kidney and dialysis

MDPI

Review

Advanced Chronic Kidney Disease and Patient Education

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Abstract

Chronic kidney disease (CKD) remains a significant global health challenge, with its advanced stages necessitating timely and comprehensive patient education, particularly regarding kidney replacement therapy (KRT). Early initiation of education is crucial, as it enhances patient understanding and supports shared decision-making with healthcare teams, ultimately leading to better health outcomes. Evidence demonstrates that CKD education not only increases disease-specific knowledge, but also confers multiple benefits, including reduced healthcare utilization, greater adoption of self-management, delayed KRT initiation, improved survival, higher adherence to therapies, and increased transplant evaluation. Despite these advantages, a disconnect persists between the educational content desired by patients and what is prioritized by healthcare professionals. Structured educational interventions have been shown to improve patients' ability to make informed decisions about KRT, with studies indicating that after targeted education, the vast majority of patients can articulate their therapy preferences. Furthermore, national and international guidelines highlight the necessity of embedding patient education as a core component of CKD care to empower patients and improve the quality of life. However, challenges remain, including disparities in access, health literacy, and the consistency of educational delivery. There is currently no standardized approach on how to effectively educate CKD patients. This review provides a comprehensive analysis of all aspects of pre-dialysis education and best practices for advanced CKD patient education.

Keywords: patient education; chronic kidney disease; advanced kidney disease; dialysis; kidney replacement therapy

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1. Introduction

Chronic kidney disease (CKD) represents a major and escalating global health burden, affecting an estimated 850 million people worldwide—more than 10% of the global population and nearly double the number of individuals living with diabetes mellitus [1]. This prevalence is likely underestimated due to insufficient early detection and screening programs, especially in low- and middle-income countries (LMICs) [2]. In the United States alone, approximately 35.5 million adults—about 1 in 7—are estimated to have CKD, with a staggering 9 out of 10 adults unaware of their condition [3]. The silent progression and widespread unawareness of CKD highlight the critical need for robust patient education and early intervention strategies.

CKD is defined by a gradual, often asymptomatic decline in kidney function, typically measured by a reduction in the glomerular filtration rate (GFR) and the presence of albuminuria. The presence of kidney dysfunction for at least three months leads to a diagnosis

of CKD. It is crucial for providers to be aware that the definition of CKD is not confined solely to just these lab values.

The current classification system for CKD incorporates three key components: the underlying cause, GFR category (G1–G5), and albuminuria category (A1–A3). Advanced CKD is typically defined as GFR values below 30 mL/min/1.73 m^2 (G4 and above) and/or severely increased albuminuria (A3), both of which are associated with a higher risk of progression to end-stage kidney disease (ESKD) and other complications [4].

Despite well-established preventive strategies, a significant proportion of individuals with CKD progress to kidney failure, necessitating kidney replacement therapy (KRT) such as dialysis or transplantation. In the U.S., approximately 33% of adults with advanced CKD are unaware of their disease severity [3]. The risk of progression is influenced by a multitude of factors, including age, comorbidities, genetic predisposition, and social determinants of health. The global burden of CKD is rising rapidly. By 2030, the number of people requiring KRT is projected to more than double, with the greatest increases expected in LMICs, which are already facing substantial healthcare resource constraints [2].

Historically, education programs for CKD patients and their families were recommended to begin when the GFR dropped below 30 mL/min/1.73 m^2. However, the Kidney Disease: Improving Global Outcomes (KDIGO) 2024 Clinical Practice Guideline now advocates for a more nuanced approach, recommending the use of externally validated risk equations to estimate the absolute risk of kidney failure in patients with CKD stages G3–G5. Specifically, a two-year kidney failure risk threshold of greater than 40% should guide the timing of modality education, preparation for KRT (including vascular access planning), and referral for transplantation, in addition to traditional GFR-based criteria and other clinical considerations [4]. Several risk prediction models, such as the Kidney Failure Risk Equation (KFRE) [5–8], Kaiser Permanente North West (KPNW) [9], Veterans Affairs [10], and Z6 Score [11] models, are recommended by KDIGO for estimating the 2- and/or 5-year risk of kidney failure. These validated risk equations often use variables such as the GFR, creatinine or cystatin C, urine albumin-to-creatinine ratio, age, and sex. While these tools enhance individualized risk assessment and care planning, it is important to note that their accuracy may be limited in patients with early-stage CKD (G1–G2), where they may overestimate the risk of progression [4].

Patient education is a cornerstone of CKD management, with substantial evidence demonstrating its role in improving outcomes across all stages of the disease. Education efforts to promote self-management allow patients to improve their quality of life while taking on tasks to help reduce the impact of disease, such as the adoption of lifestyle changes and adherence to medication regimens. Early and ongoing education helps empower patients to better manage risk factors such as hypertension and diabetes—measures that are essential for slowing disease progression and reducing the risk of complications [12]. Education also enhances patient engagement, leading to higher rates of planned dialysis starts, increased pre-emptive transplant listings, and improved satisfaction with care [13–22]. Conversely, a lack of education is associated with poorer outcomes, including higher rates of unplanned dialysis initiation and increased mortality [12,23–26].

For individuals with advanced CKD, education becomes even more critical, as treatment decisions are highly preference-sensitive and must be tailored to each patient's values, lifestyle, and clinical circumstances. Shared decision-making between patients and providers is essential to ensure that choices regarding dialysis modalities, transplantation, or conservative kidney management (CKM) align with patient goals and expectations [27]. Selecting the most appropriate treatment plan for kidney failure is a complex process influenced by a range of factors, including patient health status, comorbidities, resource availability, expertise, cultural beliefs, family obligations, and personal preferences [1,28,29].

Additional considerations such as the patient's education level, desire for independence, wait time for transplantation, proximity to dialysis centers, and age at treatment initiation also play significant roles in decision-making [1,29–31]. For some, CKM may be the preferred approach particularly in the context of advanced age, frailty, or significant comorbidities, underscoring the importance of individualized care planning and comprehensive education [1,32].

Despite the demonstrated benefits of patient education, there is a lack of consensus on the most effective ways to organize and deliver CKD education. While a variety of studies exist, strategies on how to best educate CKD patients are notably scarce. There is currently no standardized approach regarding when to initiate education, who should be involved, which topics to cover, or how to structure educational programs. This lack of standardization presents challenges in ensuring that all patients receive timely, relevant, and effective education tailored to their needs and circumstances. Existing reviews are often restricted to patient-specific patient populations, modalities, topics within CKD, or specific teaching techniques. In contrast, this review integrates all aspects of pre-dialysis education and provides a practical summary that can be used by providers to tailor their own educational programs. Specifically, we will explore health literacy among patients with CKD, the evidence supporting the benefits of education in CKD, and patients' perceptions of the education provided, and examine the best practice for patient education in CKD. A literature search from January 2020 to January 2025 was conducted using MEDLINE and PubMed. Search terms included chronic kidney disease, chronic kidney insufficiency, renal failure, ESKD, ESRD, and patient education.

2. Health Literacy in Chronic Kidney Disease

Health literacy, defined as an individual's ability to access, understand, and apply health information for informed decision-making, plays a critical role in managing chronic conditions like CKD [33–35]. Approximately 88% of U.S. adults lack the necessary skills to effectively utilize health information and services for informed decision-making [36–38]. It is estimated that 25% of CKD patients have limited health literacy skills, with a higher prevalence among older adults, racial minorities, and those of a lower socioeconomic status [39,40].

Systematic reviews demonstrate that limited health literacy independently correlates with adverse clinical events, increased healthcare utilization, and mortality in CKD populations [39].

CKD patients with limited health literacy were found to exhibit lower estimated GFRs, higher proteinuria, and worse blood pressure control compared to their counterparts [39,41]. Cohort studies also reveal associations between low health literacy and missed dialysis sessions, cardiovascular complications, and reduced transplant accessibility. Patients on the transplant waiting list, pre-emptive transplantation, and living donor transplantation were associated with higher health literacy [42]. Younger patients, women, and those with higher socioeconomic status are more likely to engage actively in shared decision-making, whereas limited health literacy often restricts participation in medical decision-making unless interventions are tailored to specific needs [43].

Disparities are further highlighted in non-Hispanic Black populations, where limited health literacy affects 28% of individuals with mild-to-moderate CKD—nearly six times the rate observed in non-Hispanic white patients [41]. The complexity of CKD management, which requires strict dietary adherence, medication compliance, and frequent medical interactions, amplifies the challenges posed by low health literacy [41,44]. Patients often struggle to navigate treatment options, interpret lab results, or engage in shared decision-making with providers [45]. Shame associated with low literacy may prevent patients from

disclosing their challenges, necessitating proactive screening and targeted support [46]. Tools like patient decision aids (PDAs) aim to standardize information and clarify treatment risks and benefits.

Decision support tools and educational materials are often frequently written at a ninth-grade reading level, far above the sixth-grade benchmark needed for accessibility [41,47]. This gap contributes to misunderstandings, missed dialysis sessions, and suboptimal self-care behaviors, particularly among vulnerable populations [39]. Verbal education as opposed to written communication can also be helpful in patients with low health literacy—as it can be more fluid and can be tailored to the patient's current needs and understanding.

The concept of health literacy has evolved to recognize the responsibility of healthcare organizations to enable equitable access to information and support, shifting the focus from mere understanding to actionable knowledge [34,35,37,38,48]. Strategies to promote health literacy include identifying patients' preferred learning methods, use of plain language, providing language translation services and culturally appropriate materials, and integrating community health workers into education efforts—particularly in underserved and minority populations [37,43,48–51].

3. Benefits of Patient Education in Chronic Kidney Disease

Research demonstrates that structured educational interventions empower patients to make informed decisions, adhere to treatment plans, and engage in self-management strategies that slow disease progression and reduce complications. Patients lacking education are more likely to experience the unplanned initiation of hemodialysis, often requiring catheters, whereas those receiving structured guidance on vascular access planning use permanent arteriovenous fistulas more frequently, lowering infection risks. Studies show that CKD education extends the time to dialysis initiation by equipping patients with knowledge about dietary modifications, medication adherence, and risk factor management, thereby preserving residual kidney function [16,52,53]. This delay in dialysis necessity not only improves quality of life but also reduces healthcare costs. Educational interventions also improve clinical markers and treatment adherence. Patients educated about blood pressure goals demonstrate better blood pressure control, directly mitigating cardiovascular risks prevalent in CKD populations [54]. For example, trials have revealed that patients exposed to educational booklets and interactive sessions exhibit higher rates of selecting self-care dialysis modalities like peritoneal dialysis, which associates with greater autonomy and fewer hospitalizations [17,25]. A randomized trial (n = 70) showed that education doubled patients' intention to pursue home dialysis, which offers greater autonomy and survival benefits [17]. One of the most impactful findings comes from a 2015 randomized trial (n = 335) showing that patients receiving 60–75 min educational sessions about KRT modalities survived 8 months longer post-dialysis initiation compared to those receiving usual care [18]. This mortality benefit underscores the life-saving potential of early education.

A 2016 systematic review of 26 studies involving 5403 participants established that multifaceted education programs combining face-to-face teaching, written materials, and follow-ups improve knowledge retention and self-management behaviors [14]. These programs are most effective when they include interactive workshops and family involvement, addressing the complex needs of CKD patients who often face cognitive and functional decline as the disease advances [14,55]. A 2023 systematic review demonstrated that the teach-back method—where patients restate instructions in their own words—significantly improves medication adherence and fluid management, especially in low-literacy populations [56]. This approach bridges knowledge gaps by ensuring comprehension, reducing errors in self-care practices. Supporting this, a 2024 randomized controlled trial (n = 84) showed that a 6-month health literacy education program (HLEP)

improved both mental health and self-management behaviors, with participants reporting reduced depression and better adherence to their treatment regimen [57]. These findings emphasize the dual psychological and physiological benefits of education.

Psychosocial benefits emerge prominently in educated cohorts. CKD-specific education alleviates anxiety by clarifying disease trajectories and treatment expectations, fostering a sense of control over health outcomes. Support groups and community forums integrated into educational frameworks provide emotional resilience through peer learning, reducing feelings of isolation common in advanced CKD [55]. Surveys indicate that patients receiving tailored education report improved mood and perceived health status, factors linked to better long-term adherence and survival [12].

Table 1 summarizes patients' benefits from CKD education.

Table 1. Summary of patient benefits with CKD education.

Benefits of Chronic Kidney Disease Education
Enhance Patient Understanding
• Make informed decisions
• Knowledge retention
• Improved mental health and self-management behaviors
• Autonomy with self-care dialysis modalities
Improved Health Outcomes
• Adhere to treatment plans
• Reduce complications
• Lower infection risks (vascular access planning)
• Decrease cardiovascular risks by better blood pressure control
Delay Kidney Disease progression
• Knowledge of dietary modifications
• Medication adherence
• Risk factor management
Reduced Healthcare Costs
• Prevention of complications
• Knowledge of all treatments including conservative kidney management
Promote Home Kidney Replacement Modalities
• Promote patient autonomy
Increase Rate of Kidney Transplant
• Early referrals for transplant evaluation
• Pre-emptive transplant candidacy
• Early identification of possible living donors

Patient Education for Unplanned Dialysis

Approximately 24 to 29% of patients globally initiate dialysis in an unplanned manner. Unplanned starts stem from a multitude of etiologies such as rapid progression, lack of planning, or late presentation to healthcare professionals, and are associated with higher morbidity, mortality, and healthcare costs [58]. Transitional Care Units (TCUs) are specialized programs designed to support patients who "crash" into dialysis during the critical time. TCUs focus on education, emotional support, and personalized care coordination to help patients choose their dialysis modality—whether in-center hemodialysis, home hemodialysis, or peritoneal dialysis—while addressing the physical and psychological challenges of kidney failure. TCUs typically operate in two settings: integrated units within existing dialysis centers, which allow patients to receive in-center treatments, and standalone units affiliated with home dialysis programs, offering quieter environments for hands-on training with home dialysis machines. Programs often span 4–8 weeks and involve multidisciplinary teams, including nephrologists, nurses, dietitians, and social workers, to address medical, educational, and psychosocial needs [59].

A primary benefit of TCUs is their emphasis on patient education and empowerment. Structured programs provide detailed training on dialysis modalities, fluid management, and transplant options, reducing fear and confusion often associated with starting dialysis. For example, the Satellite Healthcare Optimal Transitions Program uses home dialysis machines for gentler initiation and includes a dedicated "self-care" phase for hands-on training, which has been shown to increase readiness for home therapies [60]. This education helps patients align treatment choices with personal goals, such as maintaining independence or employment [59].

Clinically, TCUs improve outcomes by ensuring timely vascular access placement and medication management, reducing complications like infections or cardiovascular events [61]. Studies show that TCU participants experience fewer hospitalizations and better adherence to treatment [59]. Notably, TCU patients are significantly more likely to be referred for kidney transplants and achieve arteriovenous access, with one study showing a 42% higher transplant wait-listing rate and 70% arteriovenous access use compared to controls [62].

By integrating medical, educational, and emotional support, TCUs bridge the gap between CKD diagnosis and sustainable dialysis care. They empower patients to make informed decisions, improve clinical outcomes, and reduce systemic costs, reshaping dialysis care through patient-centered approaches.

4. Patient Perception of Education in Chronic Kidney Disease

Patient perceptions of education reveal several key themes. Many patients find CKD education helpful; however, patients want to see improved education materials and for content to be presented in an unbiased manner [61]. A significant number of patients express a desire for more information about CKD, including its definition, ways to slow progression, treatment options for ESKD, dietary changes, and potential complications [55,63,64]. Patients have also expressed interest in educational courses outside the office visit as well as content made available via digital platforms [55,61].

Studies indicate that a substantial portion of patients do not receive comprehensive education about all types of KRTs. Mehrotra et al. examined data from patients at 229 dialysis units and found that 30% of the patients reported that treatment options were not presented to them until dialysis was started, and 48% reported that the treatment options were presented either after the first dialysis session or less than one month prior to dialysis. Among the patients who reported that dialysis options were not presented to them until dialysis was started, 28% knew about their kidney failure for $\geq$1 year ($\geq$4 months, 47%) and 29% had been seeing a nephrologist for $\geq$1 year ($\geq$4 months, 42%). When asked if the patients had been provided with enough information regarding the KRTs, 68% indicated that they had received more than enough or enough information and 17% indicated that they received little or no information [65].

Furthermore, a multinational survey of 3867 patients across 36 countries found that while the majority (78%) evaluated general information about kidney disease and treatment as helpful, 39% did not recall being told about alternative treatment options other than their current one. Satisfaction levels also varied, with patients being more satisfied with information on in-center hemodialysis (90%) and transplantation (87%) compared to peritoneal dialysis (79%) or home hemodialysis (61%), and they were more satisfied with information from healthcare professionals vs. other sources such as social media. Many respondents (64%) could not remember receiving education on how to manage their kidney disease in daily life [66].

Additional research highlights that patients often have gaps in their CKD knowledge, leading to misconceptions about the causes, symptoms, and prognosis of the disease. There

was a discrepancy between anxiety at diagnosis and the later feeling of the irrelevance of CKD. A lack of CKD symptoms and physicians' attitudes reduced the sense of seriousness. The patients failed to associate lifestyle and cardiovascular disease with CKD. Some were willing to make lifestyle changes. Not all were well-informed about the consequences that CKD might have. The participants expressed the need for tailored information. Healthcare providers should be aware that they, often unknowingly, deliver the wrong signals about the severity of CKD, which can influence patient behavior toward their lifestyle and willingness to enhance self-management. Provider identification of the pre-existing perspectives and misconceptions of CKD that could be present helps provide tailored and patient-centered information [67]. Techniques such as motivational interviewing can help patients stay engaged and encourage the share of information—allowing providers to identify barriers and strengthen motivations for behavioral change [68].

Patients report suboptimal knowledge uptake from both written information and consultations, which can lead to barriers to self-management. Some patients report that information did not often promote CKD self-management and written information was not provided, especially from primary care providers. With patients with advanced CKD, they noted that both oral and written information from nephrologists was overwhelming. Written education in these groups was not often used due to limited health literacy or the perception that it was too confronting. Patients also described situations of overestimation by the healthcare provider in all settings [69–71]. For example, healthcare providers discussed too many topics or assumed patients had basic knowledge about kidneys. In these situations, patients struggle to ask for clarification or express their needs. Healthcare providers may overestimate patients' understanding or provide overwhelming amounts of information, making it difficult for patients to ask for clarification [69].

Studies also highlight the importance of staff training in enhancing patient education. Combes et al. conducted semi-structured interviews in four hospitals with 96 clinical and managerial staff and 93 dialysis patients, exploring the experiences and views of pre-dialysis education. Most patients found pre-dialysis education helpful and staff valued its role in supporting patient decision-making. However, patients wanted to see teaching methods and materials improved and biases eliminated. Staff were less aware than patients of how informal staff–patient conversations can influence patients' treatment decision-making. Many staff members felt ill-equipped to talk about KRTs in a balanced and unbiased manner. Patients' abilities to make treatment decisions were found to be adversely affected in the pre-dialysis period by emotional distress. All staff, irrespective of their role, need to be trained about all treatment options so that informal conversations with patients are free from bias [61].

Combes et al. also argue for a more individualized approach to pre-dialysis education that is more like counseling than education and would demand a higher level of skill and training for specialist pre-dialysis education staff. The study concludes that even if these improvements are made to pre-dialysis education, not all patients will benefit, since some find decision-making in the pre-dialysis period too complex or are unable to engage with education due to illness or emotional distress. Therefore, the study recommends that pre-dialysis education focuses on ongoing KRT education, providing ongoing review of treatment choices, instead of focusing on treatment decisions. Emotional distress surrounding CKD diagnosis can result in patients opting to wait to decide on a treatment plan and may not be engaged with their providers. Staff training on communication, empathy, and cultural sensitivity can help improve patient engagement. Emotional support to help overcome the distress of the transition to ESKD will also be essential to ensure all patients can benefit from KRT education [63]. Figure 1 describes components of staff training for CKD education.

Figure 1. Components of staff training in patient education.

A 2024 study analyzing 337 CKD patients revealed strong preferences for small-group sessions (45%), monthly meetings (38%), and peer support integration (62%), highlighting the importance of tailored educational formats [55]. These preferences align with evidence that personalized approaches improve engagement, particularly for patients with varying health literacy levels and socioeconomic backgrounds [12,55].

Table 2 is a summary of studies regarding patient perception of CKD education.

Table 2. Summary of studies regarding patient perception of CKD education.

Patient Perception of CKD Education			
Study	**Population**	**Results**	**Key Themes**
Exploring patient needs and preferences (Allen et al., 2024 [55])	Cross-sectional survey of CKD patients 21 years and older (N = 337)	• Topics of interest include: CKD definition, creatinine, GFR and kidney diet • 46% were willing to attend classes • 33% preferred digital modalities • 53% are interested in peer support	Comprehensive education about CKD Integration of digital content
A longitudinal qualitative study to explore and optimize self-management in mild to end stage chronic kidney disease with limited health literacy (Boonstra et al., 2022 [69])	Semi-structured in-depth reviews and focus groups of CKD patients (N = 24)	• CKD elusiveness • Suboptimal intake of knowledge • Not taking a front-seat role • Maintaining change	Optimization of self-management by early education and applying patient-centered strategies
What Patients with Mild-to-Moderate Kidney Disease Know, Think, and Feel about their disease (Van Dipten et al., 2018 [67])	Patients with mild-moderate kidney disease (N = 25)	• Feeling of irrelevance due to absence of CKD symptoms of physicians' minimization of seriousness of CKD • Patients failed to connect lifestyle and cardiovascular disease with CKD • Patients report tailoring information to their needs along with empathy helps	Comprehensive education about CKD Empathy, emotional support Tailoring education to patient's needs

Table 2. *Cont.*

Patient Perception of CKD Education			
Study	**Population**	**Results**	**Key Themes**
How does pre-dialysis education need to change? (Combes et al., 2017 [61])	Qualitative study, 4 hospitals, 96 staff and 93 dialysis patients	• Patients want to see teaching methods and materials improve, bias eliminated • Informal staff-patient conversations can influence decision-making • Treatment decisions were adversely affected by emotional distress	Elimination of bias Staff training Call for ongoing KRT education and review of treatment choices Emotional support
Patients' perceptions of information and education for RRT (Van Biesen et al., 2014 [66])	36 countries (N = 3867) patients on hemodialysis (in-center) or had a functioning graft	• 39% did not recall alternative treatment options aside from current one (in-center) • 79% felt involved with treatment selection, 29% felt they had no free choice • 64% could not remember receiving education on how to manage kidney disease in daily life	Call to eliminate bias in KRT modalities Improvement in the perception of the patients to choose an alternative modality
Patient education and access of ESRD patients to RRT beyond in-center hemodialysis (Mehrotra et al., 2005 [65])	299 dialysis units (N = 1365)	• 48% reported delayed presentation of KRT discussion • Majority were not presented with home dialysis modalities or renal transplantation	Incomplete presentation of treatment options

5. Ideal Education Programs for Chronic Kidney Disease

Applying adult learning theory enhances patient education by recognizing self-direction, prior experience, and the need for relevance. Effective strategies stem from Malcolm Knowles' andragogy, emphasizing autonomy, experiential learning, and collaboration [72]. Autonomy is fostered through on-demand resources for managing conditions. Experiential learning uses real-world scenarios to improve problem-solving and clinical reasoning [73]. Collaboration involves techniques such as teach-back and respect for cultural context [74]. Key principles include scaffolding learning within the Zone of Proximal Development, where new skills build upon existing knowledge [75]. Simulation exercises at the edge of learners' abilities, coupled with psychological safety, improve engagement [76]. Self-directed learning is supported through collaborative goal-setting, ensuring relevance to patients' lives. For example, diabetes education combining self-directed portals, hands-on exercises, and regular check-ins aligns with these principles. Multimodal reinforcement, using visuals and native-language materials, addresses diverse learning needs [77]. By integrating adult learning theory, patient education transforms from passive information delivery to an empowering partnership, improving adherence and building strong therapeutic relationships. This approach ensures education adapts to individual needs and aspirations, facilitating lasting behavior change.

The study by Koch-Weser et al. examined patient education programs for kidney failure treatment across four U.S. sites through session observations, educator interviews, and slide analysis. Researchers found that educational content varied widely in quality and accuracy, often overemphasizing in-center hemodialysis while neglecting conservative management options. Sessions lacked critical decision-making elements like prognosis discussions, mental health considerations, advance care planning, cost analysis, and dietary guidance. Educators reported that patients were frequently referred too late, leading to

urgent decision-making and overwhelming emotional responses, particularly in group settings. Materials often failed to meet health literacy standards, and sessions rarely provided personalized information to support shared decision-making. Nephrologists were minimally involved in curriculum development or delivery, creating disconnects between clinical care and education. Key gaps included insufficient focus on patient-centered communication, prognosis transparency, and psychosocial support. The study concludes that standardizing education programs is essential to address content deficiencies, improve health literacy practices, and integrate nephrologists more effectively. Recommendations include earlier patient referrals, tailored content delivery, and alignment with best practices for shared decision-making to empower patients in treatment choices. Limitations include limited generalizability due to the small number of sites studied [27].

The 2015 article by Isnard Bagnis et al. outlines quality standards for pre-dialysis education developed through a European expert consensus conference held in Zurich (March 2013). The conference aimed to establish best practices for educating ESKD patients about KRT options, focusing on three core areas: team structure, educational objectives, and quality assessment [78].

Experts emphasized the need for specialized education teams comprising nephrologists, nurses, dietitians, pharmacists, and social workers to deliver comprehensive KRT education. Education should prioritize empowering patients to make well-informed decisions by clarifying treatment options, understanding the impact of lifestyle choices, and the long-term risks of untreated CKD. Sessions must address emotional and psychological needs, as patients often face distress during decision-making. The consensus highlighted the importance of presenting all KRT modalities (hemodialysis, peritoneal dialysis, transplantation) neutrally, avoiding institutional or staff biases that could skew patient choices [78].

The standards stress the continuous evaluation of educational quality through patient feedback and outcome tracking, such as modality selection rates and post-education health metrics. The consensus statement acknowledges that real-world implementation requires adaptability to patient needs, staff training to eliminate unconscious biases, and the integration of psychosocial support. While the consensus provides a framework, subsequent research advocates shifting toward continuous KRT education that extends into the treatment phase, allowing patients to revisit decisions as their clinical and emotional circumstances evolve [78].

Shukla et al. advocate for standardized education frameworks to address heterogeneity in existing programs. Current education initiatives vary in terminology, structure, and content. This variability complicates efforts to evaluate and replicate successful interventions. The Template for Intervention Description and Replication (TIDieR) framework is proposed as a tool to systematically design, compare, and refine education protocols. By applying TIDieR, nephrology practices can develop interventions that improve shared decision-making and informed KRT selection, aligning with guidelines [79].

Effective education programs should combine knowledge domains such as CKD pathophysiology, KRT options, and self-care strategies, delivered through structured formats. For example, combining initial audiovisual materials with personalized counseling sessions has increased home dialysis selection rates to 70–85% in some studies. Repeated educational sessions further enhance outcomes, though benefits plateau after three sessions, with only 15–26% of patients attending multiple sessions. Despite the consensus on core content among professional organizations, empirical evidence is lacking to prioritize specific educational components or delivery methods (e.g., group vs. individual sessions) [79]. Targeting education to people with CKD who are at a high risk of CKD

progression might yield a better outcome than routine care not only for the individual but also for the healthcare system.

The review underscores the role of shared decision-making in addressing high levels of patient decisional conflict and low disease awareness. Programs like the Trial to Evaluate and Assess the effect of comprehensive pre-kidney failure education on home dialysis among VETerans (TEACH-VET) illustrate how standardized curricula can empower patients to make informed choices [79,80]. However, resource constraints and inconsistent reimbursement models disincentivize providers from offering these programs universally. The authors call for policy reforms to support scalable, equitable access to pre-kidney failure education, noting that current efforts remain fragmented and underutilized [79].

In summary, Shukla et al. argue that standardizing patient-centered education protocols can reduce variability, improve shared decision-making, and increase home dialysis adoption. This requires coordinated efforts to align terminology, content, and delivery methods while addressing systemic barriers to implementation. Such standardization is essential to achieving equitable, informed KRT selection and improving outcomes for patients with advanced CKD [79].

Van Eck Van Der Sluijs et al. examined 12 articles on dialysis education which identified key good practices emphasizing complete, objective pre-dialysis education for CKD patients to improve shared decision-making and outcomes. Structured programs, like standardized group sessions with follow-ups, significantly increase peritoneal dialysis adoption and reduce early mortality. Patient-centered tools, including decision aids (e.g., *My Kidneys, My Choice*), enhance treatment understanding and prioritize patient preferences, leading to higher self-care dialysis intentions. Multidisciplinary education teams improve home dialysis rates and decrease dialysis incidence/mortality. Effective practices also involve continuous self-management training for hemodialysis patients and proactive prognosis discussions, supported by decision aids that reduce decisional conflict [81].

From the KDIGO Controversies Conference in 2019 by Chan et al., patient education for dialysis initiation and modality choice focuses on early, comprehensive, and patient-centered approaches. Education begins in CKD stage G4, emphasizing understanding kidney failure, treatment options (transplantation, hemodialysis, peritoneal dialysis), and lifestyle implications. It should employ decision aids, facility tours, and patient testimonials to ensure informed, shared decision-making. Content is tailored to literacy, cultural norms, and patient goals, integrating telehealth tools for accessibility [82].

In the KDIGO 2024 Clinical Practice Guideline for the Evaluation and Management of CKD, patient education is addressed with some guidance on implementation. It states that education initiatives should address three main issues: standardized educational topics and resources, strategies to provide education effectively, and patient-centered concepts (Figure 2). Standardized educational topics should cover three main subjects including knowledge about CKD, treatment to slow progression and complications of CKD, and knowledge about KRT options [4].

The National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (KDOQI) agrees that if educational materials are written for patients and families, the materials should be explained clearly, preferably set at fifth-grade level to optimize understanding. Educational materials should be written and explained clearly in plain language. Cultural customization of materials may also enhance patient uptake of information. Engaging community healthcare workers in education efforts can be beneficial in providing patient/caregiver education by allowing for cultural concordant communication [4,83]. Diaz-Martinez et al. studied the effectiveness of community health worker-led CKD education and found that 85% (n = 85) expressed positive intent to seek further care (including doctor visits, CKD monitoring, and further testing) after receiving education [49].

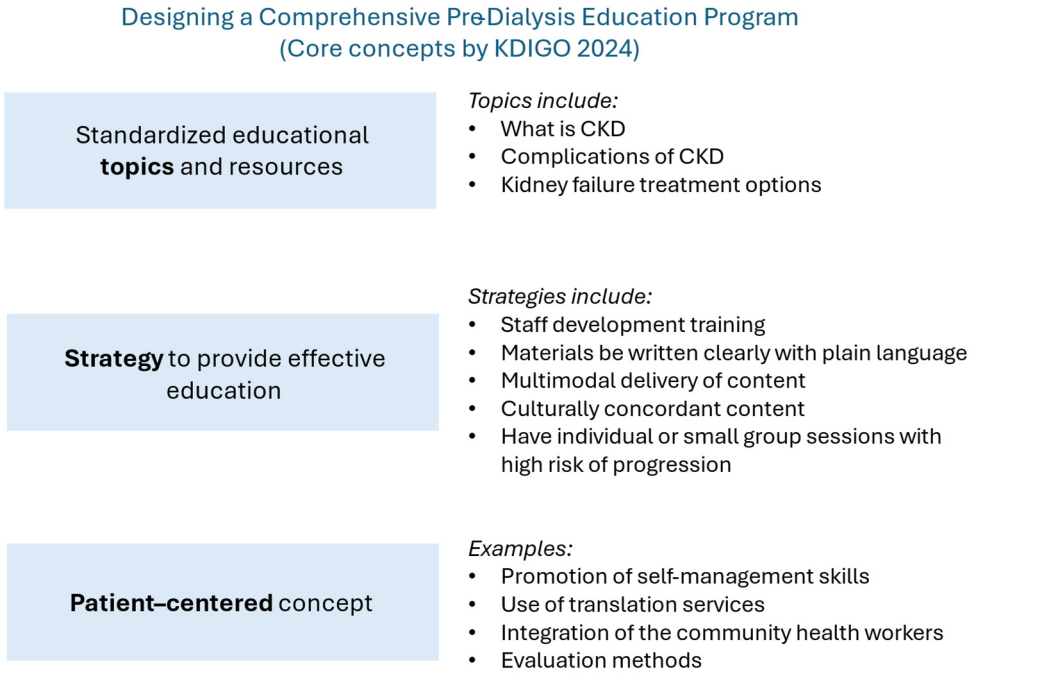

Figure 2. Designing a comprehensive pre-dialysis education program. Adapted from Stevens et al., 2024 [4].

To maximize the reach of patient education and to address the needs of patients with low health literacy, alternatives to print materials for the delivery of educational content should be considered, such as virtually delivered educational content, the inclusion of family members/caregivers in education sessions, and interactive virtual group education sessions for live question and answer opportunities [84].

Table 3 illustrates the components for an ideal patient education program on CKD.

Table 3. Components to include for an ideal patient education program on CKD.

Components for a Successful Pre-Dialysis Education Program
• Promotion of self-management skills
• Staff training to eliminate bias
• Respect for cultural context
• Employment of teach-back method
• Translational services/Translated materials
• Standardization of program
• Multimodal education materials
• Multidisciplinary team involvement
• Ongoing KRT education
• Health literacy training for educators/providers
• Quality assessment

Adapted from Stevens et al., 2024 [4], Jagodage et al., 2024 [56], and Combes et al., 2017 [61].

6. Discussion

As the burden of CKD continues to rise, healthcare providers continue to be in search of effective strategies to best educate patients. Recent studies highlight the need to promote self-management and empower patients and families to make decisions that suit their needs. Organizations play a crucial role in ensuring information is presented in an unbiased manner to allow patients to be able to make informed decisions, which emphasizes the role that physicians and providers have in treatment outcomes and health implications.

The health literacy among patients with CKD is low, at about 25%. Within CKD, low health literacy has been associated with a low GFR, higher reported cardiovascular

disease, worse blood pressure control, poor self-management skills, missed dialysis sessions, more emergency care visits, more kidney disease-related hospitalizations, higher morbidity/mortality, and fewer transplant referrals [12,23–26]. Improving patient knowledge within CKD has been linked with a reduced number of hospitalizations, a reduced number of emergency care visits, an increased time to commencement of KRT, higher rates of self-managed dialysis modalities, increased survival, reduced patient anxiety, an increased likelihood of patients being employed after KRT, more adherence to therapies, increased transplantation evaluation, and more pre-emptive transplants [12,85].

There is a lot of variation in patient education initiatives. Consensus conferences, national, and international guidelines have given recommendations on structuring patient education [4,78,82]. Patients should be referred to education when the two-year kidney failure risk threshold of greater than 40% is reached in addition to traditional GFR-based criteria (<30 mL/min/1.73 m^2) and other clinical considerations [4]. The education should take a multidisciplinary approach, including nephrology providers, nurses, dietitians, and social workers. Engaging with family members or caregivers in a CKD education program will also help facilitate self-care management and psychosocial support [4,78,82].

The delivery of the curriculum is challenging to define precisely due to the diversity of learner populations and the variety of learning styles. Additionally, different types of content may be better suited to different teaching methods. Evidence shows that assessing the patient and setting goals improves patient education and outcomes, indicating that an initial one-on-one session—or even an office visit—can be particularly beneficial for implementing this approach [86]. Although repeated sessions have been shown to enhance outcomes, Shukla et al. found that fewer than 25% of participants attended multiple sessions [79].

Educational programs can incorporate a range of methods, including written materials, individualized instruction, group sessions (either in-person or virtual), videos, and other teaching techniques [78]. The ideal structure for education depends on understanding the demographics and characteristics of the target population, which allows for customization of the curriculum and delivery methods to best meet local needs. This tailored approach helps ensure that educational strategies are effective and relevant for the specific audience.

The use of technology helps deliver content that may be convenient to patients and will likely increase in utilization, especially with the newer generation. Web-based applications are the most popular platform [87]. However, most of the content is not written at an appropriate literacy level of sixth grade or lower [4,47,88]. CKD education driven by artificial intelligence is also starting to be widely available and integrated into web-based search engines, which can have incorrect information [89]. Providers need to be aware of patient misconceptions and sources of information to allow appropriate treatment decisions. Tele-education has been shown to be feasible and to improve patient outcomes in several non-CKD conditions. It is at least noninferior to face-to-face education in increasing patient home dialysis selection rates and confidence in dialysis decision-making [80,84,90].

It is challenging to provide concrete, absolute recommendations for content because the educational goals of providers often differ from those of patients. In advanced CKD, providers typically view education as a way to disseminate information so that patients can make informed decisions about KRT. However, studies show that patients want to learn more about their condition, including its definition, ways to slow its progression, treatment options for ESKD, dietary changes, and potential complications [27,55,63,64].

Although there is overlap between provider and patient priorities, this difference supports the need for multiple educational sessions. Patient education should facilitate shared decision-making by incorporating decision aids, facility tours, and patient testimonials whenever possible to enhance information retention. Regardless of the content, it

must be tailored to the patient's language, literacy level, and cultural background to be effective [4,82].

There remain significant barriers to implementing patient education programs in advanced CKD, including limited provider incentives, a lack of reimbursement structures, and insufficient prioritization of education in clinical quality measures [12]. To address these challenges, innovative payment models that reward early identification, risk stratification, and comprehensive patient education are needed, alongside policies that embed education-specific goals into quality metrics. Expanding reimbursement for CKD education, leveraging technology for broader access, and supporting interdisciplinary care teams can further motivate healthcare systems and providers to prioritize patient education [12,79]. Ultimately, incentivizing these programs not only empowers patients to manage their health but also yields substantial cost savings by preventing complications and reducing the need for expensive interventions such as dialysis.

7. Conclusions

There are clear benefits to providing education in CKD but it currently lacks standardization. There is such variability in studies focusing on standardizing education that it is difficult to apply directly to individual practices. There are reviews and consensus statements emerging that are working to provide guidance regarding education. Overall, education initiatives for CKD should focus on standardized topics covering CKD knowledge, treatment strategies, and kidney failure management. The delivery of education should be effective through clear, culturally adapted materials tailored to patient literacy, and should take a patient-centered approach involving multidisciplinary teams, community health workers, and family caregivers. Education strategies and materials will need to be continually evaluated for patient understanding and can be guided through teach-backs, surveys, or measurable outcomes.

8. Future Direction

Moving forward, patient education in CKD should prioritize the design and validation of patient-centered educational approaches tailored to the distinct needs of different patient groups. Personalized, culturally competent approaches that integrate interdisciplinary care teams and leverage digital tools help address disparities in access and health literacy. Educational programs are expected to prioritize early-stage interventions, focusing on risk factor management, nutrition guidance, and shared decision-making to slow disease progression and improve the quality of life [55]. Innovations may include tailored content delivered through diverse formats—such as low-literacy materials, podcasts, and interactive mobile or web-based apps—to accommodate varying learning preferences and socioeconomic backgrounds [91]. In addition, more studies should be performed on the feasibility of digital platforms, such as telehealth and mobile apps, and how they can improve access and promote patient engagement. Embedding community health workers or peer support networks could enhance engagement, particularly in underserved communities [12,91].

Advancements in technology, including electronic health record-integrated platforms, will enable more precise tracking of patient needs and outcomes, facilitating real-time adjustments to educational strategies. Group education models and "teach-the-teacher" programs may become more prevalent to improve scalability and cost-effectiveness while maintaining individualized care [91]. Future research should focus on effective strategies to engage and improve the care of CKD patients with varying degrees of health literacy. Another area of focus should evaluate the long-term impact of these educational interventions on critical outcomes like dialysis initiation timelines, transplant access, and mortality rates, particularly in high-risk populations [12,55,91]. By centering patient preferences and

addressing social determinants of health, CKD education can evolve into a more equitable, patient-driven component of comprehensive kidney care [55].

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Abbreviations

The following abbreviations are used in this manuscript

CKD	Chronic kidney disease
CKM	Conservative kidney management
ESKD	End-stage kidney disease
ESRD	End-stage renal disease
GFR	Glomerular filtration rate
KDIGO	Kidney Disease: Improving Global Outcomes
KDOQI	Kidney Disease Outcomes Quality Initiative
KFRE	Kidney failure risk equation
KPNW	Kaiser Permanente North West
KRT	Kidney replacement therapy
LMICs	Low- and middle-income countries
PDAs	Patient decision aids
TCUs	Transitional care units
TIDieR	Template for Intervention Description and Replication

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