

Living Well With Kidney Disease and Effective Symptom Management: Consensus Conference Proceedings



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Chronic kidney disease (CKD) confers a high burden of uremic symptoms that may be underrecognized, underdiagnosed, and undertreated. Unpleasant symptoms, such as CKD-associated pruritus and emotional/psychological distress, often occur within symptom clusters, and treating 1 symptom may potentially alleviate other symptoms in that cluster. The Living Well with Kidney Disease and Effective Symptom Management Consensus Conference convened health experts and leaders of kidney advocacy groups and kidney networks worldwide to discuss the effects of unpleasant symptoms related to CKD on the health and well-being of those affected, and to consider strategies for optimal symptom management. Optimizing symptom management is a cornerstone of conservative and preservative management which aim to prevent or delay dialysis initiation. In persons with kidney dysfunction requiring dialysis (KDRD), incremental transition to dialysis and home dialysis modalities offer personalized approaches. KDRD is proposed as the preferred term given the negative connotations of “failure” as a kidney descriptor, and the success stories in CKD journeys. Engaging persons with CKD to identify and prioritize their personal values and individual needs must be central to ensure their active participation in CKD management, including KDRD. Person-centered communication and care are required to ensure diversity, equity, and inclusion; education/awareness that considers the health literacy of persons with CKD; and shared decision-making among the person with CKD, care partners, and providers. By putting the needs of people with CKD, including effective symptom management, at the center of their treatment, CKD can be optimally treated in a way that aligns with their goals.

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KEYWORDS: chronic kidney disease; conservative management; person-centered care; quality of life; symptom clusters; unpleasant symptoms

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INTRODUCTION

The theme of the 2021 World Kidney Day was Living Well with Kidney Disease in an effort to enhance education and awareness of the paramount goal of empowering people with CKD to be in control of their treatment and remain active participants in life.¹ The 2022 World Kidney Day highlights the importance of

Health Literacy in Kidney Care.² The International Federation of Kidney Foundations–World Kidney Alliance (IFKF–WKA) Living Well with Kidney Disease Consensus Conference focused on effective symptom management in CKD at a hybrid meeting—both virtual and in-person—in Honolulu, Hawaii on December 2, 2021. The conference was chaired by Kamyar Kalantar-Zadeh, MD, MPH, PhD, the immediate past president of the IFKF–WKA and Co-Chair of World Kidney Day.

Conference Participants, Aim, and Methods

The conference brought together 24 participants, including clinicians, leaders of advocacy groups representing people with CKD and kidney networks, editorial leaders of major nephrology journals, and other stakeholders, including people with CKD from across the globe to discuss topics of importance to CKD care. The aim of the conference was to develop consensus recommendations to help guide the effective management of symptoms in CKD. The conference was arranged into 6 sessions with presentations from 3 or 4 expert participants on each topic followed by panel discussions to allow for consensus building. The topics covered included effective management of unpleasant symptoms (see definition below); interventions to enrich quality of life; specific treatment strategies for pruritus, fatigue, pain, sleep, and mental health; expansion of conservative and preservative management as well as incremental dialysis initiation and home dialysis therapies as person-centered approaches; strategies to empower people with CKD and their care partners; and the use of terminologies without negative connotations such as “failure.” This article summarizes the main presentations developed by the conference participants on these topics, including reports of their own research findings, summaries of the latest evidence, as well as their personal experiences. Key consensus recommendations developed from the discussions at the conference are provided in Table 1.

Perspectives on Symptom Burden From People With CKD

As kidney disease progresses, affected persons experience an increasing burden of adverse uremic symptoms.³ These symptoms can impair their health-related quality of life (HRQOL) by interfering with social relationships, causing financial instability, and contributing to overall poor well-being.³ In order to identify approaches to person-centered symptom management that optimize HRQOL, it is important to understand the preferences, priorities, and individual needs of persons with CKD.

At the consensus conference, Siu-Fai Lui, MD, the current president of the IFKF–WKA, presented results

from a worldwide survey conducted in early 2021, of 4807 people with CKD from 7 member centers of the IFKF–WKA (Bangladesh, Hungary, Italy, India Tanker Foundation, India Renal Foundation, Hong Kong, and Malaysia). The survey assessed well-being using a 10-point scale (a score of 1 equated to “not well” and a score of 10 equated to “very well”), and the frequency of physical, psychological, and life effects on people with CKD (Figure 1).⁴ The average overall score for well-being across member nations ranged from 5.8 in Bangladesh to 6.8 in Malaysia, suggesting that there is scope to improve well-being in CKD. The most common physical effects reported were fatigue and sleep problems (each reported in the top 5 physical effects at all 7 centers), and pruritus (reported in the top 5 physical effects at most centers) with fatigue being the most impactful physical symptom reported across all of the countries and foundations surveyed (reported by 55%–71% of respondents). The most common psychological effects reported included concerns about the future, anxiety, stress, and depression (each reported in the top 5 psychological effects at all 7 centers), and the most common life effects included financial, ability to work, ability to travel, and lifestyle changes (each reported in the top 5 life effects at most centers). Additionally, Maurizio Gallieni, MD presented views from Italian people with CKD gathered through Facebook groups “Emodialisi Domiciliare: questa sconosciuta!” (“Home Hemodialysis: the unknown!”); “#Dialisi Peritoneale,” (“Peritoneal Dialysis”); and “Emodializzati e Trapiantati di Rene!” (“Hemodialyzed and Kidney Transplanted!”). These perspectives highlighted the burden of symptoms, as well as the importance of psychological and social support, logistics, communication, and access to information in coping with unpleasant symptoms (Table 2, selected key quotes have also been included within relevant sections of this article). These life effects and sequelae of symptom burden were also echoed by consensus conference attendees with CKD, underscoring the shared experiences of people with CKD globally.

Importantly, there has been an exciting change in attitude among clinicians and investigators, with accompanying growing interest among major nephrology journals, to recruit and include voices that reflect the needs of people with CKD.^{5,6} Consequently, people with CKD have identified symptom management as a high priority area, even prioritizing alleviation of symptoms over other health outcomes such as survival and biochemical indices.^{7,8} A key message from consensus conference attendees with CKD was that quality of life supersedes quantity of life. Advocacy group leaders highlighted that symptom burden has a major effect on quality of life, and whereas there has

Table 1. Living well with kidney disease and effective symptom management consensus conference recommendations

Domain	Specific recommendations
Perspectives on symptom burden from people with CKD	<ul style="list-style-type: none"> • People with CKD should be engaged by clinicians in identifying and prioritizing which symptoms affect their HRQOL, as well as determining the underlying causes and potential treatment options for these symptoms, in order to optimize symptom management. • A holistic approach to symptom evaluation and management by clinicians is needed that also considers genetic/biological (omics), behavioral, and environmental factors, as well as social determinants of health.
Unpleasant symptoms (e.g., CKD-associated pruritus) and symptom clusters in CKD	<ul style="list-style-type: none"> • With respect to effective symptom management and across all aspects of kidney health, frequent and clear communication between the clinician and the person they are treating is crucial before, during, and after treatment, and should be ongoing throughout the journey of the person with CKD. • Symptom management by clinicians should include detailed assessment of unpleasant symptoms, such as pruritus. • Further research into symptoms as clusters in CKD, is of paramount importance given that the treatment of 1 symptom in a symptom cluster may potentially alleviate other related symptoms.
Emotional symptoms, anxiety, and mental health in CKD	<ul style="list-style-type: none"> • Clinicians should be aware that emotional and psychological symptoms of kidney health have equal importance to physical well-being. • Early identification of unpleasant symptoms by clinicians is critically important, and both pharmacological and non-pharmacological treatment strategies including evidence-based psychological interventions should be considered in their management. • Systematic strategies for the screening, diagnosis, and treatment of unpleasant symptoms by clinicians should be culturally sensitive and take into consideration health literacy.
Effect of incremental dialysis and home dialysis on CKD symptoms	<ul style="list-style-type: none"> • KDRD, also known as or including the descriptors “end-stage” renal or kidney, and disease, disorder, or “failure,” should not be considered a single disease by nephrologists but as a spectrum with stages of evolution, and individualized and incremental dialysis transition can be used to assist the management of the kidney disorders as function gradually declines. • Using a personalized approach, home dialysis should be considered and discussed with a person with CKD by clinicians and/or dialysis nurses as a means to empower them by increasing their independence, freedom, and self-management. • Nephrologist and/or dialysis nurses, and persons with CKD and their care partners should advocate for a personalized and individualized approach to dialysis therapy, in lieu of a “one-size-fits-all” approach.
Conservative management and person-centered terminology in CKD	<ul style="list-style-type: none"> • Given that dialysis may not always exert the intended effect of restoring health in some people with CKD, conservative and preservative nondialytic management can also be considered by nephrologists as a comprehensive approach in the treatment of advanced CKD that focuses on the preservation of remaining kidney function and optimization of HRQOL. • Conservative and preservative management should include proactive symptom management by clinicians, dietary interventions under the direction of dietitians, advance-care planning by palliative care physicians, psychological support by psychologists and/or counselors, and social and family support from kidney support groups. All of these aspects should consider cultural and spiritual domains of care. • Person-centered terminology used by clinicians should be clear and precise and emphasize positive language that inspires hope, while terms with negative connotations including the descriptors “end-stage” and “failure” should be avoided. • Conservative and preservative management should not be equated as supportive care that results in a lack or rationing of care by clinicians.
Diversity, equity, and inclusion, and supportive care in CKD	<ul style="list-style-type: none"> • Prioritization of diversity, equity, and inclusion by all involved clinicians are critically important in the management of unpleasant symptoms in CKD. • Peer mentorship, involvement of CKD ambassadors within communities, and moderated kidney support groups have an important role in the supportive care of people with CKD as needed.

CKD, chronic kidney disease; HRQOL, health-related quality of life; KDRD, kidney dysfunction requiring dialysis.

traditionally been greater emphasis on clinical outcomes as an index of quality of care, this metric may not necessarily reflect experiences of people with CKD. Multiple conference participants noted that in current clinical practice, symptoms may be underrecognized, underestimated and consequently undertreated in people with CKD. Although routine standardized symptom assessment is an important tool to optimize quality of care,⁹ symptoms may be vague, difficult to quantify and distinguish from non-CKD symptoms, and may subsequently be downplayed by clinicians over time. Therefore, a holistic approach to symptom evaluation and management is needed that also considers genetic or biological (omics), behavioral, and environmental factors, as well as social determinants of health.

Recommendations for Clinicians

In order to optimally treat the unpleasant symptoms associated with CKD, clinicians, and consensus conference attendees with CKD agreed that it is crucial for clinicians to:

- Engage the person with CKD: ask them what is troubling or concerning them, keeping in mind that they are unlikely to ever be “symptom free”;
- Listen to the person with CKD: identify and investigate the underlying causes of symptoms reported by them;
- Appreciate what matters most to the person with CKD: understand their “why,” i.e., focus on each person’s values, goals, and individual needs, which may be central to motivating them to pursue optimal health in lieu of solely emphasizing clinical outcome measures, such as laboratory results;

Frequency of the most common impacts experienced by people with CKD

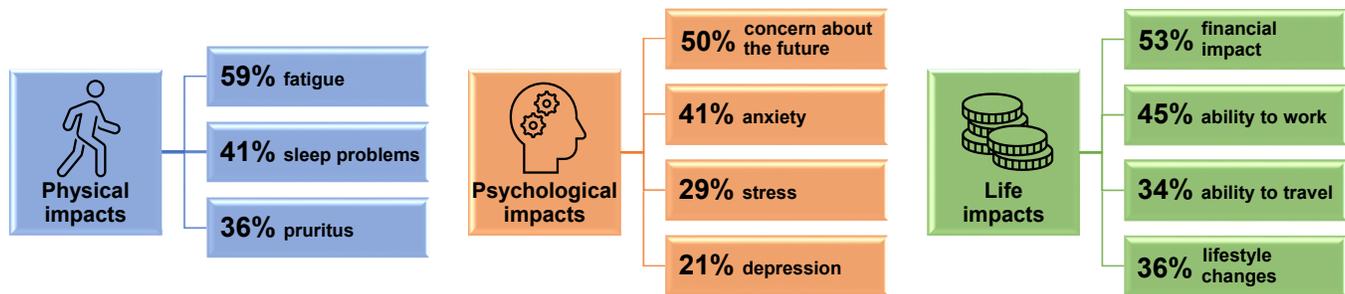


Figure 1. Survey results of 4807 people with CKD from 7 member centers of the IFKF–WKA carried out at the beginning of 2021. This survey assessed the frequency of the most common* physical, psychological, and life effects on people with CKD.⁴

CKD, chronic kidney disease; IFKF–WKA, International Federation of Kidney Foundations–World Kidney Alliance.

Mean average frequencies calculated from available data: pruritus ($n = 5$ centers), and life effects ($n = 6$ centers each).

*Most common effects were those reported within the top 5 effects at most centers: the most common physical effects reported were fatigue and sleep problems (each reported in the top 5 at all centers), and pruritus (reported in the top 5 at most centers); the most common psychological effects were concern about the future, anxiety, stress, and depression (each reported in the top 5 at all centers); the most common life effects were financial, ability to work, ability to travel, and lifestyle changes (each reported in the top 5 at most centers). Figure created based on data presented at the consensus conference by Siu-Fai Lui, MD.

- Consider and discuss all treatment options and their implications with the person with CKD: this should include both benefits and potential risks of treatment, as well as person-centered approaches to effectively manage symptoms;
- Ensure optimized treatment for the individual person with CKD: be sure that the person with CKD feels comfortable with the treatment and trusts those treating them; align treatment needs with the aspirations of the person with CKD to minimize the effect their condition has on their quality of life;
- Understand that there are emotional and psychological effects of CKD, in addition to physical sequelae: clinicians should remember that each person with CKD has a network of family and friends, and clinicians should consider the wider effect of CKD on the people they treat. How is CKD changing or interfering with the person with CKD and their family?

Table 2. Perspectives on whether the health care system meets their needs and what improvements could be made gathered from people with chronic kidney disease through the Facebook groups “Emodialisi Domiciliare: questa sconosciuta!” (“Home Hemodialysis: the unknown!”) “#Dialisi Peritoneale,” (“Peritoneal Dialysis”) and “Emodializzati e Trapiantati di Rene!” (“Hemodialyzed and Kidney Transplanted!”) in November 2021

Domain	Specific recommendations
Burden of symptoms	<ul style="list-style-type: none"> • “My nephrologist failed to resolve posthemodialysis problems: weakness, hypotension, very frequent vomiting.” • “Sleep deprivation, pain, itch, fatigue, psychological problems are considered inevitable aspects of dialysis treatment and are often not addressed. I stopped asking for help regarding these issues because it appears that nothing can be done.” • “Often, when I ask for a painkiller during hemodialysis, it is denied.” • “If I have symptoms and I suspect that my body weight is too low, nothing is done to re-evaluate it despite my questions. I have to beg for bio-impedance analysis.” • “Diet is an unresolved issue, and nutritionists with experience on dialysis patients are lacking.”
Psychological and social support, including logistic issues	<ul style="list-style-type: none"> • “The network of support and psychological support (self-help groups, for example) to help patients and relatives is totally missing. As the wife of an end-stage kidney disease patient, I can say that it changes the life of the whole family.” • “In dialysis, the main concern has been to provide all the material tools and supports to obtain the adequacy of the treatment and guarantee access to it. The psychology of patients and caregivers, as well as social assistance and family support, have remained in the background.” • “There is no possibility to choose the dialysis shift: to dialyze in the afternoon, I had to move to a different, faraway dialysis unit.” • “Dialysis units should better support patients in the process of kidney transplant list registration. I was left alone organizing all the exams.” • “Family caregivers of home dialysis should be better followed by the dialysis unit, including a financial incentive.” • “Transport to the dialysis unit is a significant problem: more home dialysis is the answer.”
Lack of communication/ information	<ul style="list-style-type: none"> • “There is a lack of information on home hemodialysis. I discovered the existence of this practice after 2 and a half years of dialysis in the hospital, only through a Facebook group. No one had told me about this possibility. Now I am on frequent home hemodialysis, and the postdialysis problems disappeared: it changed my life.” • “Nephrologists in dialysis units lack knowledge, or they do not communicate properly.” • “We need a little more humanity, sensitivity, availability.”

Table created from patient perspectives gathered, translated, and presented at the consensus conference by Maurizio Gallieni, MD. Quotations have been included with permission.

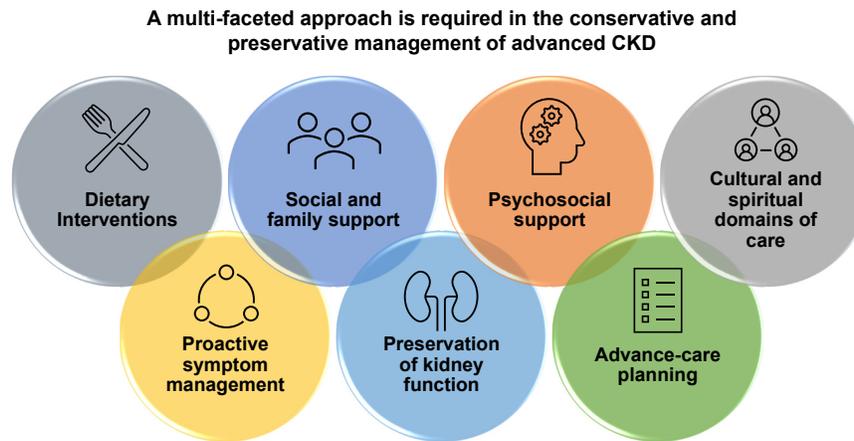


Figure 2. A multifaceted approach is required in the conservative and preservative management of CKD.^{9,46} CKD, chronic kidney disease.

Importance of Communication and Shared Decision-Making

Key inter-related themes discussed at the consensus conference included the prioritization of both communication and shared decision-making. In terms of communication, attendees agreed that clear, honest, and open dialogue between clinicians and the people they treat enables them to partner together to identify optimal treatment strategies and person-centered solutions. Advocacy group leaders also underscored that the following are imperative: (i) the person with CKD feels supported in selecting the “right” clinician(s) for their individual needs and preferences (i.e., those who will listen to them, believe them, and advocate on their behalf), and that (ii) communication between the clinician and the people they treat should be ongoing throughout the journey of the person with CKD (occurring before, during, and after treatment), with progress and treatment choices periodically revisited as the goals, preferences, and conditions of the person with CKD evolve over time.

In terms of shared decision-making, attendees agreed that a holistic approach is required to address the physical, mental, and emotional needs of persons with CKD, and should leverage the expertise of multidisciplinary professionals across different fields. Furthermore, attendees emphasized that this care team should include the person with CKD themselves and give them a central role and voice in their shared decision-making. Finally, given that various aspects of CKD may require multidisciplinary care, advocacy group leaders highlighted the following: (i) the importance of communication among the involved healthcare professionals to ensure optimal care, and (ii) the critical role that healthcare professionals and “navigators” may have in guiding people with CKD across an increasingly complex health care system. For example, greater access to case managers and other types of “advocates”

could help address a major unmet need in care coordination. Clinician time with those they treat may be limited, in part, by the emphasis on laboratory findings and comorbidities. Thus, running dedicated symptom management clinics for people with high symptom burden and/or using validated instruments to assess patient-reported outcome measures completed before or in-between clinic visits may be highly efficient methods for bringing greater attention to symptom burden, HRQOL, and other person-centered outcomes.

Unpleasant Symptoms and Symptom Clusters in CKD

“Sleep deprivation, pain, itch, fatigue, psychological problems are considered inevitable aspects of dialysis treatment and are often not addressed,”

Perspective from a person with CKD (Table 2).

“Unpleasant” symptoms are symptoms that are a cause of subjective suffering for people with CKD or their care-partner(s) that adversely affects their HRQOL and for which they often seek effective management.³ CKD-associated pruritus is an example of an unpleasant symptom.

CKD-associated Pruritus

Uremic pruritus or CKD-associated pruritus is defined as chronic itching observed in people with CKD who have significantly abnormal kidney function and advanced stages of kidney damage: this is a diagnosis of exclusion.¹⁰ The Dialysis Outcomes and Practice Patterns Study I/II studies found chronic itching to have a lifetime prevalence of 35% in people with CKD on hemodialysis.¹¹ This symptom may be underappreciated by clinicians due to a lack of awareness of how frequently people with CKD are bothered by pruritus and consequently inadequately managed.^{12,13} Whereas, most (84%–91%) people with CKD have mild or moderate itching intensity, 9 to 16%

experience severe or very severe itching.^{11,14} People with CKD and severe itching were found to be more likely to miss hemodialysis sessions than those without itching,¹⁵ and those who missed hemodialysis were more likely to have poor outcomes.¹⁶

People with CKD-associated pruritus may additionally experience psychosocial burden resulting from interference with sleep, including induction, waking, duration and quality, which may then adversely affect their quality of life¹⁴ and survival.¹⁷ Advocacy group leaders at the consensus conference emphasized that the symptom of itching is a high-priority area. Both clinicians and people with CKD agreed that clinicians should routinely ask the people they treat about the presence of unpleasant symptoms, particularly chronic itching. Moreover, there should also be assessment of the effect of symptom burden, such as, “How does itching affect your daily life?”.

Nondialysis Treatment of CKD-associated Pruritus

The pathology of CKD-associated pruritus is complex and multifactorial, and may act via opioid receptor pathways.¹⁸ Therapies for CKD-associated pruritus include emollients, ultraviolet B phototherapy, electroacupuncture, gabapentin or pregabalin, nalfurafine or nalbupine, mirtazapine or sertraline,^{10,19} as well as difelikefalin. Difelikefalin is a kappa opioid-receptor agonist and the first drug approved by the US Food and Drug Administration and the European Commission specifically for the treatment of moderate-to-severe pruritus associated with CKD in adults undergoing hemodialysis.^{20,21} In the KALM-1 phase 3 trial, difelikefalin was shown to cause a clinically meaningful reduction in itch intensity versus placebo and was generally well tolerated.²² Reductions in itch intensity were accompanied by improvements in itch-related quality of life, and comparable effects were seen with or without prior use of itch medication.²²

Symptom Clusters in CKD

Symptom clusters are comprised of 2 or more concurrent symptoms that may share a common underlying biological pathway: this is a concept that was first explored in oncology²³ and has in recent years also been applied to CKD. Symptom clusters in CKD is an evolving area of investigation that warrants further study using standardized, validated symptom instruments, and statistical clustering models. These methods allow robust and precise symptom phenotyping and have previously been used to identify the SPADE cluster (sleep dysfunction, pain, anxiety, depression, and energy/fatigue),²⁴ a cluster which may also occur in CKD. Unpleasant symptoms in CKD can manifest in a variety of clusters including those relating to gastrointestinal,

neurological, psychological, pain, cardiopulmonary, dermatologic, sleep or fatigue and sexual functions.²⁵ In people with end-stage kidney disease (ESKD), itching has been shown to co-occur with other symptoms such as anxiety or stress, depression, fatigue, pain, feeling washed out after hemodialysis, restless legs syndrome, and sleep disturbances, and these symptoms may comprise a symptom cluster.²⁶ Fatigue is common across the spectrum of kidney disease,²⁷ is debilitating for people with CKD,²⁸ and most people with itching suffer from disturbed or restless sleep.^{12,17} Fatigue, sexual symptoms (such as reduced interest in sex and inability to become aroused), and restless legs were identified as major driving symptoms in a symptom cluster in a study of people with advanced CKD.²⁹ Recognition that unpleasant symptoms, such as itching, may often occur in clusters in people with CKD is part of an emerging paradigm in how symptoms are managed, in which the treatment of 1 symptom may potentially alleviate other symptoms in that cluster and therefore improve overall symptom burden.

Emotional Symptoms, Anxiety, and Mental Health in CKD

“The psychology of patients and caregivers, as well as social assistance and family support, have remained in the background,” Perspective from a person with CKD (Table 2).

Psychological Effect

People living with CKD are required to make ongoing psychological adjustments over the course of their disease, which can be stressful and overwhelming, and may contribute to depression and anxiety. As noted earlier, results from a survey of people with CKD from 7 member centers of the IFKF–WKA showed that people with CKD commonly have concerns about the future, and may suffer from anxiety, stress, and depression. Consensus conference attendees with CKD emphasized that the psychological symptoms of kidney disease carry equal weight to physical symptoms, and that a positive and supportive management approach that also extends to the care partners of people with CKD is needed.

Depression and Anxiety

Depression and anxiety are common in ESKD, affecting 20 to 50% and 12 to 52% of people with ESKD, respectively.^{30–34} For example, in a study of 170 people with CKD on maintenance dialysis, 29.1% experienced moderate or severe anxiety and 21.4% experienced moderate or severe depression.³⁰ In surveys of people with CKD on hemodialysis, it has been shown that precipitants of anxiety include seeing paramedics enter the hemodialysis unit, experiencing a different technician cannulating their vascular access and connecting

them to the hemodialysis machine, and the frequent alarms sounding on the hemodialysis apparatus.³⁰

Studies suggest that depression and anxiety are highly undertreated and underdiagnosed in people with ESKD,³⁵ are associated with worse clinical outcomes in people with moderate to advanced CKD,³⁶ and may fluctuate over the course of CKD progression, although there are comparatively less data on depression and anxiety in earlier stages of CKD. Social determinants of health that have been associated with depression and anxiety in CKD include sex, race or ethnicity, education, employment, marital status, and specific comorbidities (e.g., psychiatric illness, diabetes mellitus, hypertension, cardiovascular heart disease, and hypoalbuminemia).^{34,37}

Although there are knowledge gaps with respect to effective treatment options for depression and anxiety in ESKD, early identification and treatment of emotional symptoms is critical. Pharmacological treatment approaches are frequently used, but non-pharmacological approaches, including pragmatic and evidence-based psychological interventions should also be considered. Education on the management and treatment of depression and anxiety is also important for the multidisciplinary team, including clinicians, nurses, technicians, dietitians, and social workers. Systematic and standardized approaches for screening, diagnosing, and treating depression and anxiety in people with CKD should include a multidisciplinary approach involving the person with CKD and their care-partner(s), be culturally sensitive, take into consideration health literacy, and allow for advance-care planning.

Effect of Incremental Dialysis and Home Dialysis on Symptoms

“There is no possibility to choose the dialysis shift,”
Perspective from a person with CKD (Table 2).

Dialysis-based Treatment Options

Dialysis-based treatment options include in-center hemodialysis, peritoneal dialysis, and home hemodialysis. Notably, there are many different treatment protocols available for peritoneal dialysis and home hemodialysis depending on the individual’s needs, whereas traditional in-center hemodialysis sessions have traditionally been anchored to 3 times a week treatment schedules using a “one-size-fits-all” approach.³⁸ This stands in contrast to other medical settings where there are a range of treatment options and protocols that are tailored to the individual, such as in oncology which leverages phenotyping and subcategorization to provide personalized therapy.³⁸

Diagnosis of ESKD is dually objective (based on laboratory criteria and receipt of kidney-replacement therapy over a defined period) and subjective (based on development of uremic symptoms). Given that multiple end-organs in the body may be affected by uremia, there may be significant heterogeneity in how people manifest ESKD. This underscores that advanced kidney disease is not a single entity but rather a spectrum and/or group of diseases with a wide range of symptoms.³⁹ Despite the vast majority (90% of people with CKD) receiving the same 3 times a week in-center hemodialysis regimen, some people may still have residual kidney function upon transitioning to dialysis and therefore have different requirements for “dose” of kidney-replacement therapy.³⁹ Therefore, a more gradual approach such as incremental dialysis, is a rational step in management.

Incremental Dialysis

It is necessary to recast how clinicians think about advanced kidney ailments, moving away from ESKD as a single “end-stage” disorder and toward considering KDRD as having stages of evolution (please also see the following section for related discussion on person-centered terminology).³⁹ Accordingly, treatment should be individualized and take an approach to dialysis of assisting the declining kidney function (i.e., kidney-assistance therapy) instead of replacing it (i.e., kidney-replacement therapy). This approach entails utilizing a gradual transition to dialysis, in which people with KDRD are initially administered once-weekly or twice-weekly hemodialysis based on residual kidney function, and tailoring treatment to more frequent sessions as residual kidney function declines.³⁹ Consensus conference attendees with CKD agreed that if circumstances allow, people requiring dialysis may benefit from an incremental transition to treatment *in lieu* of commencing a 3 times a week schedule at the outset.

Home Dialysis

“There is a lack of information on home hemodialysis,”

Perspective from a person with CKD (Table 2).

Home dialysis has been shown to improve clinical outcomes for people with CKD compared with in-center dialysis, and symptoms may be better managed using this approach.⁴⁰ In Hong Kong, 76% of people with CKD receiving dialysis were on home dialysis in 2013, with the majority receiving peritoneal dialysis.⁴¹ Home dialysis may be preferable for people with CKD as it offers a continuous rather than intermittent treatment (i.e., as with conventional hemodialysis) as well as for healthcare systems in terms of cost-effectiveness.⁴² The Advancing American Kidney Health Initiative Executive Order in the United States has also made it a

national goal to increase the adoption of home dialysis by 2025.⁴³

Conference attendees with CKD indicated that home dialysis can enhance the independence, freedom, and control of people with CKD, and therefore lead to greater empowerment; though it was noted that this approach may not be well-suited for every individual. Conference attendees also emphasized that greater education on and awareness of home dialysis options is needed by people with CKD and their care partners, as well as nurses, technicians, dietitians, and social workers with whom people with CKD more frequently interact at dialysis clinics. More education on home dialysis would help to allay the fear of the unknown if people with CKD are reluctant to consider this option. There is also need for structured and standardized training programs that teach people with CKD to home dialyze, as well as for care partners who may be assisting with home dialysis. Nevertheless, as shown in Hong Kong, most people with KDRD are able to undertake home dialysis successfully. Because there is currently a shortage of nurses and technicians in the field of nephrology, dialysis treatments that can be independently implemented by people with KDRD at home may also alleviate this workforce crisis, and it was also suggested a medical insurance incentive could be considered for people with KDRD who chose home dialysis.

Conference attendees with CKD also highlighted that persons with KDRD should not be forced to fit into a system, algorithm, or business model: for example, a “one-size-fits-all” approach for dialysis is clearly inappropriate, and clinicians should instead advocate for an individualized and tailored treatment strategy. A more person-centered management approach with broader consideration of how kidney disease affects people with regards to their physical function, independence, and HRQOL is essential. In turn, such an approach may benefit the economy by enabling people with CKD to continue or return to the workforce and contribute to society. It was emphasized that a modality or schedule change can make a major difference in the lifestyle of a person with KDRD. They require more effective, comprehensive, and innovative educational approaches about their treatment options so that they are able to make informed decisions—effective and individualized education is at the crux of empowering people with CKD to be able to choose the treatment that is best suited for them.

Conservative Management and Person-Centered Terminology in CKD

Conservative Management

Conventional care has traditionally been focused on preparing people with CKD for kidney-replacement

therapy, namely dialysis, as kidney function declines.⁴⁴ In contrast, conservative and preservative management focuses on nondialytic approaches that slow CKD progression and delay or avoid the need for dialysis, including prioritization of managing unpleasant symptoms without dialysis.⁴⁴ Whereas dialysis has been the default treatment strategy for KDRD over 5 decades, there has been a major clinical gap in providing alternative dialysis-free treatment strategies for the management of advanced CKD.⁴⁵ Given that dialysis may not always exert the intended effect of improving quality of life or restoring health,⁹ in some people with CKD, conservative care in which symptom management is a cornerstone may be a more person-centered strategy.^{9,44}

Conservative and preservative management involves the active and comprehensive medical management of CKD using nondialytic strategies with a focus on the preservation of remaining kidney function and optimizing HRQOL.⁹ A multifaceted approach is required that encompasses dietary interventions, proactive symptom management, advance-care planning, social and family support, psychological support, and cultural and spiritual domains of care (Figure 2).^{9,46} For example, lifestyle factors such as dietary intake, physical activity, and management of psychological stress may affect CKD progression and overall well-being,^{47–50} and there has been growing interest in understanding how plant-based diets rich in fruits and vegetables paired with pharmacologic interventions that mitigate hyperkalemia can be used to ameliorate decline in kidney function.^{51,52}

Consensus conference attendees with CKD also agreed that people with CKD need greater education to understand the gravity of coexisting conditions such as high blood pressure and diabetes, and why lifestyle changes are needed to address those conditions, so that they are engaged in and empowered to manage their health, thereby avoiding or delaying the need for dialysis.

Person-Centered Terminology

People with CKD and their families have expressed dissatisfaction over the descriptors of “end-stage” or “failure” for kidney disease.^{53,54} To avoid use of these descriptors, preferred terms include CKD stage 5 treated with dialysis or kidney-assistance therapy and KDRD. Further, terms to avoid include end-stage renal disease or kidney disease, end-stage renal or kidney failure, dialysis-dependent CKD, and kidney failure, given that the descriptor “failure” has a negative connotation.⁵⁵ Indeed, a change in terminology should ideally fulfill the following criteria: it should neither be vague nor undermine hope and should reflect the

nature and severity of the ailment, which in turn should create more person-centric terminology.

Consensus conference attendees with CKD explained that they embody the role of being “patients” only when they are in the medical setting (i.e., at medical appointments and/or when undergoing treatment). Given their desire to be treated with dignity as individuals, some advocacy group leaders indicated that they prefer to refer to themselves as “dialyzors” rather than patients when they are receiving dialysis treatment. The use of “normal” when describing symptoms of CKD was also considered inappropriate for the following reasons: these symptoms may be unacceptable for the individual, should not be considered inevitable, and should be addressed by clinicians. It was also discussed that language needs to be focused on the positive rather than the negative and should not have a connotation of blaming the individual for their condition. For example, rather than kidney failure, the emphasis should be on preserving any kidney success. Accordingly, dialyzors should never be told they are not “adequate” with respect to dialysis efficiency, nor should noncompliance ever be used in relation to dialysis, and kidney failure with replacement therapy might be better described as KDRD as proposed earlier.

Diversity, Equity, Inclusion, and Supportive Care in CKD

Social Determinants of Health

People who identify as Black and non-Hispanic have been shown to be 4 times more likely than non-Hispanic White people to have kidney disease in the United States.⁵⁶ KDRD incidence has also been shown to be higher in Hispanic/Latino than non-Hispanic people in the United States, and can vary by type of Hispanic/Latino heritage.⁵⁷ Once transplanted with a kidney, the 3 year and 5 year unadjusted graft survival rates in the United States by race or ethnicity were as follows: 81% and 69% for White people; 84% and 69% for those who identify as Hispanic/Latino; and 73% and 57% for African American people, respectively.⁵⁸ The disparities seen by race and ethnicity in people with CKD have been most extensively studied in the United States, but have also been observed in other countries across the world.⁵⁹ Stress due to structural racism, neighborhood violence, and/or poverty may contribute to dysfunction of key regulatory pathways involved in inflammation.⁶⁰

In Hawaii, where the consensus conference was held, diabetes is a leading cause of kidney disease in the Native Hawaiian/Pacific Islander population. Indeed, there is a disproportionately high burden of complications from diabetes in all indigenous peoples irrespective of their location across the world.⁶¹

Therefore, diabetes prevention and self-management programs in these populations are essential. In addition, because rural and remote communities may be disadvantaged by their location, community screening programs that visit these areas are valuable to address this geographical disparity. Furthermore, equity in access to healthcare and treatment more broadly, are vital to redressing racial disparities. Moreover, education is needed so that clinicians understand how to relate to the people they treat sympathetically, without prejudging what they will understand and what is an appropriate treatment for them.

Supportive Care

“As the wife of an end-stage kidney disease patient, I can say that it changes the life of the whole family,” Perspective from a family member of a person with CKD (Table 2).

Clinicians and consensus conference attendees with CKD discussed that navigating the medical system can be confusing and frightening, which should be acknowledged and addressed. It may also take time for people with CKD to come to terms with information relating to their kidney health, as difficult news may not be processed straightaway, and patience from clinicians and other providers is of utmost importance. In addition, the choices of people with CKD and the solutions that are best suited for them may not be what is expected and/or preferred by their family and friends.

Some people with CKD may be afraid or reluctant to join support groups and learn more about their condition, and in some cases may think of the dialysis waiting room as their only support group. When people with CKD do have access to support groups, they may not be in the right mindset as they are coming to terms with their health status, and they may then find it challenging to connect in a group setting. For this reason, peer mentorship can help to link a person with CKD with an engaged member of the kidney community to reassure them that they are not alone in their journey. Furthermore, CKD ambassadors can help to bridge their conversations with other members of kidney communities. Finally, online support groups were discussed as another around-the-clock support for people with CKD and vehicle for connection. People with CKD at the conference also underscored that these groups should include a moderator to oversee the content and ensure that misinformation is not disseminated to the community of people with CKD.

CONCLUSION

People with CKD have a high burden of unpleasant symptoms that may be underrecognized, underdiagnosed, and undertreated. The Living Well with

Kidney Disease Consensus Conference provided a valuable opportunity to convene healthcare providers, advocates, people with CKD, and their care partners from around the world to discuss approaches to ensuring the optimal management of unpleasant symptoms in CKD. It was agreed that it is of paramount importance to reframe clinicians' and other multidisciplinary providers' perceptions by engaging persons with CKD in defining their personal values, preferences, goals, and individual needs. Approaches that were considered to offer personalized care included conservative and preservative management with the aim to prevent or delay dialysis, incremental transition to dialysis and home dialysis modalities.

The Standardized Outcomes in Nephrology–Peritoneal Dialysis Life Participation consensus publication recently highlighted the need for a validated, standardized tool to assess life participation in individuals receiving peritoneal dialysis and discussed the characteristics required for such a tool. Similar to the findings of this consensus conference, important aspects identified included consideration of social and cultural backgrounds with an outcome measure flexible enough to encompass the activities valued by the individual.^{6,2} This consensus conference adds to their findings in stressing the importance of capturing the effects of unpleasant symptoms on individuals to help ensure these symptoms are adequately assessed and appropriately treated. In order to achieve this, any tools for assessing life participation need to consider health literacy of the people with CKD. Indeed, the theme for the 2022 World Kidney Day is Kidney Health for All to bridge the knowledge gap for better kidney care with an emphasis on improving health literacy.²

In conclusion, this consensus conference highlighted that person-centered communication and care, as well as education and awareness that considers health literacy are of paramount importance in CKD treatment. Furthermore, it underscored that shared decision-making that critically involves people with CKD and their care partners is essential to ensuring optimal kidney disease management. These factors are fundamental to ensuring that the healthcare system as a whole operates in a way that aligns with the goals of persons with CKD and delivers care that places the needs of people with CKD at the very center.

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