

# Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care

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**Patients with advanced chronic kidney disease (CKD) have a high burden of physical and psychosocial symptoms, poor outcomes, and high costs of care. Current paradigms of care for this highly vulnerable population are variable, prognostic and assessment tools are limited, and quality of care, particularly regarding conservative and palliative care, is suboptimal. The KDIGO Controversies Conference on Supportive Care in CKD reviewed the current state of knowledge in order to define a roadmap to guide clinical and research activities focused on improving the outcomes of people living with advanced CKD, including those on dialysis. An international group of multidisciplinary experts in CKD, palliative care, methodology, economics, and education identified the key issues related to palliative care in this population. The conference led to a working plan to address outstanding issues in this arena, and this executive summary serves as an output to guide future work, including the development of globally applicable guidelines.**

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**KEYWORDS:** chronic kidney disease; conservative care; palliative care; supportive care; symptoms; withdrawal of dialysis

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Patients with advanced chronic kidney disease (CKD) have a high burden of physical and psychosocial symptoms, poor outcomes, and high costs of care. Annual mortality of patients on dialysis exceeds 20%. Withdrawal from dialysis is a common cause of death for dialysis patients worldwide, reflecting their poor health-related quality of life (HRQL), although this may be owing to nonmedical reasons in low-income and lower-middle-income countries. The high level of disability and symptom burden in some patients with advanced CKD is not necessarily improved by dialysis. To improve the quality of care, it is now recognized that palliative care principles need to be integrated into the routine care of these patients. Despite great need, palliative care is underutilized among patients with advanced CKD compared with other chronic disease populations, even in countries where such care is available.<sup>1,2</sup> Rates of hospitalization, intensive care unit admissions, and other intensive treatments are higher for CKD patients in the last month of life compared with other severe chronic illnesses, including chronic obstructive lung disease, congestive heart failure, and advanced liver disease.<sup>3</sup> Current evidence suggests that end-of-life care practices are not consistent with preferences of patients with advanced CKD (i.e., GFR categories G4 and G5).<sup>4</sup> The majority of dialysis patients die in acute care facilities, receiving high-intensity care that may be unwanted.<sup>1</sup> Health systems and policies that integrate palliative care are urgently required to optimize the care of CKD patients. To achieve international, multidisciplinary, transparent, and unbiased analysis, Kidney

Disease: Improving Global Outcomes (KDIGO), in partnership with the International Society of Nephrology, brought together experts from around the world to a Controversies Conference on Supportive Care in CKD in Mexico City in December 2013.

**CONFERENCE METHODS AND PARTICIPANTS**

Drs Sara Davison (University of Alberta, Edmonton, AB, Canada) and Gregorio Obrador (Universidad Panamericana School of Medicine, Mexico City, Mexico) co-chaired this conference. The objectives were to (1) develop consensus on a definition and conceptual framework for kidney supportive care; (2) summarize the current state of knowledge of kidney supportive care; (3) discuss what recommendations could be derived from the available knowledge; and (4) assess what needs to be undertaken to improve the evidence base for clinical management and policy development. The conference format and deliberations allowed for consensus building, and were based on work and literature reviews performed before the meeting, presentations at the meeting, and formulations of action plans after the meeting. The overall aim of this conference was to discuss issues related to the international application of supportive medicine to CKD patients with the ultimate goal of working toward the development of globally applicable guidelines.

A total of 45 participants with representation from all parts of the world attended, including leading worldwide experts in supportive care, nephrology, epidemiology, health economics, and research, in order to ensure diverse perspectives and inform the discussions. Four clinical fellows were included with the goal of building clinical and research capacity in kidney supportive care.

The key areas discussed included the following: (1) symptom assessment and management; (2) prognostication; (3) shared decision making and advance care planning (ACP); (4) withdrawal of dialysis; and (5) conservative (nondialysis) care. The scope of this conference was limited to patients with

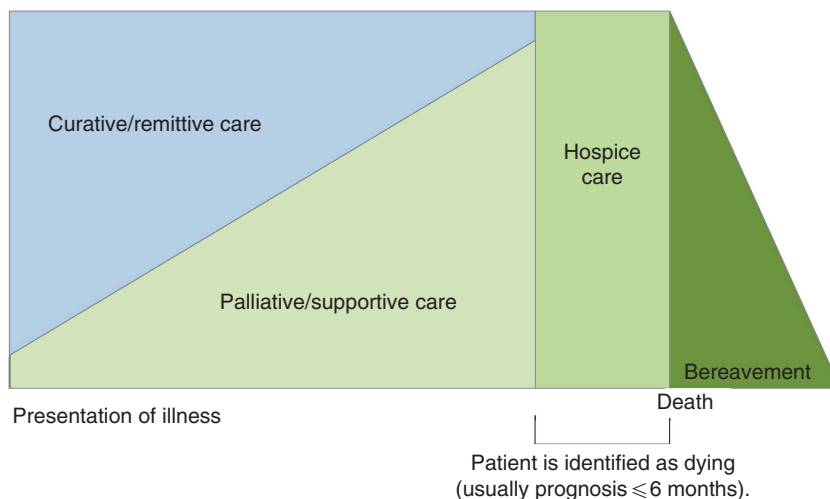
established CKD, mostly under the care of nephrologists. Issues related to patients with acute kidney injury and kidney transplantation were not addressed. Owing to a dearth of evidence in pediatric patients, this work focused on adults. Participants were involved in plenary sessions and breakout groups to foster discussion and critical review of data and to develop recommendations for clinical guidance and research. Further conference details can be found at the KDIGO website.<sup>5</sup>

**DEFINITION AND CONCEPTUAL FRAMEWORK FOR KIDNEY SUPPORTIVE CARE**

To ensure that all discussions and outputs were anchored in a common definition, we adopted the World Health Organization definition of palliative care.<sup>6</sup> *Palliative care, therefore, is an approach that improves the HRQL of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.* However, the term ‘supportive care’ is used throughout this report rather than ‘palliative care’ because patients and health-care professionals prefer it,<sup>7–9</sup> and we use it here with the understanding that, in this context, we are considering supportive care for those with advanced disease.

Kidney supportive care involves services that are aimed at improving the HRQL for patients with established CKD, at any age, and can be provided together with therapies intended to prolong life, such as dialysis.<sup>10,11</sup> Supportive care helps patients cope with living, as well as dying, regardless of life expectancy. Hospice/terminal care, also referred to as end-of-life care, shares the same philosophy, but it is under the larger umbrella of supportive care, and it is typically limited to patients who are believed to be within months of death (Figure 1).

The following sections describe the key discussion points and recommendations of the various workgroups.



**Figure 1 | Conceptual framework for supportive care in chronic kidney disease (CKD).**

## SYMPTOM ASSESSMENT AND MANAGEMENT

Patients with advanced CKD experience a multiplicity of symptoms, and these symptoms constitute a large burden for patients and caregivers. Eight validated global symptom assessment tools of varying length and utility exist for CKD patients,<sup>12</sup> including the Edmonton Symptom Assessment System-revised: Renal,<sup>13–15</sup> the Palliative Care Outcome Scale–Renal,<sup>16,17</sup> and the Dialysis Symptom Index.<sup>18</sup> These tools have been translated into several languages, and they are appropriate for routine screening in renal programs to identify patients' common and troublesome symptoms, including patients who are in the last days of life.<sup>12–14,19–25</sup>

Regular symptom assessment using validated tools helps redirect treatment toward a patient-centered care model and provides the opportunity for discussions about appropriate supportive care options. Patient-centered care emphasizes treatment that matters most to patients and aligns treatment to patients' values, preferences, and goals. Patients with advanced CKD have identified symptom assessment and management as a top priority.<sup>26,27</sup> Patients should also be screened for depressive symptoms using standardized instruments that have well-documented evidence for validity in CKD.<sup>28–31</sup>

One of the controversies is uncertainty about what health-care providers should do with symptom screening information once identified. Many health-care providers, especially in low-income and lower-middle-income countries, have limited access to expertise or resources to pursue effective treatment options. Given the burden of illness, there was clear consensus that resources are needed to address somatic symptoms and depression in this population. The International Association for Hospice and Palliative Care, following a request by the World Health Organization, developed a list of essential medicines for symptom management in palliative care. The group recommended the development of a similar list of essential medicines in the context of advanced CKD. Limitations related to gaps in quality of evidence in this population, and the wide variations in the affordability and accessibility of medications in various parts of the world, were noted.

Developing treatment strategies is difficult given the complexity of CKD patients and the considerable variation in the level of evidence for management strategies for different symptoms. Many of the recommendations have been extrapolated from treatments used successfully in the general population. Studies to evaluate treatment efficacy in CKD are often underpowered and typically do not address outcomes that are most relevant to patients, such as overall symptom burden and HRQL. Extrapolation from the general literature, however, may guide treatment, especially where promising interventions have a low risk to high benefit ratio. Several nonpharmacologic and pharmacologic management strategies are potentially effective for managing multiple symptoms concurrently, and they may have a synergistic effect on overall HRQL. Nonpharmacological interventions may apply in multiple contexts including varying socio-

economic and cultural contexts. Table 1 provides a high-level summary of the literature synthesis for some of the common symptoms experienced by CKD patients.

Participants acknowledged that there is sufficient evidence to support the development of guidelines to aid in the stepwise clinical approach to several symptoms in CKD, including uremic pruritus, sleep disturbances, restless legs syndrome, pain, and depression. However, the workgroup also recognized that evidence gaps remain and thus research on the effective management of specific symptoms in CKD populations is a priority. Robust guideline development would be aided by longer-term studies on the relative effectiveness of treatment strategies and with the evaluation of algorithmic approaches that include clinically relevant outcomes such as adequate control of bothersome symptoms, overall symptom burden, and HRQL. Recommendations for symptom assessment and management are outlined in Table 2.

## THE VALUE OF ESTIMATING PROGNOSIS IN CKD

The ability to prognosticate and communicate prognosis to CKD patients is of immense importance. Overoptimistic estimations of prognosis may lead to inappropriately aggressive treatment.<sup>32</sup> Validated integrated prognostic tools help in identifying and prioritizing patients with whom conversations about goals of care and conservative options would be beneficial. Most patients with advanced CKD will eventually experience progressive functional decline associated with physical and psychological symptoms, but these illness trajectories appear particularly variable.<sup>33,34</sup> Predicting these trajectories and communicating prognosis are integral to quality care and shared decision making, and it aids timely and effective planning of supportive services.

Despite the fact that most patients want to know their prognosis and future illness trajectories, evidence suggests that sharing this information is not yet a standard clinical practice.<sup>4,35</sup> The conferees advocated that CKD patients in whom the prognosis is particularly poor should be informed that dialysis might not confer a survival advantage or improve HRQL or functional status over medical management. It was acknowledged, however, that ethnicity and cultural factors may influence the willingness to know and/or communicate prognosis.

The number of studies that attempt to combine prognostic factors into clinically useful prediction tools is small.<sup>36,37</sup> The 'Surprise Question' 'Would you be surprised if this patient were to die in the next 12 months?' is a simple and useful clinical tool to identify dialysis patients at a high risk for early mortality.<sup>38</sup> Functional decline often signals shortened survival, acting as a sentinel event that can be readily observed and measured. The modified Karnofsky activity scale or screening activities of daily living may be a simple and reliable means for identifying patients at risk for early death.<sup>39</sup> To date, there are no studies in the nondialysis CKD population examining the value of these assessment tools.

Conferees agreed that developing prognostic models for clinically meaningful outcomes is a high priority in

**Table 1 | Symptoms in CKD: literature synthesis**

Symptom	Summary of prevalence and severity	Impact	Management
Uremic pruritus	24 studies representing 19,226 dialysis patients reported a mean prevalence of 40.6%. <sup>79–102</sup> In studies reporting severity, 24.5% of patients experienced severe pruritus.	Associated with decreased HRQL, and contributes to other symptoms such as poor sleep and depression. <sup>80,86–88,98,102,103</sup>	The highest levels of evidence for efficacy are for topical agents (e.g., capsaicin, emollients if concurrent dry skin), oral medications (e.g., gabapentinoids), and ultraviolet B therapy.
Sleep disorders	40 studies, representing 7391 patients, reported a mean prevalence of 60.1%. This included 14 studies of sleep disturbances—not otherwise specified (prevalence 54.9%); <sup>104–117</sup> 11 studies of poor sleep quality defined by Pittsburgh Sleep Quality Index score (PSQI) > 5 (prevalence of 65.4%); <sup>118–128</sup> 4 studies of poor sleep quality defined by PSQI ≥ 5 (prevalence 83.1%); <sup>129–132</sup> 1 study of poor sleep quality defined by PSQI ≥ 6 (prevalence 75%); <sup>133</sup> and 14 studies of insomnia (prevalence 60.8%). <sup>108,110,113,120,134–143</sup> Severity was reported variably.	Associated with fatigue, <sup>144,145</sup> poor HRQL, <sup>107,118,119,122,124,126,146–150</sup> and depression. <sup>118,119,122,146,149–151</sup>	Management involves basic sleep hygiene measures, management of concurrent symptoms, nonpharmacologic interventions including exercise and cognitive behavioral therapy, and pharmacologic management including simple sedatives.
Restless legs syndrome (RLS)	Prevalence ~ 10–20% of long-term dialysis patients when strict diagnostic criteria were applied. <sup>152</sup> Approximately 80% of RLS sufferers also experience the sleep disorder periodic limb movements (PLMS).	Associated with impaired sleep and HRQL, <sup>153</sup> premature withdrawal from dialysis, <sup>154</sup> and increased cardiovascular morbidity and mortality. <sup>155</sup>	Nonpharmacologic measures may include removal of stimulants, good sleep hygiene, changes in the dialysis regime, aerobic exercise, <sup>156–158</sup> pneumatic compression devices, <sup>159–161</sup> and correction of hyperphosphatemia and iron deficiency. Pharmacologic approaches might include cessation of medications that interfere with the dopamine pathway, or trials of levodopa, nonergot dopamine agonists, or low-dose gabapentinoids.
Anorexia	18 studies, representing 3122 patients, reported a prevalence of 56% (range 9–82%).	Associated with malnutrition, poor HRQL, depression, greater hospitalization rates, and increased mortality. <sup>162–164</sup>	Management has not been studied systematically in CKD.
Nausea	14 studies, representing 1774 patients, reported a prevalence of 46% (range 9–90%).	Impact has not been assessed systematically in CKD.	Management has not been studied systematically in CKD.
Vomiting	12 studies, representing 1511 patients, reported a prevalence of 23% (range 11–68%).	Impact has not been assessed systematically in CKD.	Management has not been studied systematically in CKD.
Constipation	17 studies, representing 2001 patients, reported a prevalence of 40% (range 8–65%).	Impact has not been assessed systematically in CKD.	Management has not been studied systematically in CKD.
Diarrhea	10 studies, representing 921 patients, reported a prevalence of 21% (range 8–33%).	Impact has not been assessed systematically in CKD.	Management has not been studied systematically in CKD.
Depression	A systematic review of observational studies reported a prevalence of 21.5% in CKD stages 1–4 (95% CI 11.1–37.2), 22.8% in dialysis patients (CI 18.8–27.6), and 25.7% in kidney transplant recipients (CI 12.8–44.9) based on interview assessment. <sup>165</sup> Using self or clinician rating scales, prevalence of depressive symptoms was 26.5% in CKD stages 1–4 (CI 18.5–36.5), 39.3% in dialysis patients (CI 36.8–42.0), and 26.6% in kidney transplant recipients (CI 20.9–33.1).	Associated with increased morbidity, hospitalization, and mortality rates, <sup>166–169</sup> and is integral to the assessment of HRQL.	A systematic review assessed pharmacologic treatment in CKD stages 3–5, including 28 studies assessing 24 antidepressants. <sup>170</sup> Included were two RCTs of fluoxetine and escitalopram versus placebo in HD patients, both of which did not demonstrate efficacy. However, the 9 non-RCTs all suggested benefit. Side effects were common but mild. Efficacy of nonpharmacologic treatments (e.g., more frequent hemodialysis, <sup>171,172</sup> cognitive behavioral therapy, <sup>173,174</sup> and exercise <sup>175,176</sup> ) have also been demonstrated.
Pain	Since 1992, 50 publications representing over 7500 CKD patients (36 of these studies involve prevalent HD patients) showed that ~ 58% of CKD patients experience pain, and many rate their pain as moderate or severe in intensity. <sup>12</sup> Although data on peritoneal dialysis patients and stage 5 CKD patients cared for conservatively without dialysis are more limited, evidence suggests similar prevalence rates and severity to HD patients. <sup>17,177,178</sup>	Data consistently show that pain and/or overall symptom burden is associated strongly with substantially lower HRQL and greater psychosocial distress, insomnia, and depressive symptoms. <sup>12–14,19</sup>	Management is determined by both etiology and severity. Nonpharmacological approaches may be appropriate (such as exercise and local heat) for musculoskeletal pain. For pharmacologic management, an adapted World Health Organization (WHO) analgesic ladder that takes into account pharmacokinetic data of analgesics in CKD is recommended. <sup>12</sup> This may include the conservative dosing of opioids for moderate to severe pain that adversely affects physical function and HRQL and that does not respond to nonopioid analgesics. Before commencing opioids, clinicians should assess risk of substance abuse, and obtain informed consent following a discussion of goals, expectations, potential risks, and alternatives. Opioid risk mitigation strategies should be used. There are no studies on the long-term use of any analgesics in patients with CKD, and thus careful attention must be paid to issues of efficacy and safety.

Abbreviations: CI, confidence interval; CKD, chronic kidney disease; HD, hemodialysis; HRQL, health-related quality of life; RCT, randomized controlled trial.

**Table 2 | Symptom assessment and management recommendations**

- Symptom assessment and management is an integral component of quality care for patients with advanced CKD. Regular global symptom screening using validated tools such as the ESAS-r:Renal and POS-renal<sup>16,17</sup> should be incorporated into routine clinical practice.
- Symptom management requires a stepwise approach. First-line treatment includes nonpharmacological interventions and then advancing to more complex therapies. Second-line treatment is pharmacologic therapy. Consideration should be given to low-dose pharmacological therapy that may have efficacy across several symptoms.
- Current evidence is sufficient to support the development of clinical guidelines to aid in the stepwise approach to uremic pruritus, sleep disturbances, restless legs syndrome, pain, and depression in CKD.
- Symptom management is a research priority in CKD. Particular attention is required on the relative effectiveness of management strategies, including the impact on outcomes most relevant to patients such as overall symptom burden, physical function, and HRQL.

Abbreviations: CKD, chronic kidney disease; ESAS-r:Renal, Edmonton Symptom Assessment System-revised: Renal; HRQL, health-related quality of life; POS-renal, Palliative Care Outcome Scale-Renal.

**Table 3 | Estimating prognosis recommendations**

- Estimate and communicate prognosis to patients and family, balancing biomedical facts with relevant emotional, social, cultural, and spiritual issues. Such communication should be viewed as an integral component of shared decision making in order to align treatment goals with patient preferences. It will aid in the timely identification of patients who are most likely to benefit from supportive care and is essential for quality care.
- Determine the international perspective on the value of prognostication tools in CKD.
- Develop a comprehensive methodological guideline for designing and assessing the quality of prognostic tools in CKD. This should extend beyond survival to include outcomes that matter most to patients and families in diverse countries and cultures, such as HRQL.
- Derive and validate prognostic tools for clinical outcomes that are most relevant to patients using existing and future databases.

Abbreviations: CKD, chronic kidney disease; HRQL, health-related quality of life.

nephrology to aid in the development of appropriate care plans that best meet the needs of individual patients. Methods of communicating prognosis and integrating biomedical facts with the emotional, social, and spiritual realities of the patient should be developed and evaluated. Research into methods of how to communicate the uncertainty of predicting outcomes and individual patient trajectories should receive priority given the importance of this information in care planning. The group identified the need to use prognostication tools for multiple purposes: administrative (resource planning); research (enrollment criteria for studies); clinician (develop care plan); patient (inform decision making); and clinician and patient: shared decision making for patient-centered care and identification of patients at high risk who might benefit from intervention. Importantly, there is a need to confirm the relevance of existing tools across all populations. At present, there is little variation in the use of these tools with respect to the clinical, cultural, social, and religious context. Validation of the tools for other cultures is an important next step. Table 3 describes the recommendations of the group with respect to estimating prognosis.

#### SHARED DECISION MAKING AND ACP IN CKD

There was consensus to endorse patient-centered care as a means of achieving better health outcomes and greater patient satisfaction,<sup>40</sup> and that this requires shared decision making.<sup>41</sup> Shared decision making is a process of communication by which physicians and patients agree on a specific course of

action based on a common understanding of the patient's treatment goals, taking into account the benefits and harms of treatment options, and the likelihood of achieving the outcomes that are most important to individual patients. This is particularly relevant before the initiation of dialysis, where patients should understand the benefits, burdens, and alternatives to dialysis. Such discussions should be held in a culturally appropriate context and with a culturally appropriate decision-making team. It is important to realize that in many cultures the family and even society have a large role in decision making. Education, therefore, should be culturally and societally sensitive and appropriate to the health literacy of the individual and caregivers. Barriers to decision making such as cognitive dysfunction, depression, and socioeconomic factors need to be recognized and addressed. Evidence suggests that shared decision making is currently poorly integrated into CKD care, and that many CKD patients are inadequately prepared for either living with CKD or dealing with end-of-life issues.<sup>26,42</sup>

The workgroup recognized ACP as a process that involves understanding, communication, and discussion between a patient, the family (or other caregiver), and staff for the purpose of clarifying preferences for end-of-life care. It lays out a set of relationships, values, and processes for approaching end-of-life decisions for individual people, including attention to ethical, psychosocial, and spiritual issues relating to starting, continuing, withholding, and stopping dialysis.<sup>43</sup> In the care of patients with advanced CKD, neither prognosis

**Table 4 | Shared decision making and ACP recommendations**

- Shared decision making is recommended to align treatment with patient and family goals, values, and preferences. Because patients' health status, preferences, and treatment options may change over time, shared decision making requires a flexible approach of reevaluation and redirection to ensure that the goals of care and treatment plans remain aligned with patients' values and preferences.
- The treatment care team should engage in ACP. These discussions should start early in the illness trajectory and should include discussions about health states in which patients would want to withhold or withdraw dialysis.

Abbreviation: ACP, advance care planning.

**Table 5 | Withdrawal of dialysis recommendations**

- Withdrawal from dialysis is ethically and clinically acceptable after a process of shared decision making. It is incumbent upon all providers caring for a patient contemplating stopping dialysis to address potentially remedial factors contributing to the decision such as depression or other symptoms such as pain as well as potentially reversible social factors.
- Situations in which it is appropriate to withdraw dialysis include the following:<sup>57</sup>
  - Patients with decision-making capacity, who being fully informed and making voluntary choices, refuse dialysis or request that dialysis be discontinued.
  - Patients who no longer possess decision-making capacity who have previously indicated refusal of dialysis through appropriate ACP.
  - Patients who no longer possess decision-making capacity and whose properly appointed legal agents/surrogates refuse dialysis or request that it be discontinued.
  - Patients with irreversible, profound neurological impairment such that they lack signs of thought, sensation, purposeful behavior, and awareness of self and environment.
- Ensuring access to appropriate supportive and/or hospice care is an integral part of the care following a decision to withdraw dialysis.

Abbreviation: ACP, advance care planning.

nor end-of-life care discussions are routine.<sup>4</sup> Failure to discuss health states in which patients would no longer want certain life-prolonging treatments, including dialysis, results in patients' treatment preferences not being respected and in potentially unwanted suffering, and overuse of limited health-care resources. Neither the family nor physicians are accurate in predicting patients' preferences for life-sustaining treatments, including ongoing dialysis.<sup>44,45</sup> Many CKD patients welcome the opportunity to engage in these discussions with their care team.<sup>4,46</sup> Research has shown that open, honest discussions with patients with advanced CKD about prognosis and end-of-life care promote self-reliance, alleviate fear and uncertainty, and reinforce both trust and hope.<sup>47</sup> These discussions should be part of the education process that occurs when patients are presented with dialysis options, and at the time of sentinel events such as hospitalizations, acute illness, and decline in functional status or HRQL.

New tools<sup>48</sup> and online resources,<sup>49</sup> including skill-based training, can help facilitate ACP for staff, patients, and family with CKD.<sup>50–52</sup> Although the full impact of ACP on end-of-life care for CKD patients remains to be established, current evidence supports ACP as a means of improving end-of-life care, decreasing inappropriate life-sustaining treatment, increasing the use of hospice and supportive care, preventing hospitalizations, and increasing compliance with patients' end-of-life wishes.<sup>53–55</sup> Table 4 lists the recommendations for shared decision-making and ACP activities in CKD populations.

#### PROCESSES FOR WITHDRAWAL OF DIALYSIS

Reported rates of death preceded by dialysis withdrawal vary across studies and national renal registries.<sup>56</sup> With shared

decision making that balances beneficence, nonmaleficence, and justice, withdrawal from dialysis is ethically and clinically acceptable (see Table 5 for recommendations).<sup>57</sup> The work-group advocated that dialysis centers should develop written guidance on how and when to discuss withdrawal and how to manage patients after withdrawal.

There are currently no uniformly accepted definitions of withdrawal of dialysis. Therefore, definitions are needed to encompass the different practices related to availability of dialysis and other health-care resources in low-income and lower-middle-income countries. This will improve the accuracy of data collection by national registries, enable robust audits of clinical practice, and inform research. It is important to demonstrate objectively the need for, and enable the development of, supportive care services to support patients withdrawing from dialysis. There are significant differences in practice patterns between countries regarding dialysis withdrawal.<sup>58</sup> Many of these relate to variation in culture and physician perception about legality of withdrawal. The decision-making process around dialysis withdrawal should be sensitive to local cultural norms and individual patient attitudes regarding locus of decision making (patient, family, or wider societal group).

#### ADVOCATING FOR AND DEFINING COMPREHENSIVE CONSERVATIVE CARE FOR PATIENTS WITH ADVANCED CKD

Conferees recognized that dialysis improves survival in the large majority of patients. For others, dialysis may offer limited, if any, survival or HRQL advantage. For these patients, dialysis should not be viewed as the default therapy. Participants agreed that dialysis should be framed explicitly as

**Table 6 | Definition of comprehensive conservative care**

'Comprehensive conservative care' is planned holistic patient-centered care for patients with G5 CKD that includes the following:

- Interventions to delay progression of kidney disease and minimize risk of adverse events or complications
- Shared decision making
- Active symptom management
- Detailed communication including advance care planning
- Psychological support
- Social and family support
- Cultural and spiritual domains of care

Comprehensive conservative care does not include dialysis.

Abbreviations: CKD, chronic kidney disease; G5, glomerular filtration rate category 5 CKD.

**Table 7 | Distinct conservative care populations**

*Comprehensive conservative care.* Conservative care that is chosen or medically advised.

*Choice-restricted conservative care.* Conservative care for patients in whom resource constraints prevent or limit access to renal replacement therapy; therefore, a choice for conservative care cannot be recognized.

*Unrecognized G5 CKD.* Chronic kidney disease is present but has not been recognized or diagnosed; therefore, a choice for conservative care cannot be recognized.

Abbreviations: CKD, chronic kidney disease; G5, glomerular filtration rate category 5 CKD.

a treatment choice. For patients unlikely to benefit, positive alternatives to dialysis, in the form of comprehensive conservative care, should be provided.<sup>59–62</sup>

Although conservative kidney care is recognized and delivered widely,<sup>63–66</sup> the conservative care population within CKD has not been categorized clearly, nor the care elements well defined. The lack of a clear definition has severely constrained recognition of the health-care needs of this population, and has prevented systematic study to build evidence on ways to best improve care and outcomes. Therefore, the conferees proposed a detailed and specific definition for kidney conservative care suggesting the term '*comprehensive conservative care*'. This term will encapsulate the full range of management and interventions involved (Table 6). Participants further proposed three distinct groups that need to be distinguished within the conservative care population. These groups are as follows: (1) those receiving *comprehensive conservative care*, where conservative care is either chosen or medically advised; (2) those receiving '*choice-restricted conservative care*', where resource constraints have prevented or limited access to renal replacement therapy (and therefore a choice for conservative care cannot be recognized); and (3) those with *unrecognized G5 CKD*, where CKD is present but has not yet been recognized or diagnosed (Table 7). Population-based studies have recently begun to identify and quantify this latter group of patients. Perspectives from lower-middle-income countries, where access to dialysis may be limited, and high-income countries, where kidney replacement therapy is more widely available and treatment choice is more often a reality, have vetted the distinctions between these groups. Table 8 outlines the recommendations for comprehensive conservative care.

Participants recognized the limitation in currently available data regarding the benefits and harms of dialysis versus conservative care of older or frail patients with advanced CKD and multiple comorbidities. Given the ethical challenges of randomizing between dialysis and conservative care, study designs have been observational rather than experimental, with all the inherent biases. Variability in eGFR estimation has posed a particular challenge for study design and comparative analyses. With all these limitations, existing evidence suggests that the survival advantage of dialysis disappears in patients  $\geq 75$  years of age with high levels of comorbidity and/or poor functional status.<sup>67–70</sup>

Hospitalization rates are reduced and home death rates increased for patients cared for with comprehensive conservative care.<sup>1,2</sup> Data on patient-centered outcomes with comprehensive conservative care are limited; therefore, further research is an important priority (Table 8).

#### THE NEED FOR EDUCATION IN SUPPORTIVE CARE FOR CKD POPULATIONS

The conferees recommended formal education in CKD supportive care. They did so based on the considerable variation in end-of-life care practices between and within countries, and reports from nephrologists of feeling inadequately prepared to deal with the end-of-life challenges inherent in the care of their patients.<sup>71,72</sup> This lack of feeling prepared is not surprising given the minimal training in supportive care and communication skills currently received by nephrology trainees.<sup>52,73–75</sup>

Participants also recognized that many countries are placing increased emphasis on the provision of supportive and end-of-life care by 'generalist' and community providers or those with no specific or accredited training in supportive care, as a

**Table 8 | Conservative care recommendations**

- Comprehensive conservative care should be provided as a viable, quality treatment option for patients who are unlikely to benefit from dialysis.
- A multiprofessional team should ideally deliver comprehensive conservative care. Composition will likely vary between and within countries, potentially including the following: (1) nephrologist/nurse/psychosocial worker/counselor or psychologist/dietician/allied health professionals/chaplain; (2) family doctors/community staff/health-care volunteers; and (3) integration and/or liaison with specialist supportive care, according to country and region.
- Additional training or expertise in comprehensive conservative care is recommended, and this care should be accessible across settings (e.g., home, hospital, hospice, and nursing homes).
- Further research into conservative care is a priority for the international nephrology community. Research priorities include the following:
  1. Develop international consensus on the terminology and definitions of comprehensive conservative care to promote shared understanding and consistent clinical practice, research, and policy.
  2. Determine the illness trajectory for those managed conservatively and how this compares and contrasts with those managed with dialysis.
  3. Study the HRQL, symptoms, functional status, illness, and care experiences including family experiences, hospitalizations, survival, and quality of dying of patients treated with comprehensive conservative care.
  4. Determine effective and cost-effective models for the provision of comprehensive conservative care across diverse health systems.

Abbreviation: HRQL, health-related quality of life.

**Table 9 | Recommendations for supportive care in CKD populations**

1. Primary supportive care should be available to all patients with advanced CKD and their families throughout the entire course of their illness. Provision of supportive care should be based on need rather than solely an estimation of survival. To optimally deliver primary supportive care, multiprofessional renal teams should do the following:
  - (a) Identify those patients who are most likely to benefit from supportive care interventions.
  - (b) Assess and manage symptoms effectively.
  - (c) Estimate and communicate prognosis (survival and future illness trajectory) to the best of their ability.
  - (d) Develop appropriate goals of care that address individual patients' preferences, goals, and values.
  - (e) Possess knowledge of, and experience with, available local supportive care services, and be aware of when and how to refer.
  - (f) Assist with care coordination including referral to specialist supportive care and hospice service as available and appropriate
2. Education: supportive care should be recognized as a core competency and therefore constitutes an essential component of continuing medical education for practicing nephrologists, as well as the nephrology curriculum for trainees.
3. The nephrology community should actively support and participate in kidney supportive care research to address knowledge gaps and advocate for policy change. Research priorities include the following:
  - (a) Determine optimal models of integrated kidney supportive care to best meet the needs of patients and families, taking into account various health-care systems, cultures, and available resources.
  - (b) Define quality of supportive care metrics and optimal methods of integration into payment and accreditation/regulatory models for patients with CKD.
  - (c) Determine education and skill needs across various settings and disciplines to address the shortages worldwide of providers trained in the supportive care skills required to optimally care for CKD patients. In addition, develop effective curricula leading to measurable provider behavior change and improved care to address current deficits.

Abbreviation: CKD, chronic kidney disease.

component of usual care. Although the conferees acknowledged that this is an ideal situation (i.e., normalization of supportive care into general practice), they also recognized that supportive care of patients with advanced CKD needs to be systematically integrated into the treatment patients receive from their renal care teams, who deliver much of their care. Improved partnerships with specialist supportive care colleagues will be required for more complex patients, particularly as they transition to end-of-life care.<sup>76</sup>

Skills that assist care providers with difficult conversations, such as sharing bad news, discussing limited prognosis, and addressing uncertainty and transitions including end of life, can be taught. Communication curricula from other health conditions such as oncology have been used as a model in nephrology.<sup>51,52</sup> The failure of professional societies to address deficiencies in training impedes adoption of high-quality supportive care practice patterns. Conferees recommended that supportive care be recognized as a core competency and therefore an essential component of medical

education for all practicing nephrologists and trainees (see Table 9).

#### **COSTS AND CONSEQUENCES OF HEALTH-CARE UTILIZATION FOR A SUPPORTIVE CARE FRAMEWORK IN CKD**

Rational use of finite health-care resources is necessary to promote health-care system sustainability. Supportive/palliative care has mostly been evaluated in populations with cancer, and prospective evaluations of the costs and benefits of supportive/palliative models (including nondialytic care) for people with advanced CKD have yet to be systematically conducted. A single evaluation of hospice use among dialysis patients reported significantly lower costs compared with those who did not use hospice.<sup>1</sup> Growing evidence suggests that supportive care models in other disease areas improve value by coordinating care to patient-specific goals and needs and hence increase care quality and consistently report lower costs relative to comparative treatments.<sup>77</sup> These lower costs are driven primarily by a reduced number of hospitalizations,



including emergency department and intensive care admissions, reductions in 30-day readmission rates, and fewer deaths in acute-care facilities. However, advanced CKD is a unique condition in terms of its treatment resource use (i.e., ongoing dialysis) and the varying HRQL with each treatment. The incremental cost-effectiveness ratio for dialysis relative to no dialysis has been estimated as high as \$110,814 USD per quality-adjusted life-year, but it could reach \$250,000 for patients with multiple comorbidities.<sup>78</sup> This implies a high opportunity cost to health-care systems for the provision of dialysis, at the expense of other treatments. Comprehensive models of kidney supportive care are not cost neutral, nor are they simply the absence of dialysis services. It is difficult to project accurately cost benefits of supportive care from other conditions given the highly variable paths to death, including withholding or withdrawal of dialysis, and the often-prolonged need for kidney supportive care that may be over several years as opposed to several weeks. Future studies need to identify, measure, and value all resources associated with kidney supportive care, including pharmacotherapies, inpatient, outpatient, community, and hospice care, as well as out-of-pocket costs to patients and families.

Economic evaluation of the costs and health outcomes of kidney supportive care is required to inform health-care planning and facilitate appropriate resource allocation decisions. The conferees advocate for a societal perspective to be adopted in any economic evaluation. In addition, there is need for the identification of the most feasible methods to collect cost data among this population, and the need to identify the most appropriate health outcome measures to assess benefits from kidney supportive care.

#### **CHALLENGES OF DEVELOPING MODELS OF SUPPORTIVE CARE IN CKD POPULATIONS**

Models of delivering supportive/palliative care currently being used do not necessarily meet the needs of patients with advanced CKD. Current palliative care and hospice practices can result in limited access for patients with advanced CKD, as some still restrict access to patients with cancer, and because in general access depends on patients having predictable disease trajectories and a prognosis limited to a few months or less. Patients with advanced CKD can be expected to have poor functional capacity, high symptom burden, and the need for quality supportive care for many months, if not years, before death. Models of kidney supportive care also need to coordinate care for patients with multiple chronic conditions, who are treated across multiple health-care settings and by multiple care providers. Adding to the complexity is the unique body of knowledge that is required to address (1) complex decision making regarding the appropriate initiation, continuation, and withdrawal of dialysis; (2) the variability in illness trajectories, irrespective of treatment modality; (3) severe and complex clusters of symptoms that may differ in etiology and hence management from those seen in other conditions; and (4) the altered pharmacokinetics and pharmacodynamics associated with kidney failure requiring

alternative management strategies. Given these unique features, further research is needed to inform our understanding and delivery of kidney supportive care. Adaptation of existing paradigms and innovative supportive care models will need to be developed and evaluated for CKD patients.

#### **CONCLUSIONS**

The conferees recognized a critical worldwide requirement for coordinated supportive care, individualized to patients, to optimize the quality of care for patients with advanced CKD. Table 9 summarizes conference participants' recommendations regarding key activities required to improve the outcomes of CKD patients.

Access to supportive care services should be available for all CKD patients. The extent and form of these services will depend on local resources. In all jurisdictions, there is an identified need to incorporate supportive care principles into widespread practice for CKD patients, using a framework that is in keeping with public and health-care policies.

A multipronged approach is required to fundamentally change the care delivery model. This includes leveraging existing supportive care models and services, and customizing them for the unique challenges of CKD patients and families. Aligning payments and policies will be essential. Support from professional societies for training and continuing professional development for all health-care professionals in supportive care will be important, as will integration into medical and nursing school curricula. Despite the growing interest in the area, major gaps remain in understanding the optimal treatments and approaches to delivering supportive care in CKD populations, both on and off dialysis. A robust international, culturally sensitive research agenda in this area is essential. Although resources differ between countries and regions, the responsibility to support patients and families as they approach end of life is ubiquitous.

The KDIGO conference participants anticipate that this conference and future planned work will provide the impetus to study and implement supportive care services for patients with advanced CKD worldwide. Through international collaboration, advances can be made in designing, implementing, and testing effective and efficient models of integrated supportive care for CKD populations.

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