

# Barriers to Education and Shared Decision Making in the Chronic Kidney Disease Population: A Narrative Review

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## Abstract

**Purpose of review:** Provision of education to inform decision making for renal replacement therapy (RRT) is a key component in the management of chronic kidney disease (CKD), yet patients report suboptimal satisfaction with the process of selecting a dialysis modality. Our purpose is to review the influencers of RRT decision making in the CKD population, which will better inform the process of shared decision making between clinicians and patients.

**Sources of information:** PubMed and Google Scholar.

**Methods:** A narrative review was performed using the main terms “chronic kidney disease,” “CKD,” “dialysis,” “review,” “decision-making,” “decision aids,” “education,” and “barriers.” Only articles in English were accessed. The existing literature was critically analyzed from a theoretical and contextual perspective and thematic analysis was performed.

**Key findings:** Eight common themes were identified as influencers for decision making. “Patient-focused” themes including social influence, values and beliefs, comprehension, autonomy and sociodemographics, and “clinician-focused” themes including screening, communication, and engagement. Early predialysis education and decision aids can effectively improve decision making. Patient-valued outcomes need to be more fully integrated into clinical guidelines.

**Limitations:** This is not a systematic review; therefore, no formal tool was utilized to evaluate the rigor and quality of studies included and findings may not be generalizable.

**Implications:** Standardized comprehensive RRT education programs through multidisciplinary health teams can help optimize CKD patient education and shared decision making. Involving patients in the research process itself and implementing patient values and preferences into clinical guidelines can help to achieve a patient-centered model of care.

## Abrégé

**Contexte motivant la revue :** La transmission d'informations en vue d'éclairer la prise de décision en matière de thérapie de remplacement rénal (TRR) est un élément clé de la prise en charge des patients atteints d'insuffisance rénale chronique (IRC). Malgré cela, les patients rapportent des niveaux sous-optimaux de satisfaction en regard du processus de sélection d'une modalité de dialyse. Notre objectif est d'examiner les facteurs influençant la prise de décision dans le choix d'une TRR chez une population de patients atteints d'IRC, ce qui aura pour effet de mieux guider le processus de prise de décision partagée entre les cliniciens et les patients.

**Sources :** Les bases de données PubMed et Google Scholar.

**Méthodologie :** On a procédé à un examen narratif de la littérature à l'aide des principaux termes suivants : insuffisance rénale chronique (*chronic kidney disease*), IRC (*CKD*), dialyse (*dialysis*), revue (*review*), prise de décision (*decision making*), aides à la décision (*decision aids*), éducation (*education*), et obstacles (*barriers*). Seuls les articles en anglais ont été consultés. La littérature existante a fait l'objet d'une critique rigoureuse d'un point de vue théorique et contextuel, et une analyse thématique a été réalisée.

**Principaux résultats :** Nous avons relevé huit thèmes communs influençant la prise de décision. Ces thèmes se divisent en deux catégories : i) les thèmes liés au patient, soit l'influence sociale, ses valeurs et croyances, sa compréhension, son autonomie et ses caractéristiques socio-démographiques, et; ii) les thèmes liés au clinicien, soit le dépistage, la communication et son implication. Informer le patient et lui fournir des aides à la décision tôt dans le processus pré-dialyse s'avère efficace pour faciliter la prise de décision. Les résultats attendus par les patients devraient être mieux intégrés aux protocoles cliniques.



**Limites :** Cet examen ne constitue pas une revue systématique. Dès lors, aucun outil officiel n'a été employé pour évaluer la rigueur et la qualité des études retenues. Les résultats pourraient ne pas être généralisables.

**Implications :** En matière de TRR, des programmes informatifs complets et normalisés, offerts par l'entremise d'équipes pluridisciplinaires en santé, pourraient contribuer à optimiser la transmission d'informations aux patients atteints d'IRC et éclairer la prise de décision partagée. La participation des patients au processus de recherche et l'intégration de leurs valeurs et de leurs préférences dans les protocoles cliniques pourraient favoriser l'élaboration d'un modèle de soins mieux axé sur le patient.

### Keywords

CKD, education, shared decision making, influencers, barriers, patient-centered

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### What was known before

There are numerous barriers to effective education and informed decision making in the chronic kidney disease (CKD) population.<sup>1</sup> This review helps to identify barriers at the patient level and solutions at the clinician level.

### What this adds

There are numerous methods available for patients and clinicians to bring about informed decision making in the CKD population. Patient-valued outcomes should be determined and integrated into clinical guidelines to assist in shared decision making (SDM).

### Introduction

In recent years, there has been a clear shift toward a more patient-centered approach in health care.<sup>2,3</sup> Patient-centered care is a holistic approach where a strong clinician-patient relationship and the establishment of common ground are emphasized.<sup>2</sup> The UK Supreme Court recently ruled that the standard of risks, benefits, and alternative treatments provided by physicians are now to be determined by what a reasonable patient would deem important, rather than a reasonable physician; this has also been adopted by many states in the United States.<sup>4</sup> Clinicians are expected to provide patients with the education and support they need to enable understanding and integration of complex medical information to make informed decisions. This process, now referred to as "shared decision-making" (SDM), implies that medical decisions are made collaboratively in accordance with the best available evidence provided by the clinician and the values and preferences of the patient.<sup>4,5</sup>

Barriers to CKD patient education are present at three levels.<sup>1</sup> At the patient level, barriers include low levels of

health literacy, minimal awareness of kidney health in the general public, a low readiness to learn, and comorbidities.<sup>1,6</sup> At the clinician level, there are time and resource constraints, lack of confidence in communicating the complexity of CKD, competing demands, and a lack of consensus on when to diagnose and educate patients.<sup>1,7</sup> Finally, at the systematic level, barriers include limited monetary incentives for education, lack of access to decision aids, inadequate multidisciplinary care teams, and a lack of role clarity and communication between different specialties.<sup>1,6</sup>

The objective of this article is to review what influences CKD patients' treatment decisions and the available approaches for clinicians designed to overcome these barriers and aid in educating patients. This requires an understanding of patient experiences and needs during the treatment decision-making process. Both patient-physician and patient-multidisciplinary team models of care are examined throughout the review.

### Methods

We performed a narrative review on prevalent barriers to effective education and SDM in the CKD population to provide current information on what influences decisions in the CKD population and suggest practical solutions for clinicians. In our search of PubMed and Google Scholar, the main terms used were, "chronic kidney disease," "CKD," "review," "decision-making," "decision aids," "education," and "barriers." Between June 2016 and July 2018, two authors, B.C. and L.M., reviewed 162 articles, with only articles in English published after 1990 accessed. Both B.C. and L.M. came to a consensus on the articles included in the review through collaboration and discussion. We critically examined the existing literature from a theoretical and contextual perspective and performed thematic analysis looking for key themes that were

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**Table 1.** Summary of Patient-Focused Themes That Influence RRT Decision Making and the Various Solutions to Overcome Patient Barriers to Education and SDM via Clinician-Focused Themes.

Themes	Descriptions
<b>I. Patient-Focused</b>	
	<b>Influences</b>
<b>Social Influences:</b> The relationship patients have with family, friends, clinicians, and other patients	<ul style="list-style-type: none"> <li>• Past experiences with dialysis</li> <li>• Being married/living with a partner</li> <li>• Partnership with nephrologist</li> <li>• Experiences of other patients</li> </ul>
<b>Values and Beliefs:</b> What is most important to patients and the beliefs they hold	<ul style="list-style-type: none"> <li>• Individualized standardization of care</li> <li>• Preservation of QOL and lifestyle</li> <li>• Differing values between HD/PD users</li> <li>• Performance indicators less valued by patients</li> <li>• Values and beliefs change over time</li> </ul>
<b>Comprehension:</b> The degree to which patients understand the information they are being educated with	<ul style="list-style-type: none"> <li>• Quality of predialysis education</li> <li>• Amount of end-of-life support</li> <li>• Gap between perceived and actual knowledge</li> <li>• Low health literacy and numeracy</li> <li>• Lack of tailored education</li> </ul>
<b>Autonomy:</b> Patients' need for control over their health and the amount of independence in decision making	<ul style="list-style-type: none"> <li>• Lack of knowledge curtails autonomy</li> <li>• Level of confidence</li> <li>• Decisional conflict</li> <li>• Lack of "choice" over dialysis</li> </ul>
<b>Sociodemographics:</b> Patients' age, sex, race, comorbidities, and socioeconomic status	<ul style="list-style-type: none"> <li>• Lower informed and executive level decision making with age</li> <li>• Complexity managing comorbidities</li> <li>• Lower health-related QOL in women</li> <li>• Lower rates of kidney transplantation in those of low socioeconomic status</li> <li>• Poorer access to care and mistrust in those of ethnic minorities</li> </ul>
<b>2. Clinician-Focused</b>	
	<b>Practical Implications</b>
<b>Screening:</b> Exposing potential patient barriers to effective education and SDM	<ul style="list-style-type: none"> <li>• Screen for: psychological/cognitive status, level of function, preferences, health literacy and behavioral stage of change</li> <li>• Cognitive Behavioral Therapy/Psychoeducation</li> <li>• Geriatric Assessment</li> <li>• Health literacy screening tools</li> </ul>
<b>Communication:</b> Utilizing effective methods of transferring knowledge to patients	<ul style="list-style-type: none"> <li>• Structured education sessions covering all RRT options</li> <li>• Motivational interviewing</li> <li>• Framing information and risk</li> <li>• Personalizing information</li> <li>• 3-step SDM model</li> <li>• Improved support for caregivers</li> <li>• Role clarification between specialists</li> </ul>
<b>Engagement:</b> Encouraging patients to become active members of the health care team	<ul style="list-style-type: none"> <li>• Decision aids</li> <li>• Utilize patient technology</li> <li>• Patient-held records</li> <li>• Education via social media</li> <li>• SDM with multidisciplinary team</li> </ul>

Note. RRT = renal replacement therapy; SDM = shared decision-making; QOL = quality of life; HD = hemodialysis; PD = peritoneal dialysis.

most common across numerous studies and reviews. While no formal instrument or model was used to evaluate the rigor or quality of studies, B.C. and L.M. met several times to review the studies included, discussed the study design, suitability, and quality and came to a consensus. Upon completion, 12 themes were identified by B.C., narrowed down into eight themes and divided into "patient-focused"

and "clinician-focused" through team consensus. The 5 patient-focused themes are: social influence, values and beliefs, comprehension, autonomy, and sociodemographics. The 3 clinician-focused themes are: screening, communication, and engagement. Credibility was achieved through approval of themes by L.H. who has extensive experience in CKD qualitative research. Table 1 summarizes our findings.

## Review

### Patient-Focused Themes

**Social influence.** Patients' interpersonal relationships, including with family, friends, clinicians, and other patients, significantly influence their health care decision making.<sup>8-10</sup> When deciding on a dialysis modality, patients commonly refer to past experiences of themselves or relatives to help aid their decision.<sup>10,11</sup> Family is also important pertaining to education around dialysis modality, as decisions are often collaborative between the patient and family.<sup>10</sup> Being married or living with another person is associated with a higher likelihood of choosing peritoneal dialysis (PD) over other modalities due to the presence of an adequate support system.<sup>12</sup>

The relationship between the patient and nephrologist is vital to fruitful SDM. It has been shown that a trusting relationship between patients and physicians enables acceptance of medical advice and information provided by the physician.<sup>6,10</sup> This is important, as the education nephrologists provide around dialysis options has been shown to be a vital component of decision making.<sup>13,14</sup> Patients value physicians who show empathy, mutual trust and warmth, take time to provide information, and involve them in decisions.<sup>2</sup> Time and patience must be allowed for a "partnership" to develop and informed SDM to be implemented.<sup>15</sup>

Lastly, relationships with other patients can have a meaningful impact on decision making.<sup>16,17</sup> Patients refrained from pursuing a kidney transplant when someone they knew had an unsuccessful transplantation.<sup>18</sup> Similarly, other patients' experiences with vascular access was perceived to be as important as information regarding vascular access provided by their health care team.<sup>18,19</sup>

**Values and beliefs.** Patients with CKD possess unique values and beliefs that must be considered when developing a standardized approach to education. Van den Bosch et al have shown a need for predialysis education programs to be structured to cover all RRT modalities, so that every patient can make an informed decision.<sup>20</sup> Yet, while standardization may increase patients' disability-free life expectancy, it has been criticized as being too narrow and limits patient autonomy.<sup>21</sup> Therefore, Pfaff et al have established multiple "individualized standardization of care" approaches to overcome the limitations of both standardization and individualization when applied on their own.<sup>21</sup> For CKD, one way this can be achieved is through a multidisciplinary care team.<sup>22</sup> Ideally, this should include a nephrologist, CKD nurse, social worker, dietician, psychologist, physical therapist and expert patient.<sup>23</sup> This would allow RRT education to be adapted to each patient's needs and assist them in choosing their preferred modality.

Patients place a high value on preserving their quality of life (QOL).<sup>8,10</sup> Maintaining QOL and minimizing disruption of their lifestyle carries the most influence on the type of

RRT chosen.<sup>8,10</sup> There are specific factors that come into play in choosing between in-center hemodialysis (HD) and PD. PD users value maintaining a flexible schedule, autonomy, and being able to dialyze at home and overnight; conversely, in-center HD users value a planned schedule and having someone else take care of them and are generally older with more comorbidities compared to PD users.<sup>10,12,24</sup> The choice of home-based modalities (PD, home-HD) are superior to in-center HD from both a patient outcome and economic standpoint.<sup>25,26</sup> While studies have shown that many patients in the past were not informed of home-based modalities prior to initiating in-center HD,<sup>27,28</sup> there has been a recent push for a "home-first"-based approach.<sup>29</sup> This movement may have significant impact on CKD education given the potential for unintentional bias and the influence of physician judgment, with patient values and preferences still an essential consideration.<sup>30-32</sup>

Exemplifying the complexity of patient beliefs around RRT decision making, patients stated several reasons for preferring to stay on HD over pursuing kidney transplantation including fears of surgery and organ rejection, advanced age, and not wanting something foreign inside of them.<sup>18</sup> Other studies have found that patients refused to change treatments because they were more comfortable maintaining their current method, despite potential advantageous outcomes of switching.<sup>16,19</sup> Additionally, patient beliefs and preferences can change throughout the decision-making process and must be revisited, particularly if there has been a life event, such as loss of a partner, or a medical event, such as a stroke.<sup>15,32</sup>

There is a disparity between established performance indicators and patient values. Many patients do not value clinical targets, such as blood pressure, glucose levels, and "optimal" vascular access use with a fistula during the decision-making process.<sup>10,19</sup> Inadequate educational support, along with minimal impact of performance indicators on patients' QOL, are implicated as playing a role in this disparity.<sup>10</sup> Nissenon argues that to improve patient QOL, there must be a shift of focus from these basic indicators of care, to the factors that drive poor outcomes, such as infections, cardiovascular disease, diabetes, depression and end-of-life care.<sup>33</sup> With this shift, there have been many positive associations shown between patient experience and subjective and objective health outcomes, adherence, preventative care, and use of resources.<sup>34</sup> However, most valued patient-outcomes are underreported in the literature.<sup>35</sup> Evidence-based medicine around modality and access is particularly limited when it comes to treating elderly patients with CKD, who may be suffering from multiple comorbidities.<sup>36</sup> Patient-centered strategies must be implemented where treatment plans and quality metrics are aligned with the needs and goals of patients with CKD to optimize their QOL.<sup>36</sup> This begins with the appropriate incorporation of patients into the research process itself to realize their priorities, values, and experiences in recommendations for practice.<sup>37,38</sup>

**Comprehension.** While giving information to patients is relatively straightforward, understanding and integrating the information into their decision making remains a challenge for patients. A qualitative study found that CKD patients were often uncertain of their prognosis, had trouble accepting the severity of their disease due to its asymptomatic nature and did not understand the significance of dialysis on their morbidity and mortality, nor how it worked.<sup>6</sup> Davison has demonstrated a lack of end-of-life support integrated into standardized CKD management, with less than 10% of participants (n = 584) having discussed end-of-life concerns with their nephrologist in the past year and 61% regretting their decision to start dialysis.<sup>39</sup>

Lack of comprehension affects dialysis modality selection, with poor uptake of home-based modalities being associated with a lack of predialysis educational support<sup>12,40</sup> and dialysis knowledge.<sup>10</sup> Even with knowledge of their disease and treatment options, there was no association with independent decision making, indicating a gap between perceived and actual knowledge.<sup>41</sup> This discrepancy can be linked to patients' health literacy.

Health literacy is the ability of an individual to attain, process, and appreciate basic medical information and risks.<sup>7</sup> There is strong evidence of low health literacy and numeracy in patients with CKD compared to the general population.<sup>1,42,43</sup> This is a patient quality metric that must be incorporated into CKD guidelines, with Jain and Green reporting on several "red flags" that can be identified through screening and communication techniques that can be used to increase understanding.<sup>42</sup> CKD requires a high level of self-management and without adequate health literacy, care can be associated with many adverse outcomes, including increased hospital admissions, lower adherence to self-care plans, higher rates of treatment errors, and underutilization of preventive services.<sup>7,42-44</sup> Limited health literacy is preventing patients with CKD from engaging in and making informed decisions about their health.<sup>7</sup> Without adequate health literacy you cannot have SDM in its truest sense.<sup>45</sup>

While there are many negative associations between low health literacy and health outcomes, more research is needed to determine the effect of interventions on outcomes in the CKD population. Tailoring educational resources to health literacy and numeracy level has shown improvement in outcomes in the diabetes population; therefore, this may be beneficial in the CKD population, too.<sup>1,28</sup> To address health literacy in the CKD population, well-designed written education materials, with guidelines recommending a literacy level of grade 5, combined with oral instruction, can enhance patient health knowledge and recall.<sup>7,43</sup> Further techniques to improve health literacy include training physicians in communication skills,<sup>7,42</sup> simplifying words and concepts, involving family members and caregivers in discussions<sup>46</sup> and utilizing the "teach-back" technique.<sup>44,47</sup>

**Autonomy.** Another theme that influences decision making in CKD patients is the need for control and autonomy.<sup>9</sup> Murray et al found that patients with CKD maintain a need for their preferences and wishes to determine future decisions, to feel a sense of individuality and to be capable of caring for themselves.<sup>8</sup> Patients consistently attempt to preserve their autonomy and lifestyle, which is a common reason for choosing home-based therapies.<sup>9-11,16</sup> Sometimes, patients must choose between longer survival and preserving their QOL.<sup>48</sup> Therefore, more efforts should be aimed at increasing patient comprehension, such as through predialysis education programs and decision aids, to empower high quality, autonomous RRT patient decisions.

Knowledge regarding patients' disease, treatment options, and self-management, especially through predialysis educational programs, allows patients to influence their own health and make confident treatment decisions.<sup>11,41</sup> The amount of confidence one has in making decisions was found to be directly related to independent decision making, however, there was significant disparity between how much patients wanted to participate in decision making and the actual participation that occurred.<sup>41</sup> SDM cannot be accomplished without clinicians conveying autonomy to the patient. However, there are certain ethnic cultures where autonomous decisions are not part of the social norm.<sup>45</sup> Therefore, physicians must elucidate patient preferences regarding autonomous decision making.

When patients do not feel control around the decision-making process, decisional conflict becomes a significant barrier to effective decision making.<sup>8</sup> This is worsened when patients receive inadequate education, are uncertain of the consequences, have not reflected on their values, or feel pressured to make a particular choice.<sup>8,49</sup> One study found that numerous patients only pursued kidney transplantation at the behest of their nephrologist or social worker.<sup>50</sup> While this can be argued to be a good outcome since transplantation is the gold standard for RRT with increased QOL and survival, and decreased costs to the health care system,<sup>51</sup> coercion is not appropriate.<sup>32</sup> A prevalent issue encountered by patients deciding on dialysis is the feeling of having to "choose" dialysis or death.<sup>9,10,16,48</sup> When patients do not find a resolution they are more likely to prolong the decision-making process, feel regret, and place blame on their health care team.<sup>8</sup>

**Sociodemographics.** A person's age, comorbidities, sex, race, and socioeconomic status influence decision-making for patients with CKD. Age is a factor that can affect the level of patient involvement in decision making, with those who are younger playing a more active role in their care and utilizing more resources, such as the internet.<sup>1</sup> While elderly patients prefer the health care team to take a more active role, they still desire to be informed with the same amount of information on dialysis as younger patients.<sup>41</sup> However, it has been found that those >65 years of age had significantly lower

informed decision-making scores regarding the initiation of dialysis than younger patients.<sup>52</sup>

Another prominent barrier associated with advanced age is the presence of various comorbidities.<sup>47</sup> With the aging process comes increased prevalence of sensory deficits, cognitive decline, and mood disorders, along with increased risks of hypertension, cardiovascular disease, and diabetes associated with CKD.<sup>47,53</sup> It has been shown that impaired executive level decision making is a common finding in end-stage renal disease (ESRD) patients undergoing HD and has a prevalence of 31% to 61% in those >70 years of age.<sup>54</sup>

With regards to sex, it has been discovered that women with ESRD have higher rates of depression, anxiety, and personality disorders, and those on HD have lower scores pertaining to health-related QOL than men.<sup>55</sup> In addition, women shoulder more responsibility when it comes to assimilating the family unit to life with ESRD.<sup>55</sup>

When it comes to race, there is a schism in experience on dialysis between African American patients and Caucasian patients. Studies have observed that African Americans report having better QOL and health outcomes on in-center HD compared to Caucasians.<sup>18,56,57</sup> There are many possible explanations for this racial disparity including sociocultural differences and the difference in experience with access to care prior to starting dialysis.<sup>58</sup>

There are many barriers faced by those of ethnic minorities and low socioeconomic status. For instance, the Indigenous populations across Canada, the United States, Australia, and New Zealand have one-third to one-half the rate of kidney transplantation compared to non-Indigenous people due to poor access and longer waiting times.<sup>59</sup> With regards to both African American and Hispanic patients, there are also the barriers of lower rates of deceased kidney donation and mistrust in medical professionals.<sup>60</sup> Involving informal sources of information, such as family and community members in patient education can potentially overcome these sociocultural barriers and mistrust.<sup>1</sup>

### *Clinician-Focused Themes*

How do health care teams overcome these patient-level barriers? We have identified 3 themes to be considered and utilized by clinicians when navigating the potential barriers discussed throughout our “patient-focused themes” (Table 1).

**Screening.** Before a patient can be effectively educated, it is imperative to screen patients for potential issues that can prevent them from fully receiving and comprehending the information. As part of the multidisciplinary team, case managers and social workers are vital in carrying out this role.

First, it is important to screen for mental status. The CKD population, specifically the elderly, is prone to developing mood disorders, experiencing cognitive decline, and having a lower QOL than the general population.<sup>9,47,61,62</sup> Psychological status and socioeconomic status are barriers to

pursuing live donor kidney transplantation.<sup>63</sup> Screening for mood disorders, along with cognitive impairment, is needed to ensure these patients can be given the necessary support to cope with CKD and carry out treatment plans.

While there is a high prevalence of depression amongst CKD patients, it is still underdiagnosed and undertreated.<sup>64</sup> Cognitive Behavioural Therapy and psychoeducation have been shown to have a significant benefit on reducing anxiety and depression in patients undergoing dialysis.<sup>62,65-67</sup> There is a large emotional toll associated with having CKD, especially when it comes to deciding on and initiating dialysis.<sup>38,49,68</sup> Anxiety, depression, and the emotional impact of dialysis are additional patient quality metrics that must be incorporated into CKD guidelines as they have been shown to predict patient morbidity, mortality, and QOL.<sup>62</sup> Psychologists are considered an essential part of any multi-disciplinary RRT educational program.<sup>23</sup>

Elderly or frail patients may have additional barriers such as malnutrition, motor and sensory impairments,<sup>47</sup> failed vascular access,<sup>69</sup> and being dependent in activities of daily living.<sup>70</sup> A systematic geriatric assessment, which is used to determine an elderly patient’s capabilities, has been suggested to support treatment decision making in those with ESRD.<sup>70</sup> Selecting patients to undergo this assessment may be done through either a frailty screening test or a prediction rule.<sup>70</sup> Preferences and experiences differ between patients with CKD, which can be drastically different depending on their age.<sup>47</sup> Therefore, it is important to ask what CKD means to them, how it has affected their lifestyle and family, and what support structures they have.<sup>47,68</sup>

Another area that needs to be routinely screened is health literacy due to its low levels in the CKD population and the negative consequences associated with this (refer to Comprehension theme). There are many timely ways to screen for health literacy that have been studied in CKD patients, including Rapid Estimate of Adult Literacy in Medicine (REALM), Test of Functional Health Literacy in Adults, 3-Item Brief Health Literacy Screen, and Newest Vital Sign.<sup>42</sup> Those who are elderly, of lower socioeconomic status, or of an ethnic minority should be routinely screened for health literacy as these demographics have been associated with lower health literacy.<sup>42</sup> However, these demographics need to be considered along with other patient factors, such as education level, when assessing the need to screen. Once screened, at-risk patients can be identified and their education subsequently tailored.<sup>42</sup>

To deliver care appropriately, it may be necessary to screen patients for their behavioral stage of change.<sup>13</sup> Based on the Transtheoretical Model of Behaviour Change there are 4 stages that correlate to a certain readiness to make treatment decisions.<sup>63</sup> While patients may move through different stages over time, determining what stage a patient is in can help to guide the delivery of CKD education.<sup>49</sup> Information can then be tailored to help patients move to a stage where they are prepared to make vital decisions such as selecting a dialysis modality.<sup>13,63</sup> Evidence shows that by

accommodating education to a patient's readiness level doubles their chance of making a treatment decision in the following 6 months.<sup>71</sup>

**Communication.** Effective communication and education by clinicians results in improved patient comprehension and health literacy regarding their disease and treatments, with less confusion and anxiety about future steps.<sup>11,28,41</sup> To optimize patient attention and retention, educational sessions should be limited to 15 minutes, with 3-5 points addressed, divided into simple concepts that are explained separately.<sup>47</sup> Some studies suggest focusing on a single attainable goal, which will lead to success in other areas.<sup>72</sup> To further enhance retention, repetition of information over multiple (3-6) one-on-one sessions,<sup>22,47,73</sup> as well as providing information while patients are asymptomatic and cognitively sound can be helpful.<sup>16</sup> Motivational interviewing, a counseling style that engages patients' motivational drive to change behavior, increases adherence and well-being in patients with CKD.<sup>74-76</sup>

The way information is framed is important. For example, when a physician is attempting to communicate risk, framing it in terms of Relative Risk Reduction makes it easier for patients to understand than either Absolute Risk Reduction or Number Needed to Treat.<sup>77</sup> Framing can also be beneficial when it comes to helping patients understand the context of their kidney disease. To obtain "buy-in" and translate the significance of treatment plans, clinicians should frame interventions in terms of conditions more familiar to patients such as cardiovascular disease and diabetes.<sup>53</sup> Personalizing information improves patient recall and perception of risk.<sup>7,77</sup>

Conversely, there is a framing risk, or risk of physician bias, when patients are offered a treatment without being offered the full range of options available.<sup>10,16</sup> It is known that the less a physician desires a dialysis modality, the less they will try to persuade the patient's decision.<sup>32</sup> One way to prevent this bias is to design predialysis education programs that discuss the full range of options available to patients.<sup>20</sup> To improve patients' decision-making abilities, all reasonable options must be discussed, weighing the benefits and drawbacks of each, with assessment of patient preferences and whether the patient is capable of carrying out the treatment plan.<sup>49,78</sup> This is in line with the 3-step model to SDM that Elwyn et al proposed, with the introduction of choice and exploration of patient preferences being key.<sup>45</sup> Perception is predictive of beliefs and behavior after consultation.<sup>78</sup> Clear, unbiased communication about risk is vital to avoid an "illusion of competence" and promote informed decision making.<sup>7,78</sup>

Diet and lifestyle can be a major adjustment for patients with CKD. Dietary intake of sodium, potassium, phosphate and fluid needs to be restricted.<sup>72</sup> This may be more difficult for some patients than others due to their unique cultural diet. Communication and support with caregivers is needed by

clinicians, as family and social support are important components of improving diet and exercise in patients with CKD.<sup>1</sup> By providing practical educational resources that are individualized to culture and change in accordance with lifestyle and CKD variables, adherence to the CKD diet can be maximized.<sup>72</sup>

Finally, there needs to be improvement in communication between general practitioners and nephrologists, with more direct contact and role clarification regarding management of patients with CKD.<sup>6,22</sup>

**Engagement.** Engaging patients in their care is key for effective communication to facilitate change in managing chronic disease. Decision aids have become an essential tool in SDM. For patients, use of decision aids results in improved knowledge and awareness of their values, better understanding of the risks, benefits and outcomes, more proactive behavior, less decisional conflict, and informed treatment decisions that are more aligned with their preferences and values.<sup>4,7,8,77</sup> Selection of home-based therapies and transplantation can be improved through patient engagement in the predialysis education process, by utilizing decision aids, and providing both tailored patient education and continued emotional support after dialysis initiation.<sup>13,20,29,79</sup> Patients taking part in medical decisions has additional benefits for their well-being with less anxiety and depression, more feelings of control, satisfaction with their physician, and an increase in compliance with the treatment plan.<sup>41</sup>

Another method of increasing a patient's ability to engage is by utilizing their own technology. Smart phones can be used to help patients with CKD engage in their own health care by increasing self-management techniques, such as keeping track of exercise and diet, using apps to scan food items for nutritional values, and setting reminders for medications and dialysis sessions.<sup>72</sup> In fact, this results in better adherence to medications and control of blood pressure.<sup>1</sup> Increasing self-management in HD patients can effectively decrease complications and mortality and improve QOL.<sup>64</sup>

A sense of control can also be enhanced by introducing patient-held records, allowing patients to monitor their own blood pressure, and glucose levels.<sup>7</sup> Patients are interested in receiving CKD resources online and request discussions of CKD through social media outlets, yet, health care providers are not fully utilizing social media to educate patients on CKD.<sup>1</sup> Despite these suggestions, there needs to be sense of trust and mutual respect within the physician-patient relationship or patient engagement will be difficult to maintain.<sup>80</sup> Giving each consult a personal touch can help the patient and their family to gain trust and confidence in the care they are receiving.<sup>6</sup>

Techniques for increasing patient engagement are most impactful when they complement the clinical consultation, not replace it.<sup>7</sup> In fact, patients may need even more support as they transition to take on more independent roles in their care.<sup>7</sup>

CKD patients have unique needs and to address them, a multidisciplinary team is needed.<sup>61</sup> Outcomes from a multidisciplinary education program include less unplanned urgent HD, hospital admissions, cardiovascular events, and infections, and an enhanced metabolic status after starting dialysis.<sup>1</sup>

Evidence from randomized trials support the integration of SDM and it has been shown that when patients engage in SDM, they are more inclined to choose conservative treatment options than if they had not.<sup>6,45</sup> When patients participate in pre-ESRD education and are active in their dialysis modality choice, there is a better chance of selecting PD.<sup>24,79</sup>

Furthermore, engaging the patient in the intervention decided upon is vital if the patient is to carry out the plan to its full potential.<sup>53</sup> Any intervention that is chosen will not be endorsed by the patient unless they feel it is compatible with their current lifestyle,<sup>8,53</sup> with minimal invasion into their life.<sup>10</sup> While a physician may prefer a certain intervention for their patient, it may not be the “best” option if the patient will not adhere to it. When physician and patient attitudes align over the level of patient control regarding health outcomes, patient adherence and health outcomes improve significantly.<sup>81</sup>

### *Implications for Future Research*

Future research is implicated for determining the education modalities desired and learning styles that are prevalent in the CKD population, so that education can be tailored to each patient. It would be beneficial to evaluate the formal and informal educational resources that are available to patients with CKD and determine what has the most influence on treatment decisions. Further research is needed to develop additional strategies for clinicians to overcome educational and informed decision-making barriers at the patient, clinician, and systematic levels.

### **Conclusion**

Currently, clinical guidelines are based solely on the evidenced-based paradigm, where populations are the primary focus, rather than individuals.<sup>36</sup> This can create disparity between treatment recommendations and patient values, as seen with vascular access.<sup>19</sup> We would encourage those who develop CKD guidelines to utilize the Grade of Recommendations Assessment, Development and Evaluation (GRADE) Evidence to Decision frameworks, which takes into consideration both population and patient criteria for clinical recommendations.<sup>82</sup> Due to the complexity of CKD and associated comorbidities, and the population-level focus of current research, the communication of uncertainty on an individual level pertaining to illness trajectory, prognosis, and response to treatment is needed.<sup>83</sup> There is a growing awareness of the need to better align patient-valued quality metrics with clinical guidelines and there are several proposed ways to accomplish this.<sup>36</sup> The process must begin at the study level, where patient-valued outcomes are evaluated such as

burden of symptoms, level of cognitive and physical function, and health-related QOL.<sup>36</sup> This can be done using tools such as the Assessment of Quality of Life instrument.<sup>84</sup> There is currently a lack of patient-important outcomes and absolute effect measures, reported in the existing literature.<sup>35</sup>

To address this gap, patients should be appropriately involved in the study process itself, especially in setting study goals, and SDM values, such as patient preferences, should be integrated into clinical guidelines.<sup>36,45,80,85</sup> Molnar et al outline many of the potential opportunities and challenges that are present in facilitating patient involvement in the research process, with appropriate infrastructure and funds required to be successful.<sup>37</sup> This is vital given the fact that the patient experience itself, which includes both the interpersonal aspect of care and how that care is conveyed, has been positively associated with the goals of health care professionals including patient health outcomes, adherence, and use of preventative and health care resources.<sup>34</sup>

The question remains whether CKD clinics are prepared to integrate this patient-centered model into practice. Predialysis education programs are an optimal way of exposing patient-level decision-making barriers. When implemented properly, these educational programs have produced many benefits including less emergency dialysis starts, more time dialysis-free, a higher likelihood of staying employed, increased survival, and less anxiety and fear.<sup>1,23,28</sup> Yet, in practice RRT education programs have only received moderate satisfaction from patients.<sup>22,23</sup> There are several comprehensive recommendations put forth to optimize these programs, which need to be implemented by CKD clinics to improve the delivery of education and care to patients.<sup>23,28</sup> Patient decision aids are another vital tool that should be utilized. These decision aids, along with tailored education and ongoing support to help patients cope, can effectively increase the rate of home-based dialysis modalities (home-HD and PD) and transplantation, which have health outcome and cost benefits over in-center HD.<sup>25,29,79</sup>

“Patient-centered care” needs to be the framework of every physician-patient interaction. It is through screening, communicating and engaging patients with CKD in their health care, that clinicians will be given the tools to overcome many patient-level barriers to effective education and SDM. Clinicians must be willing to manage the entire person, not just their medical problems, which requires the expertise of a multidisciplinary team.<sup>2,21</sup>

Patients with CKD have many different characteristics, perspectives, and lived experiences that impact their treatment decisions. These include social influences, values and beliefs, level of comprehension, need for autonomy, and sociodemographics. These factors influence the way patients receive education and make medical decisions, which is why clinicians must value and participate in SDM to navigate potential conflicts. Through the recommendations laid out in this narrative review, the number of informed patients can be maximized, allowing SDM involving RRT to be fulfilled.



## List of Abbreviations

CKD, chronic kidney disease; ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; QOL, quality of life; RRT, Renal Replacement Therapy; SDM, shared decision-making.

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Data and materials are available on request from the Corresponding Author.

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## References

- Narva AS, Norton JM, Boulware LE. Educating patients about CKD: the path to self-management and patient-centered care. *Clin J Am Soc Nephrol*. 2016;11:694-703.
- Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med*. 2000;51:1087-1110.
- Coulter A, Collins A. *Making Shared Decision-Making a Reality: No Decision About Me, Without Me*. London, England: King's Fund; 2011.
- Spatz ES, Krumholz HM, Moulton BW. The new era of informed consent: getting to a reasonable-patient standard through shared decision making. *JAMA*. 2016;315:2063-2064.
- Barry MJ, Edgman-Levitan S. Shared decision making—pinnacle of patient-centered care. *N Engl J Med*. 2012;366:780-781.
- Tam-Tham H, Hemmelgarn BR, Campbell DJ, et al. Primary care physicians' perceived barriers, facilitators and strategies to enhance conservative care for older adults with chronic kidney disease: a qualitative descriptive study. *Nephrol Dial Transplant*. 2016;31:1864-1870. doi:10.1093/ndt/gfv408.
- Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. *BMJ*. 2007;335:24-27.
- Murray MA, Brunier G, Chung JO, et al. A systematic review of factors influencing decision-making in adults living with chronic kidney disease. *Patient Educ Couns*. 2009;76:149-158.
- Winterbottom A, Bekker HL, Conner M, Mooney A. Choosing dialysis modality: decision making in a chronic illness context. *Health Expect*. 2014;17:710-723.
- Harwood L, Clark AM. Understanding pre-dialysis modality decision-making: A meta-synthesis of qualitative studies. *Int J Nurs Stud*. 2013;50:109-120.
- Jennette C, Derebail V, Baldwin J, et al. Renal replacement therapy and barriers to choice: using a mixed methods approach to explore the patient's perspective. *J Nephrol Soc Work/Counc Nephrol Soc Work Natl Kidney Found*. 2009;32:15-26.
- Chanouzas D, Ng KP, Fallouh B, Baharani J. What influences patient choice of treatment modality at the pre-dialysis stage? *Nephrol Dial Transplant*. 2012;27:1542-1547.
- Prakash S, McGrail A, Lewis SA, et al. Behavioral stage of change and dialysis decision-making. *Clin J Am Soc Nephrol*. 2015;10:197-204.
- Nesrallah GE, Mendelssohn DC. Reflections on education interventions and optimal dialysis starts. *Perit Dial Int*. 2013;33:358-361.
- Towle A, Godolphin W. Framework for teaching and learning informed shared decision making. *BMJ*. 1999;319:766-771.
- Morton RL, Tong A, Howard K, Snelling P, Webster AC. The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. *BMJ*. 2010;340:c112.
- Griva K, Li ZH, Lai AY, Choong MC, Foo MW. Perspectives of patients, families, and health care professionals on decision-making about dialysis modality—the good, the bad, and the misunderstandings! *Perit Dial Int*. 2013;33:280-289.
- Gordon EJ. Patients' decisions for treatment of end-stage renal disease and their implications for access to transplantation. *Soc Sci Med*. 2001;53:971-987.
- Xi W, Harwood L, Diamant MJ, et al. Patient attitudes towards the arteriovenous fistula: a qualitative study on vascular access decision making. *Nephrol Dial Transplant*. 2011;26:3302-3308.
- Van den Bosch J, Warren DS, Rutherford PA. Review of predialysis education programs: a need for standardization. *Patient Prefer Adherence*. 2015;9:1279-1291.
- Pfaff H, Driller E, Ernstmann N, et al. Standardization and Individualization in care for the elderly : proactive behavior through individualized standardization. *Open Longev Sci*. 2010;4:51-57.
- Goovaerts T, Bagnis Isnard C, Crepaldi C, et al. Continuing education: preparing patients to choose a renal replacement therapy. *J Ren Care*. 2015;41:62-75.
- Isnard Bagnis C, Crepaldi C, Dean J, et al. Quality standards for predialysis education: results from a consensus conference. *Nephrol Dial Transplant*. 2015;30:1058-1066.
- Wuerth DB, Finkelstein SH, Schwetz O, Carey H, Klinger AS, Finkelstein FO. Patients' descriptions of specific factors leading to modality selection of chronic peritoneal dialysis or hemodialysis. *Perit Dial Int*. 2002;22:184-190.
- Klarenbach SW, Tonelli M, Chui B, Manna BJ. Economic evaluation of dialysis therapies. *Nat Rev Nephrol*. 2014;10:644-652.
- Finkelstein FO, Story K, Firanek C, et al. Perceived knowledge among patients cared for by nephrologists about chronic

- kidney disease and end-stage renal disease therapies. *Kidney Int.* 2008;74:1178-1184.
27. Mehrotra R, Marsh D, Vonesh E, Peters V, Nissenson A. Patient education and access of ESRD patients to renal replacement therapies beyond in-center hemodialysis. *Kidney Int.* 2005;68:378-390.
  28. Saggi SJ, Allon M, Bernardini J, et al. Considerations in the optimal preparation of patients for dialysis. *Nat Rev Nephrol.* 2012;8:381-389.
  29. Combes G, Allen K, Sein K, Girling A, Lilford R. Taking hospital treatments home: a mixed methods case study looking at the barriers and success factors for home dialysis treatment and the influence of a target on uptake rates. *Implement Sci.* 2015;10:148.
  30. Tong A, Lesmana B, Johnson DW, Wong G, Campbell D, Craig JC. The perspectives of adults living with peritoneal dialysis: thematic synthesis of qualitative studies. *Am J Kidney Dis.* 2013;61:873-888.
  31. Walker RC, Morton RL, Palmer SC, Marshall MR, Tong A, Howard K. A discrete choice study of patient preferences for dialysis modalities. *Clin J Am Soc Nephrol.* 2018;13:100-108.
  32. Lelie A. Decision-making in nephrology: shared decision making? *Patient Educ Couns.* 2000;39:81-89.
  33. Nissenson AR. Improving outcomes for ESRD patients: shifting the quality paradigm. *Clin J Am Soc Nephrol.* 2014; 9: 430-434.
  34. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open.* 2013;3:e001570. doi:10.1136/bmjopen-2012-001570.
  35. Agarwal A, Johnston BC, Vernooij RWM, et al. Authors seldom report the most patient-important outcomes and absolute effect measures in systematic review abstracts. *J Clin Epidemiol.* 2017;81:3-12.
  36. O'Hare AM, Rodriguez RA, Bowling CB. Caring for patients with kidney disease: shifting the paradigm from evidence-based medicine to patient-centered care. *Nephrol Dial Transplant.* 2016;31:368-375.
  37. Molnar AO, Barua M, Konvalinka A, Schick-Makaroff K. Patient engagement in kidney research: opportunities and challenges ahead. *Can J Kidney Heal Dis.* 2017;4:1-11.
  38. Cassidy B, Harwood L, Getchell L, et al. Educational support around dialysis modality decision making in patients with Chronic Kidney Disease (CKD): a qualitative study. *Can J Kidney Heal Dis.* In press.
  39. Davison SN. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol.* 2010;5:195-204.
  40. Manns BJ, Taub K, Vanderstraeten C, et al. The impact of education on chronic kidney disease patients' plans to initiate dialysis with self-care dialysis: a randomized trial. *Kidney Int.* 2005;68:1777-1783.
  41. Orsino A, Cameron JI, Seidl M, Mendelssohn D, Stewart DE. Medical decision-making and information needs in end-stage renal disease patients. *Gen Hosp Psychiatry.* 2003;25:324-331.
  42. Jain D, Green JA. Health literacy in kidney disease: review of the literature and implications for clinical practice. *World J Nephrol.* 2016;5:147-151.
  43. Morony S, Flynn M, McCaffery KJ, Jansen J, Webster AC. Readability of written materials for CKD patients: a systematic review. *Am J Kidney Dis.* 2015;65:842-850.
  44. Devraj R, Borrego M, Vilay AM, Gordon EJ, Pailden J, Horowitz B. Relationship between health literacy and kidney function. *Nephrology (Carlton).* 2015;20:360-367.
  45. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med.* 2012;27:1361-1367.
  46. Prieto-Velasco M, Isnard Bagnis C, Dean J, et al. Predialysis education in practice: a questionnaire survey of centres with established programmes. *BMC Res Notes.* 2014;7:730.
  47. Collister D, Russell R, Verdon J, Beaulieu M, Levin A. Perspectives on optimizing care of patients in multidisciplinary chronic kidney disease clinics. *Can J Kidney Heal Dis.* 2016;3:32.
  48. Hemmett J, McIntyre CW. A dialysis patient's choice and a nephrologist's obligation: the need to understand and value the patient's perspective. *Semin Dial.* 2017;30:3-5.
  49. Loiselle M-C, Michaud C, O'Connor AM. Decisional needs assessment to help patients with advanced chronic kidney disease make better dialysis choices. *Nephrol Nurs J.* 2016;43:463-477493.
  50. Gordon EJ. Stability of end-stage renal disease patients' treatment decisions. *Transplant Proc.* 2001;33:3006-3009.
  51. Naylor KL, Dixon SN, Garg AX, et al. Variation in access to kidney transplantation across renal programs in Ontario, Canada. *Am J Transplant.* 2017;17:1585-1593.
  52. Song M-K, Ward SE. The extent of informed decision-making about starting dialysis: does patients' age matter? *J Nephrol.* 2014;27:571-576.
  53. Tsang JY, Blakeman T, Hegarty J, Humphreys J, Harvey G. Understanding the implementation of interventions to improve the management of chronic kidney disease in primary care: a rapid realist review. *Implement Sci.* 2016;11:47.
  54. Kurella Tamura M, Larive B, Unruh ML, et al. Prevalence and correlates of cognitive impairment in hemodialysis patients: the frequent hemodialysis network trials. *Clin J Am Soc Nephrol.* 2010;5:1429-1438.
  55. Cobo G, Hecking M, Port FK, et al. Sex and gender differences in chronic kidney disease: progression to end-stage renal disease and haemodialysis. *Clin Sci (Lond).* 2016;130:1147-1163.
  56. Kutner NG, Devins GM. A comparison of the quality of life reported by elderly whites and elderly blacks on dialysis. *Geriatr Nephrol Urol.* 1998;8:77-83.
  57. Lopes AA, Bragg-Gresham JL, Satayathum S, et al. Health-related quality of life and associated outcomes among hemodialysis patients of different ethnicities in the United States: the dialysis outcomes and practice patterns study (DOPPS). *Am J Kidney Dis.* 2003;41:605-615.
  58. Kutner NG, Zhang R, Brogan D. Race, gender, and incident dialysis patients' reported health status and quality of life. *J Am Soc Nephrol.* 2005;16:1440-1448.
  59. Cass A, Devitt J, Preece C, et al. Barriers to access by Indigenous Australians to kidney transplantation: the IMPAKT study. *Nephrology (Carlton).* 2004;9(suppl 4):S144-S146.
  60. Waterman AD, Robbins ML, Paiva AL, et al. Your path to transplant: a randomized controlled trial of a tailored computer education intervention to increase living donor kidney transplant. *BMC Nephrol.* 2014;15:166.

61. Idier L, Untas A, Koleck M, Chauveau P, Rasclé N. Assessment and effects of therapeutic patient education for patients in hemodialysis: a systematic review. *Int J Nurs Stud*. 2011;48:1570-1586.
62. Valsaraj BP, Bhat SM, Latha KS. Cognitive behaviour therapy for anxiety and depression among people undergoing haemodialysis: a randomized control trial. *J Clin Diagn Res*. 2016;10:VC06-VC10.
63. Waterman AD, Robbins ML, Peipert JD. Educating prospective kidney transplant recipients and living donors about living donation: practical and theoretical recommendations for increasing living donation rates. *Curr Transplant Reports*. 2016;3:1-9.
64. Li H, Jiang Y-F, Lin C-C. Factors associated with self-management by people undergoing hemodialysis: a descriptive study. *Int J Nurs Stud*. 2014;51:208-216.
65. Chan R, Dear BF, Titov N, Chow J, Suranyi M. Examining internet-delivered cognitive behaviour therapy for patients with chronic kidney disease on haemodialysis: a feasibility open trial. *J Psychosom Res*. 2016;89:78-84.
66. Sohn BK, Oh YK, Choi J-S, et al. Effectiveness of group cognitive behavioral therapy with mindfulness in end-stage renal disease hemodialysis patients. *Kidney Res Clin Pract*. 2018;37:77-84.
67. Al Sarairoh FA, Aloush SM, Al Azzam M, Al Bashtawy M. The effectiveness of cognitive behavioral therapy versus psychoeducation in the management of depression among patients undergoing haemodialysis. *Issues Ment Health Nurs*. 2018;39:514-518.
68. O'Hare AM, Richards C, Szarka J, et al. Emotional impact of illness and care on patients with advanced kidney disease. *Clin J Am Soc Nephrol*. 2018;13:1022-1029.
69. Al-Jaishi AA, Oliver MJ, Thomas SM, et al. Patency rates of the arteriovenous fistula for hemodialysis: a systematic review and meta-analysis. *Am J Kidney Dis*. 2014;63:464-478.
70. van Loon IN, Wouters TR, Boereboom FTJ, Bots ML, Verhaar MC, Hamaker ME. The relevance of geriatric impairments in patients starting dialysis: a systematic review. *Clin J Am Soc Nephrol*. 2016;11:1245-1259.
71. Prochaska JO, Velicer WF, Rossi JS, et al. Stages of change and decisional balance for 12 problem behaviors. *Health Psychol*. 1994;13:39-46.
72. Beto JA, Schury KA, Bansal VK. Strategies to promote adherence to nutritional advice in patients with chronic kidney disease: a narrative review and commentary. *Int J Nephrol Renovasc Dis*. 2016;9:21-33.
73. Brehaut JC, Colquhoun HL, Eva KW, et al. Practice feedback interventions: 15 suggestions for optimizing effectiveness. *Ann Intern Med*. 2016;164:435-441.
74. García-Llana H, Remor E, del Peso G, Celadilla O, Selgas R. Motivational interviewing promotes adherence and improves wellbeing in pre-dialysis patients with advanced chronic kidney disease. *J Clin Psychol Med Settings*. 2014;21:103-115.
75. Kalantar-Zadeh K. Patient education for phosphorus management in chronic kidney disease. *Patient Prefer Adherence*. 2013;7:379-390.
76. Dashtidehkordi A, Shahgholian N, Maghsoudi J, Sadeghian J. The effects of motivational interviewing on the health status of patients undergoing hemodialysis. *Iran J Nurs Midwifery Res*. 2018;23:287-291.
77. Ahmed H, Naik G, Willoughby H, Edwards AGK. Communicating risk. *BMJ*. 2012;344:e3996.
78. Makoul G, Arntson P, Schofield T. Health promotion in primary care: physician-patient communication and decision making about prescription medications. *Soc Sci Med*. 1995;41:1241-1254.
79. Prieto-Velasco M, Quiros P, Remon C, Spanish Group for the Implementation of a Shared Decision Making Process for RRT Choice with Patient Decision Aid Tools. The concordance between patients' renal replacement therapy choice and definitive modality: is it a Utopia? *PLoS ONE*. 2015;10:e0138811.
80. Cukor D, Cohen LM, Cope EL, et al. Patient and other stakeholder engagement in patient-centered outcomes research institute funded studies of patients with kidney diseases. *Clin J Am Soc Nephrol*. 2016;11:1703-1712. doi:10.2215/CJN.09780915.
81. Christensen AJ, Howren MB, Hillis SL, et al. Patient and physician beliefs about control over health: association of symmetrical beliefs with medication regimen adherence. *J Gen Intern Med*. 2010;25:397-402.
82. Alonso-Coello P, Oxman AD, Moberg J, et al. GRADE Evidence to Decision (EtD) frameworks: a systematic and transparent approach to making well informed healthcare choices. 2: clinical practice guidelines. *BMJ*. 2016;353:i2089.
83. Smith AK, White DB, Arnold RM. Uncertainty—the other side of prognosis. *N Engl J Med*. 2013;368:2448-2450.
84. Hawthorne G, Richardson J, Osborne R. The Assessment of Quality of Life (AQoL) instrument: a psychometric measure of health-related quality of life. *Qual Life Res*. 1999;8:209-224.
85. van der Weijden T, Pieterse AH, Koelewyn-van Loon MS, et al. How can clinical practice guidelines be adapted to facilitate shared decision making? a qualitative key-informant study. *BMJ Qual Saf*. 2013;22:855-863.