocial support is often informal and unstructured.	✓	✓	✓	✓
Level of Depression and Anxiety on Quality of Life Among Patients Undergoing Hemodialysis (Alshelleh et al., 2023)	Jordan	Cross-sectional	66 patients	High prevalence of depression (92.4%) and anxiety (83.3%) in hemodialysis patients, which negatively correlates with their quality of life.	✓	✓		✓
"You need a team": perspectives on interdisciplinary symptom management using patient-reported outcome measures in hemodialysis care—a qualitative study (Baragar et al., 2023)	Canada	Descriptive Qualitative	54 participants (33 clinicians, 20 patients, 1 caregiver)	Use of Patient-Reported Outcome Measures (PROMs) helps highlight symptom complexity, clarify interdisciplinary team roles, and reshape patient expectations.	✓	✓	✓	✓
Depression and anxiety in people with kidney disease: understanding symptom variability, patient experience and preferences for mental health support (Chilcot et al., 2025)	United Kingdom (UK)	Cross-sectional (Online Survey)	458 participants	Moderate-to-severe symptoms of depression (37.7%) and anxiety (26.5%) are common; sleep issues and fatigue are key support needs for the future.	✓	✓	✓	✓
Profiling mortality patterns and place of death in patients on maintenance hemodialysis: a retrospective study	India	Retrospective (Medical Record Review)	280 patients	Most patients (73.5%) died in hospital (primarily ICU); high symptom burden (edema, fatigue)	✓	✓	✓	✓



Title & Source (Author, Year)	Country	Study Design	Sample Size	Main Findings	Theme 1 Needs	Theme 2 Preferences	Theme 3 Barriers	Theme 4 Strategies
in a tertiary care academic hospital in India (Gayathri M et al., 2025)				but documentation of end-of-life planning remains low.				
Factors Associated with Symptom Burden in Adults with Chronic Kidney Disease Undergoing Hemodialysis: A Prospective Study (Gunarathne et al., 2022)	Sri Lanka	Cross-sectional & Longitudinal	118 patients (baseline), 102 (6 months)	High stress levels and illness perception are key determinants of symptom burden; poor social support exacerbates this burden.	✓		✓	✓
Palliative Care Needs and Symptom Burden in Patients Undergoing Maintenance Hemodialysis: A Systematic Review (Haneef & Abdullah, 2024)	Saudi Arabia (Author/ Journal)	Systematic Review	9 studies	Hemodialysis patients have significant palliative care needs and an extensive symptom burden (pain, itching, fatigue) that impairs quality of life.	✓		✓	✓
Emotional Support and Family Strategies for Patients with Chronic Kidney Disease Undergoing Hemodialysis (Kristian et al., 2025)	Indonesia	Qualitative (Interpretative Phenomenology)	12 participants	Families are the main emotional support system and a source of resilience, but they face psychosocial challenges such as guilt and isolation.	✓	✓		✓
Mental health status and quality of life in patients with end-stage renal disease undergoing maintenance hemodialysis (Ma et al., 2021)	China	Observational Cross-sectional	190 patients	Poor mental health status (depression, somatization) is significantly associated with decreased quality of life (QOL) in hemodialysis patients.	✓			✓
Exploring the unmet needs and experiences of informal caregivers of patients with end-stage kidney disease (ESKD) receiving haemodialysis – a qualitative study (Matthews et al., 2024)	Northern Ireland (UK)	Qualitative (Semi-Structured Interviews)	24 informal caregivers	Informal caregivers experience emotional distress, isolation, and a lack of information regarding the complexity of kidney care.	✓	✓	✓	✓
Palliative care needs and symptom burden in younger and older patients with end-stage renal disease undergoing maintenance hemodialysis: A cross-sectional study (X. Wang et al., 2022)	China	Cross-sectional	236 patients	Patients have moderate palliative care needs; elderly patients experience a heavier symptom burden compared to younger patients.	✓	✓		✓
Exploring the influencing factors of unmet palliative care needs in Chinese patients with end-stage renal disease	China	Cross-sectional	305 participants	Nearly half of the patients have moderate to severe palliative needs, influenced by functional	✓		✓	✓

Title & Source (Author, Year)	Country	Study Design	Sample Size	Main Findings	Theme 1 Needs	Theme 2 Preferences	Theme 3 Barriers	Theme 4 Strategies
undergoing maintenance hemodialysis: a cross-sectional study (X. Wang et al., 2023)				status, health literacy, and financial pressure.				

Synthesis of Results

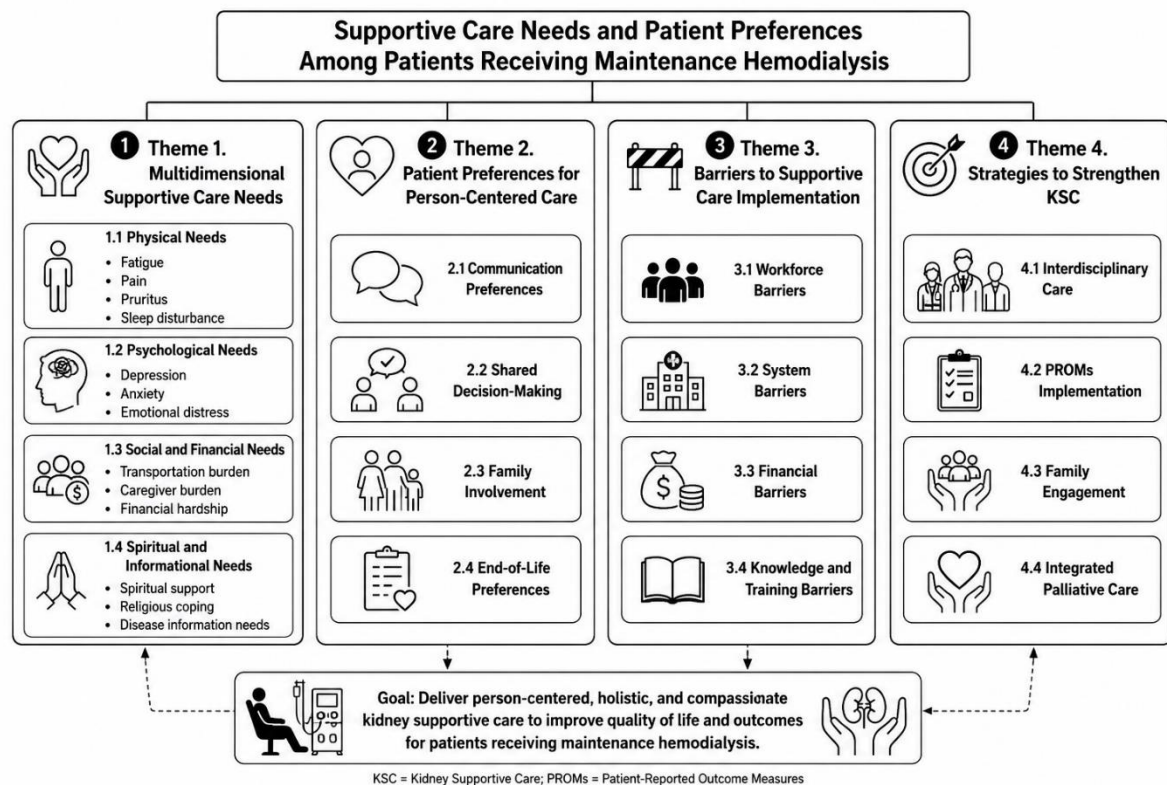


Figure 5. Illustrates The Thematic Mapping Framework: Supportive Care Needs and Patient Preferences Among CKD Patients.

Based on the reviewed studies, the evidence was synthesized into four overarching themes: (1) Multidimensional Supportive Care Needs, (2) Patient Preferences for Patient-centered Care, (3) Barriers to Supportive Care Implementation, and (4) Strategies to Strengthen KSC. The first theme, Multidimensional Supportive Care Needs, highlights the broad spectrum of unmet needs experienced by patients undergoing maintenance HD. These include physical symptoms such as fatigue, pruritus, pain, and sleep disturbances, as well as

substantial psychological distress, with reported prevalence rates of depression reaching 92% and anxiety 83% in some populations (Alshelleh et al., 2023). Patients also reported social, financial, informational, and spiritual needs, including assistance with out-of-pocket healthcare costs, transportation, disease-related education, and support for spiritual well-being (Akpakli Addo & Senoo-Dogbey, 2025; Gayathri M et al., 2025; X. Wang et al., 2022, 2023). The second theme, Patient Preferences for Patient-centered Care, reflects patients’ desire for healthcare services that align with their personal



values, beliefs, and life goals. Across studies, patients consistently emphasized the importance of quality of life and comfort over aggressive life-prolonging interventions, particularly in advanced stages of illness. Preferences included clear and culturally appropriate communication, the use of understandable language free from excessive medical terminology, active participation in shared decision-making, family involvement in care planning, and the integration of spiritual beliefs and religious practices into routine care ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Baragar et al., 2023](#); [Haneef & Abdullah, 2024](#); [Matthews et al., 2024](#)) (**Figure 3**).

The third theme, Barriers to Supportive Care Implementation, identifies several systemic and organizational challenges that hinder the delivery of comprehensive supportive care. These barriers include limited formal training in supportive and palliative care, inadequate psychosocial service provision, the absence of standardized supportive care protocols, workforce shortages, time constraints, and financial burdens experienced by both patients and healthcare systems ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Kristian et al., 2025](#)). The fourth theme, Strategies to Strengthen KSC, encompasses approaches that may enhance the delivery of holistic and patient-centered care. Key strategies identified across the literature include the integration of interdisciplinary care teams, implementation of patient-reported outcome measures (PROMs) such as IPOS-Renal, application of behavioral frameworks such as COM-B to support patient engagement and self-management, strengthening family involvement, and embedding supportive and palliative care principles within routine nephrology services ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Gayathri M et al., 2025](#); [Haneef & Abdullah, 2024](#); [X. Wang et al., 2023](#)). Collectively, these strategies aim to improve

symptom management, support patient autonomy, and promote the delivery of compassionate, culturally responsive, and patient-centered KSC.

Table 3. Illustrates Evidence Density Map

Domain	Number of Studies
Physical Needs	10
Psychological Needs	8
Social Needs	6
Spiritual Needs	5
Communication Preferences	7
Shared Decision-Making	6
Family Involvement	5
End-of-Life Preferences	4

Overall, the evidence was concentrated within the theme of Multidimensional Supportive Care Needs, particularly in the domains of physical and psychological needs. Symptoms such as fatigue, pain, pruritus, depression, and anxiety were consistently reported across multiple studies, indicating that symptom burden remains the most extensively investigated aspect of supportive care among patients receiving maintenance HD. The theme of Patient Preferences for Patient-centered Care was supported by a moderate number of studies, with communication preferences and shared decision-making being the most frequently reported subthemes. In contrast, family involvement and end-of-life preferences were less commonly addressed, suggesting that these aspects remain underexplored despite their importance in PROMs. Evidence related to Barriers to Supportive Care Implementation was primarily focused on workforce and health-system challenges, including inadequate staffing, limited supportive care training, and the absence of standardized care pathways. Financial and knowledge-related barriers were reported less frequently, indicating a need for further investigation into structural and

educational determinants of supportive care delivery (**Table 3**).

Within the theme of Strategies to Strengthen KSC, interdisciplinary care models and the use of PROMs received the greatest attention. However, relatively few studies evaluated family engagement strategies or the integration of palliative care into routine nephrology services. This finding highlights an important evidence gap regarding the implementation and effectiveness of comprehensive patient-centered supportive care interventions. Taken together, the evidence density map demonstrates that current research predominantly focuses on identifying supportive care needs, whereas comparatively fewer studies investigate implementation strategies and patient-centered interventions. These findings suggest the need for future research that moves beyond needs assessment toward the development, implementation, and evaluation of integrated KSC models.

Discussion

Principal Findings

This scoping review mapped the available evidence regarding supportive care needs and patient preferences among individuals receiving maintenance HD. Four overarching themes emerged from the evidence synthesis: multidimensional supportive care needs, patient preferences for patient-centered care, barriers to supportive care implementation, and strategies to strengthen KSC. Collectively, the evidence suggests that patients undergoing maintenance HD experience complex and often unmet physical, psychological, social, spiritual, and informational needs that extend beyond routine biomedical management. The findings further highlight the importance of aligning supportive care delivery with patients' preferences, values, and goals while addressing contextual barriers that

influence implementation across healthcare settings. These observations underscore the need for comprehensive, patient-centered, and integrated KSC approaches capable of responding to the multidimensional challenges experienced throughout the CKD trajectory.

Multidimensional Supportive Care Needs and Supportive Care Theory

The findings of this review demonstrate that patients undergoing maintenance HD experience substantial multidimensional supportive care needs that extend beyond symptom management alone. Across the included studies, patients consistently reported physical symptoms such as fatigue, pain, pruritus, and sleep disturbances, alongside psychological concerns including anxiety, depression, and emotional distress ([Gunarathne et al., 2022](#); [Haneef & Abdullah, 2024](#); [Ma et al., 2021](#); [X. Wang et al., 2022, 2023](#)). In addition, social challenges such as financial hardship, transportation difficulties, caregiver burden, and inadequate social support were frequently identified, while spiritual concerns emerged as important sources of coping, meaning, and hope throughout the illness trajectory ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Haneef & Abdullah, 2024](#); [X. Wang et al., 2023](#)). These findings indicate that supportive care needs among patients receiving maintenance HD are complex, interrelated, and often remain insufficiently addressed within routine nephrology practice ([Baragar et al., 2023](#); [Gunarathne et al., 2022](#)).

The multidimensional pattern of needs identified in this review is consistent with the Supportive Care Needs Framework, which conceptualizes supportive care as encompassing physical, psychological, social, informational, practical, and spiritual domains. Similar to findings reported in oncology and palliative care populations, patients receiving maintenance HD

experience multiple concurrent unmet needs that significantly influence quality of life and overall well-being ([Gunarathne et al., 2022](#); [Haneef & Abdullah, 2024](#); [Matthews et al., 2024](#); [X. Wang et al., 2023](#)). The evidence synthesized in this review suggests that these needs should not be viewed as isolated problems but rather as interconnected dimensions of the patient experience that require comprehensive assessment and coordinated intervention. This interpretation is supported by studies demonstrating that symptom burden, psychosocial distress, and social vulnerability frequently coexist and collectively contribute to poorer patient outcomes and reduced quality of life ([Ma et al., 2021](#); [X. Wang et al., 2022, 2023](#)).

These findings also support the principles of Total Pain Theory, which proposes that suffering arises from the interaction of physical, psychological, social, and spiritual distress. The coexistence of symptom burden, emotional distress, financial difficulties, social challenges, and spiritual concerns observed across studies highlights how the experience of CKD extends beyond physiological impairment alone ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Gunarathne et al., 2022](#); [Haneef & Abdullah, 2024](#); [X. Wang et al., 2023](#)). Consequently, effective KSC should move beyond a disease-centered approach and adopt a holistic model that systematically addresses the full spectrum of patient needs. Such an approach may contribute to improved symptom control, enhanced quality of life, greater treatment satisfaction, and more patient-centered care for individuals receiving maintenance HD ([Baragar et al., 2023](#); [Gunarathne et al., 2022](#); [Haneef & Abdullah, 2024](#)).

Patient Preferences Across Different Cultural Contexts

The findings of this review indicate that patient preferences regarding supportive

care are strongly influenced by cultural values, social norms, and healthcare system characteristics. Across the included studies, patients consistently expressed preferences for effective communication, emotional support, family involvement, spiritual care, and participation in decision-making processes ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Baragar et al., 2023](#); [Haneef & Abdullah, 2024](#)). However, the relative importance of these preferences varied across settings, suggesting that supportive care should be tailored to the sociocultural context in which care is delivered. These findings reinforce the principles of Patient-centered Care, which emphasize that healthcare decisions should be aligned not only with clinical needs but also with patients' individual values, beliefs, and life goals.

Differences in patient preferences across countries may partly reflect variations in cultural perspectives regarding autonomy and decision-making. Studies conducted in high-income Western settings frequently emphasized patient autonomy, advance care planning, and active participation in treatment decisions, reflecting healthcare systems that prioritize individual choice and self-determination ([Baragar et al., 2023](#)). In contrast, studies conducted in Asian and other collectivist contexts highlighted the importance of family involvement, shared responsibility, and relational decision-making processes ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Haneef & Abdullah, 2024](#)). In these settings, healthcare decisions are often viewed as family matters rather than solely individual choices, making family engagement a critical component of supportive care delivery.

Spirituality also emerged as an important preference across several studies, although its role appeared particularly prominent in contexts where religious and spiritual beliefs remain deeply

integrated into daily life and health-related decision-making ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Alshelleh et al., 2023](#); [Haneef & Abdullah, 2024](#)). For many patients receiving maintenance HD, spiritual support provided meaning, hope, acceptance, and psychological comfort when facing the challenges of chronic illness ([Kristian et al., 2025](#); [Ma et al., 2021](#)). These findings suggest that supportive care interventions that fail to acknowledge patients' spiritual values may overlook an important dimension of well-being, particularly in culturally and religiously diverse populations.

The observed cross-country differences further suggest that a universal model of KSC may not adequately address the diverse preferences of patients worldwide. Instead, supportive care programs should be adapted to local cultural norms, healthcare structures, and patient expectations. Integrating family-centered communication, culturally sensitive shared decision-making, and spiritual support into routine nephrology practice may improve the responsiveness and acceptability of KSC, particularly in settings where collectivist values and strong family networks play a central role in healthcare experiences ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Baragar et al., 2023](#); [Haneef & Abdullah, 2024](#)).

ASEAN and Indonesian Interpretation

The findings of this review have particular relevance for ASEAN countries, where the growing burden of CKD is frequently accompanied by disparities in healthcare resources, workforce capacity, and access to specialized supportive care services. Although the included studies originated from diverse healthcare settings, the identified multidimensional supportive care needs are highly relevant to many Southeast Asian countries, where dialysis services often remain the primary focus of

kidney care while psychosocial, spiritual, and palliative aspects receive less systematic attention ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Haneef & Abdullah, 2024](#); [X. Wang et al., 2023](#)). Consequently, patients may experience substantial unmet needs despite receiving adequate dialysis treatment, highlighting the importance of integrating supportive care principles into routine nephrology services.

The prominent role of family involvement identified across the included studies is particularly consistent with the collectivist cultural values that characterize many ASEAN societies. In contrast to healthcare systems that prioritize individual autonomy as the primary basis for decision-making, patients in Southeast Asian settings frequently rely on family members for emotional support, caregiving, financial assistance, and participation in treatment decisions ([Alshelleh et al., 2023](#); [Kristian et al., 2025](#)). This cultural orientation may explain why family support, caregiver involvement, and shared decision-making emerged as important patient preferences within the reviewed evidence ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Haneef & Abdullah, 2024](#)). Therefore, supportive care models developed in Western countries may require contextual adaptation before implementation in ASEAN settings to ensure alignment with local social and cultural realities.

Spirituality also represents a particularly important dimension within the ASEAN context, where religious beliefs and spiritual practices often influence how patients understand illness, suffering, treatment, and end-of-life issues. Across many Southeast Asian countries, spiritual coping mechanisms may help patients maintain hope, acceptance, and psychological resilience while living with long-term dialysis dependence ([Gayathri M et al., 2025](#); [Kristian et al., 2025](#)). The findings of this review suggest that spiritual

support should not be regarded as an optional component of care but rather as an integral aspect of comprehensive KSC, particularly in settings where religious and spiritual values play a central role in patients' daily lives ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Haneef & Abdullah, 2024](#)). As a result of the strong influence of these values, spiritual coping mechanisms have become a vital tool for patients in Southeast Asia in maintaining hope and psychological resilience during long-term HD.

These findings are especially relevant to Indonesia, where formal KSC services remain limited and are not yet consistently integrated into routine nephrology practice. Despite the increasing number of patients receiving maintenance HD, supportive care delivery continues to be challenged by workforce limitations, variations in service availability, and the predominance of a treatment-oriented model focused primarily on disease management ([Bello et al., 2022](#); [Davison et al., 2024](#)). At the same time, Indonesian patients often depend heavily on family networks and spiritual resources to cope with the physical, psychological, and social consequences of CKD ([Kristian et al., 2025](#)). While workforce limitations and a disease-focused model persist, the heavy reliance of Indonesian patients on family networks and spiritual resources necessitates a shift toward a more culturally responsive and holistic care framework. Consequently, the implementation of culturally responsive KSC in Indonesia should incorporate routine assessment of multidimensional supportive care needs, family-centered communication, spiritual care integration, and interdisciplinary collaboration to better align healthcare services with patient preferences and priorities ([Davison et al., 2024](#); [Lianti & Rosyid, 2024](#)).

The successful implementation of KSC within the ASEAN region necessitates a strategic shift from the direct adoption of

Western-developed models toward localized frameworks that prioritize regional healthcare infrastructure and sociocultural specificities. Taken together, the findings suggest that KSC implementation in ASEAN countries should extend beyond the direct adoption of models developed in high-income settings. Rather than relying on universal templates, adapting care programs to align with local family-centered dynamics and available resources is essential for ensuring the long-term feasibility and sustainability of supportive interventions. Instead, supportive care programs should be adapted to local healthcare infrastructure, cultural values, family dynamics, and available resources. Such contextual adaptation may improve the feasibility, acceptability, and sustainability of supportive care interventions while ensuring that care remains responsive to the unique needs and preferences of patients undergoing maintenance HD within the region ([Baragar et al., 2023](#); [Haneef & Abdullah, 2024](#); [X. Wang et al., 2023](#)).

Barriers Through an Implementation Science Lens

The findings of this review indicate that the implementation of KSC remain constrained by multiple barriers operating at individual, organizational, and health-system levels. Across the included studies, challenges included limited knowledge and awareness of supportive care principles, inadequate psychosocial and palliative care training, workforce shortages, insufficient interdisciplinary collaboration, and restricted availability of supportive care resources ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Baragar et al., 2023](#); [Chilcot et al., 2025](#); [Matthews et al., 2024](#)). These barriers contribute to a persistent gap between patients' multidimensional supportive care

needs and the services routinely delivered within HD settings.

From an implementation science perspective, these barriers can be interpreted using the COM-B framework. Within the capability domain, healthcare professionals may lack the knowledge, communication skills, and clinical competencies required to identify and address psychological, social, spiritual, and palliative care needs among patients receiving maintenance HD. Evidence from Ghana, for example, suggests that nurses often possess only partial awareness of palliative and supportive care concepts, resulting in care practices that remain predominantly focused on life-prolonging treatment rather than holistic patient support ([Akpakli Addo & Senoo-Dogbey, 2025](#)). These findings suggest that strengthening professional education and supportive care training should be considered a key implementation priority.

The opportunity component of the COM-B framework is reflected in the structural and organizational barriers identified across studies. Workforce shortages, insufficient psychosocial staff, limited access to specialist supportive care services, and inadequate integration of supportive care into routine nephrology pathways were consistently reported as obstacles to implementation ([Baragar et al., 2023](#); [Chilcot et al., 2025](#)). Even in healthcare systems with established dialysis services, the availability of trained personnel and supportive care infrastructure may remain insufficient to meet the growing demand for psychosocial support, symptom management, and advance care planning. These findings suggest that implementation efforts should extend beyond individual clinician training and address broader organizational and system-level factors that shape care delivery.

Motivational factors may also influence the adoption of KSC practices. In many settings, clinical cultures continue to prioritize disease-focused and life-sustaining interventions, potentially limiting the perceived importance of supportive care activities within routine nephrology practice ([Akpakli Addo & Senoo-Dogbey, 2025](#)). Uncertainty regarding professional responsibilities, competing clinical priorities, and limited institutional support may further reduce motivation to integrate supportive care into everyday care processes ([Matthews et al., 2024](#)). Consequently, implementation strategies should seek to promote a shared understanding of supportive care as an essential component of high-quality kidney care rather than as an optional adjunct to dialysis treatment.

The findings additionally demonstrate that successful implementation requires coordinated multilevel interventions. Examples identified within the literature include the use of PROMs to facilitate routine assessment of patient needs, development of interdisciplinary care models, workforce capacity building, and integration of supportive care into existing nephrology pathways ([Baragar et al., 2023](#)). Such strategies may help bridge the gap between patients expressed needs and healthcare delivery by supporting earlier identification of unmet needs and more patient-centered care planning. Therefore, future implementation efforts should combine educational, organizational, and policy-level approaches to ensure that KSC becomes an integrated and sustainable component of routine HD services.

The findings of this review underscore that addressing implementation barriers in KSC necessitates a transition from merely expanding clinical services to fundamentally transforming healthcare delivery through a systematic implementation science lens. Evidence

suggests that the underutilization of supportive care is rooted in multi-level challenges, ranging from limited professional awareness to organizational resource constraints. Rather than focusing solely on clinical volume, improvement requires systematic attention to the capability, opportunity, and motivation factors known as the COM-B framework that shape professional behavior and the quality of healthcare delivery. This perspective allows for a deeper understanding of why holistic care often remains neglected in favor of disease-focused interventions ([Baragar et al., 2023](#); [Chilcot et al., 2025](#)). Ultimately, leveraging these behavioral frameworks provides a strategic roadmap for developing context-specific interventions that are responsive to local resource constraints and can effectively bridge the persistent gap between patients' multidimensional needs and routine clinical practice.

Why Do Findings Differ Between Countries?

Differences in supportive care needs, patient preferences, and implementation barriers across countries were evident throughout the included studies. These variations are likely influenced by differences in healthcare infrastructure, health financing systems, workforce capacity, cultural values, and the availability of supportive and palliative care services. While patients across settings consistently reported multidimensional needs encompassing physical, psychological, social, and spiritual domains, the relative prominence of specific needs varied considerably according to local healthcare and sociocultural contexts ([Akpakli Addo & Senoo-Dogbey, 2025](#); [Baragar et al., 2023](#); [Haneef & Abdullah, 2024](#)).

In low- and middle-income countries (LMICs), unmet supportive care needs were often closely associated with socioeconomic challenges, including financial burden,

limited access to healthcare resources, inadequate supportive care services, and shortages of trained healthcare professionals ([Akpakli Addo & Senoo-Dogbey, 2025](#); [X. Wang et al., 2023](#)). For example, evidence from China demonstrated that moderate-to-severe supportive care needs were strongly associated with financial hardship and lower educational attainment, highlighting the influence of social determinants of health on patients' experiences and outcomes ([X. Wang et al., 2022, 2023](#)). Similarly, findings from Ghana suggested that resource limitations and insufficient professional training contributed to a greater emphasis on life-prolonging treatment, while psychosocial and supportive care services remained underdeveloped ([Akpakli Addo & Senoo-Dogbey, 2025](#)). Consequently, these systemic barriers underscore the critical necessity of developing financially accessible and culturally adapted care models that can bridge the persistent gap between life-prolonging technical interventions and the holistic well-being of patients in resource-constrained environments.

In contrast, studies conducted in high-income countries (HICs) tended to emphasize issues related to care coordination, communication, advance care planning, and psychosocial service delivery rather than basic access to supportive care resources. For example, Canadian studies highlighted the use of PROMs and integrated KSC models to facilitate patient-centered care and improve symptom assessment ([Baragar et al., 2023](#)). Nevertheless, even within resource-rich settings, important gaps remained, particularly regarding access to psychological support and specialized staff capable of addressing the growing demand for emotional and psychosocial care among patients receiving maintenance HD ([Chilcot](#)

et al., 2025). Ultimately, these observations highlight that even in high-resource environments, achieving truly patient-centered care requires a strategic shift beyond basic coordination toward the systematic integration of specialized psychosocial support to bridge the remaining gaps in routine nephrology practice.

Cultural factors also appear to contribute substantially to cross-country differences. In many Asian and collectivist societies, family involvement, spiritual support, and shared decision-making were frequently identified as important patient preferences, reflecting cultural norms that emphasize interdependence and collective responsibility (Akpakli Addo & Senoo-Dogbey, 2025; Alshelleh et al., 2023; Haneef & Abdullah, 2024). Conversely, studies from Western healthcare systems more commonly emphasized individual autonomy, advance care planning, and patient-led decision-making processes (Baragar et al., 2023). These differences suggest that supportive care preferences are shaped not only by clinical needs but also by cultural expectations regarding illness, caregiving, and healthcare decision-making.

The findings of this review underscore that KSC cannot be implemented through a universal, one-size-fits-all approach, as successful delivery depends heavily on its alignment with localized healthcare and sociocultural realities. While the core principles of supportive care are universally applicable across different settings, their effective operationalization requires strategic adaptation to regional healthcare structures, available resource levels, and specific cultural expectations. Recognizing these contextual differences is essential for designing supportive care interventions that are both feasible and responsive to the unique needs and preferences of patients receiving maintenance HD in different

countries (Akpakli Addo & Senoo-Dogbey, 2025; Baragar et al., 2023; Haneef & Abdullah, 2024; X. Wang et al., 2023). Ultimately, this targeted adaptation is essential for designing interventions that are truly responsive to the unique needs and preferences of patients undergoing maintenance hemodialysis, thereby bridging the gap between standard medical practice and holistic patient-centered care.

Implications for Nephrology Nursing, Policy, and Dialysis Service Redesign

The findings of this review have important implications for nephrology nursing practice, healthcare policy, and the redesign of dialysis services. The consistent identification of multidimensional supportive care needs and diverse patient preferences highlights the necessity of integrating KSC into routine HD services through interdisciplinary collaboration involving nephrologists, nurses, psychologists, dietitians, social workers, and spiritual care providers (Gunarathne et al., 2022; Haneef & Abdullah, 2024; X. Wang et al., 2022, 2023). Within this model, nephrology nurses are strategically positioned to serve as coordinators of patient-centered supportive care by conducting routine assessments of physical, psychological, social, spiritual, and informational needs; facilitating patient education; promoting shared decision-making; and strengthening family engagement throughout the care continuum. At the policy level, the findings support the incorporation of supportive care principles into national dialysis standards, clinical guidelines, and quality indicators, accompanied by investments in workforce capacity building, psychosocial support services, and supportive care competencies among healthcare professionals (Akpakli Addo & Senoo-Dogbey, 2025; Baragar et al., 2023; Gunarathne et al., 2022). Furthermore, the

findings suggest that dialysis services should be redesigned beyond a predominantly disease-focused model toward a more integrated and patient-centered approach that systematically incorporates symptom management, psychosocial care, spiritual support, advance care planning, and routine use of PROMs to identify unmet needs. In resource-constrained settings, including Indonesia and other low- and middle-income countries, the integration of telehealth and tele-nursing platforms may provide additional opportunities to improve access, continuity, and responsiveness of supportive care services ([Baragar et al., 2023](#); [Chilcot et al., 2025](#)). Collectively, these strategies may contribute to improved quality of life, enhanced patient satisfaction, better treatment experiences, and more equitable delivery of KSC for individuals undergoing maintenance HD.

Implications and limitations

This review contributes to the theoretical development of KSC by synthesizing and conceptually integrating evidence on supportive care needs, patient preferences, implementation barriers, and service improvement strategies within a patient-centered and multidimensional supportive care framework. By bringing together evidence from diverse healthcare settings, the review extends current understanding of KSC beyond symptom management alone and highlights the interconnected physical, psychological, social, spiritual, and contextual factors that shape the experiences of individuals undergoing maintenance HD. The findings also provide a conceptual foundation for adapting supportive care models across different cultural and healthcare contexts, particularly in low- and middle-income countries where supportive care services remain underdeveloped. Nevertheless,

several limitations should be acknowledged when interpreting the findings. The review excluded grey literature, including conference proceedings, dissertations, reports, and unpublished studies, which may have limited the comprehensiveness of the evidence base and increased the possibility of publication bias. The inclusion of only English- and Indonesian-language publications may have introduced language bias and potentially excluded relevant studies published in other languages. In addition, the review was restricted to a limited number of electronic databases, raising the possibility that some eligible studies were not captured despite the systematic search process. The evidence base was also dominated by cross-sectional studies, restricting insights into causal relationships and the longitudinal evolution of supportive care needs and patient preferences over time. Furthermore, variations in study settings, healthcare systems, and sociocultural contexts may influence the transferability of findings across populations. Despite these limitations, the review provides a comprehensive and theoretically informed synthesis of contemporary evidence that can support future research, guide the refinement of supportive care frameworks, and inform the development of more patient-centered KSC models in diverse clinical settings.

Relevance to Practice

The findings of this review have direct relevance for clinical practice by providing actionable guidance for the implementation of KSC across diverse healthcare settings, particularly in resource-limited environments. Dialysis nurses and nephrologists should incorporate routine supportive care screening into standard HD practice using validated assessment tools and patient-reported outcome measures to systematically identify unmet physical,

psychological, social, spiritual, informational, and practical needs throughout the disease trajectory. The findings further support the development of interdisciplinary care pathways that facilitate collaboration among nephrologists, nurses, psychologists, social workers, dietitians, palliative care specialists, and spiritual care providers to ensure comprehensive and coordinated care delivery. Given the prominent role of family involvement identified across the evidence, healthcare professionals should adopt family-centered approaches that actively engage family members in education, symptom management, treatment planning, and decision-making processes. The review also highlights the importance of initiating timely Advance Care Planning (ACP) discussions to ensure that treatment decisions remain aligned with patients' values, preferences, and goals of care, particularly as disease complexity increases. At the institutional level, healthcare organizations should integrate supportive care principles into dialysis protocols, workforce training programs, and quality improvement initiatives. Meanwhile, policymakers should prioritize the incorporation of KSC into national kidney care strategies, clinical guidelines, and reimbursement frameworks to support sustainable implementation. In LMICs, where specialist supportive care resources may be limited, culturally adapted KSC models that leverage existing nephrology services, family support networks, community resources, and telehealth-based interventions may represent practical and cost-effective approaches to improving patient-centered care and quality of life for individuals receiving maintenance HD.

Conclusion

This scoping review provides a comprehensive evidence map of supportive care needs, patient preferences, implementation barriers, and strategies to strengthen KSC among individuals undergoing maintenance HD. The synthesis highlights the central role of patient-centered KSC in addressing the complex and interconnected needs experienced throughout the disease trajectory and underscores the importance of integrating physical, psychological, social, and spiritual dimensions of care into routine HD services. The findings support a shift from predominantly disease-focused models toward more holistic, patient-centered, and culturally responsive approaches that align care delivery with patients' values, preferences, and priorities. To advance the implementation of KSC across diverse healthcare settings, future research should focus on implementation science approaches, evaluation of context-specific care models, and the development of sustainable strategies that facilitate the integration of comprehensive supportive care into routine nephrology practice.

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CrediT Authorship Contributions Statement

Meyla Sari Handayani: Conceptualization, Methodology, Investigation, Data Curation, Formal Analysis, Writing – Original Draft.

Kusman Ibrahim: Supervision, Methodology, Validation, Writing – Review & Editing.

Laili Rahayuwati: Formal Analysis, Writing – Review & Editing, Validation.

Naufal Hafizh Fauzan: Conceptualization, Investigation, Data Curation, Writing – Original Draft.

Conflicts of Interest

There is no conflict of interest.

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Supplementary Materials

Supplementary File S1-S4: contains additional materials supporting the findings of this review.

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