



KDIGO Controversies Conference on Symptom-Based Complications in Dialysis

Scope of Work

Kidney Disease: Improving Global Outcomes (KDIGO) is an international organization whose mission is to improve the care and outcomes of kidney disease patients worldwide by promoting coordination, collaboration, and integration of initiatives to develop and implement clinical practice guidelines. Periodically, KDIGO hosts conferences on topics of importance to patients with kidney disease. These conferences are designed to review the state of the art on a focused subject and set priorities for improving patient care and outcomes. In addition to highlighting areas for which additional research is needed, sometimes the conferences can lead to KDIGO guideline development efforts.

CONFERENCE BACKGROUND AND RELEVANCE

Patients with advanced kidney disease report a wide range of symptoms, and some of these symptoms become more perceptible or bothersome with worsening kidney function.¹⁻³ Many factors contribute to symptom burden, and these include uremia and its complications, aging, co-existing illnesses such as diabetes and heart failure, and medication side effects. The initiation or intensification of long-term dialysis alleviates only some of these symptoms (such as anorexia or nausea) and induces still others (such as post-hemodialysis fatigue).⁴ As such, patients with kidney failure undergoing long-term dialysis place a high priority on identifying treatments to alleviate many of the symptoms they experience.⁵⁻⁸

There is a high discordance between symptoms reported by patients and those identified by their nephrology care-providers.⁹ Until recently, nephrology care has focused primarily on numerical targets for laboratory measures rather than patient-reported outcomes such as symptoms. This focus on laboratory measures may crowd out conversations about symptoms and/or discourage patients from mentioning their symptoms during nephrology care encounters. Furthermore, many patient-reported outcome measures have either not been validated for kidney failure or developed at all



(such as for cramps).^{10, 11} Additionally, there is persistent stigma around some symptoms, such as depressive symptoms or sexual dysfunction. Finally, there is no consensus on how to standardize and incorporate symptom assessment into routine clinical care of patients undergoing long-term dialysis.¹²

Even when symptoms are identified, treatment is infrequently initiated.^{13, 14} There is no consensus whether the nephrologist or other primary care physicians should bear the primary responsibility for managing symptoms. An added concern is the lack of high-level evidence for the efficacy or safety of treatments to alleviate symptom burden in people with advanced kidney disease.¹⁵ Patients are often reluctant to take additional medications given their already high pill burden and the possibility that additional drugs will further add to symptom burden. Frequent visits for non-pharmacologic treatments, such as cognitive behavioral therapy for depression, are an added burden over and above visits for dialysis treatments.

Thus, there is a compelling need to develop and test solutions for assessing and managing the multitude of symptoms experienced by patients undergoing long-term dialysis.

CONFERENCE OVERVIEW

In 2018, KDIGO initiated a series of Controversies Conferences focused on dialysis. The first conference, *Dialysis Initiation, Modality Choice, Access, and Prescription*, cemented the understanding that choice of dialysis modality plays a central role in an individualized and goal-directed approach to initiating kidney replacement therapy. The second conference, held in 2019, addressed *Blood Pressure and Volume Management in Dialysis*, both of which are significantly and variably impacted by dialysis modality. The third meeting of the dialysis series focused on the utility and adoption of *Home Dialysis* and was held in 2021. This fourth conference in the dialysis series seeks to identify the optimal means for diagnosing, managing, and treating symptom-based complications in patients undergoing dialysis therapy.

As part of a holistic approach towards symptom-based management, the core outcomes considered will include patient-centered issues, perspectives, values, preferences, and quality of life.

Drs. Edwina Brown (Imperial College London, UK) and Raj Mehrotra (University of Washington, USA) will co-chair this conference. The format of the conference will



involve topical plenary session presentations followed by focused discussion groups that will report back to the full group for consensus building. This highly interactive conference will invite key thought leaders and relevant stakeholders, including patients, in nephrology and other related disciplines who will comprehensively review the literature and current state of understanding in this area and address clinical issues as outlined in the **Appendix: Scope of Coverage**. The conference output will include publication of a position statement that will help guide KDIGO and others on evidence-based management and future research in this area.

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APPENDIX: SCOPE OF COVERAGE

Breakout Group 1: Strategies to Incorporate Symptom Assessment into Routine Clinical Care

Will cover both physical and psychological symptoms

1. What are the current barriers for routinely assessing and documenting symptoms in in-center and home dialysis patients? Consider health-system, health care provider, and patient-level barriers.
2. How can these barriers be addressed?
 - Consider barriers in different settings:
 - Healthcare systems
 - For example, linking this assessment to reimbursement
 - Universal payment versus self-funding
 - Cultural settings
 - For example, some cultural groups may not want to divulge inner feelings and social activities
 - Consider differences in approach to symptom detection and solutions for overcoming them for in-center dialysis versus home-based dialysis modalities.
 - Potential roles of:
 - Remote monitoring
 - Dialysis partners or family caregivers
 - Whose responsibility is it to initiate the process?
 - The dialysis nurse, the family or home caregiver, the nephrologist, physician extenders, etc? Should the person who knows the patient best initiate the process?
 - Consider variations in healthcare teams:
 - For example, in certain setting there may not be a primary care doctor.
 - How can we help to reconcile differences in perception of the importance of patient-reported outcome measures (PROMS) and symptom burden? For example, through patient/care provider education or evidence-based observation of PROMs/symptom burden in relation to health outcomes?



3. Given the multitude of symptoms which can be related to dialysis treatment, medications, co-morbidities, social problems, etc., what symptoms should kidney care teams focus on?
 - Should symptoms be classified or categorized into core and non-core? If so, what should guide the designation of a symptom as a core symptom
 - People undergoing hemodialysis (HD) or peritoneal dialysis (PD) may have different symptom predominance; should symptoms be categorized differently based on the dialysis modality?

4. PROMs are typically used to assess symptom burden on dialysis. What is the best way to administer them?
 - a. What is the ideal frequency of assessment to prevent fatigue and perceived intrusion of privacy and the optimal time limit for form filling?
 - b. Who should complete assessments: patients or the healthcare team?
 - c. What is the best format for administering? Pen/paper, telephone, digitally?
 - d. Should PROMs be validated to individual populations?
 - e. How do we incorporate this symptom assessment into the patient's medical records and the overall clinical assessment?
 - i. Consider feedback to the nephrologist, other members of the healthcare team, and to the patient/family/caregiver.
 - ii. Consider systems where information technology options remain limited.



Breakout Group 2: Reducing Burden of Physical Symptoms

These symptoms include but are not limited to the following: fatigue, pain, pruritus, insomnia/sleep-disorders, restless legs, sexual dysfunction, loss of appetite, anorexia, nausea, cramps, physical function/mobility, cognitive impairment, shortness of breath, dialysis-related amyloidosis

1. What physical symptoms should kidney care teams focus on? What symptom clusters can be identified?
2. Should nephrologists and other nephrology clinical care providers differentiate between symptoms related to comorbidities, aging, and kidney failure? If so, how should this be done and applied to care delivery?
3. Is there a threshold of frequency, intensity, or intrusiveness that should be met before considering treatment for commonly experienced physical symptoms? How can we better account for existing comorbidities? Is there a listing of patient mitigating factors (cultural, social) to physical/psychological symptom detection to look out for?
4. Which physical symptoms are amenable to improvement with modification of the dialysis (HD or PD) regimen or prescription?
5. Which physical symptoms are best managed by pharmacological or non-pharmacological interventions or a combination of both?
 - What are some management strategies one could employ to minimize polypharmacy?
6. What are important considerations for developing and evaluating new treatments for physical symptoms?
7. What are important treatment considerations in the context of low- and middle-income countries?

Breakout Group 3: Optimizing Management of Psychological Symptoms

These symptoms include but are not limited to depression, anxiety, and frustration

1. Is there a threshold of frequency, intensity, or intrusiveness that should be met before considering treatment for commonly experienced psychological symptoms?
2. When monitoring psychological symptoms in patients on dialysis, what particular aspects (e.g., physical symptoms, cultural and societal factors, and carer wellbeing) should be evaluated?
3. How much can we mitigate the occurrence of psychological symptoms by adequate preparation for dialysis?
4. How much does cognitive dysfunction impact psychological symptoms? Should we routinely screen for cognitive dysfunction?
5. Are there psychological symptoms amenable to improvement with modification of the dialysis (HD or PD) regimen or prescription?
6. Which psychological symptoms are best managed by pharmacological or non-pharmacological interventions or a combination of both?
 - What are some management strategies one could employ to minimize polypharmacy?
7. What are important treatment considerations in the context of low- and middle-income countries?



Breakout Group 4: Systems-Level Opportunities to Optimize Symptom Management

Will cover both physical and psychological symptoms

1. What are the models of multidisciplinary kidney care for dialysis patients to optimize symptom management across the adult lifespan?
 - a. For example, what is the best way to manage psychological symptoms in patients on dialysis across care boundaries (diverse providers ranging from combined nephrology/palliative care; nurse-led; integrated primary care)
 - b. Role of financial incentives and reimbursement
 - c. Differences with public versus private dialysis clinics
 - d. Role of staffing—including access to allied health professionals, psychologists, social workers, dieticians, physiotherapists
 - e. Patient and family preferences for models of care
 - f. How can value-based healthcare models support symptom management?

2. What are the resource implications and costs associated with symptom assessment and management?
 - a. Patient education, data collection, healthcare activities, time involved from nursing, nephrology, patients, referrals, diagnostic tests, treatments, hospitalizations, electronic medical record (EMR) integration
 - b. Consider also health system savings and efficiencies
 - c. Consider the benefits to patients (quantitative and qualitative) and any out-of-pocket costs
 - d. If symptom assessment and management are added to the dialysis workload without any increase in resources, is there anything in current practice that can be dropped to enable the focus on symptom management to occur?

3. What changes need to be considered for training in nephrology to enable focus of care on well-being and symptoms?
 - a. Changing the conversation in a nephrologist–patient consultation to focus on well-being rather than labs
 - b. National curricula for advanced nephrology trainees; lessons from other disciplines such as nursing, psychology



- c. Training enthusiastic/interested staff at dialysis clinics. For example, Neph Talks, ANNA, RSA, supportive care workshops, peer-to-peer training and mentoring, other forums

- 4. What are the unique considerations in the context of low- and middle-income countries?
 - a. Limited dialysis sessions per week
 - b. Access to prescribed medicines
 - c. Availability of support: personnel and role of family and community members