



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 limited 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, the first KDIGO dialysis Controversies 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 KDIGO dialysis Controversies 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 KDIGO dialysis Controversies Conference 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, core outcomes considered are likely to be patient-centered issues, perspectives, values, and preferences, as well as 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

1a. What are the current barriers in assessing and documenting symptoms routinely in dialysis patients?

1b. 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
- Whose responsibility is it to initiate the process?
 - The dialysis nurse, the family/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?

2. Given the multitude of symptoms which can be related to the 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?
- People undergoing hemodialysis (HD) or peritoneal dialysis (PD) may have different symptom predominance; should symptoms be categorized differently based on the dialysis modality?

3. PROMs are typically used to assess symptom burden on dialysis. What is the best way to administer them?

- What is the ideal frequency of assessment to prevent fatigue and perceived intrusion of privacy, and the optimal time limit for form filling?
- Who should complete assessments: patients or the healthcare team?
- What is the best format for administering? Pen/paper, telephone, digitally?
- Should PROMs forms be validated to individual populations?
- How do we incorporate this symptom assessment into the patient chart and the overall clinical assessment?
 - Consider feedback to the nephrologist, other members of the healthcare team, and to the patient/family/caregiver.
 - Consider systems where information technology options remain limited.

4. What are barriers to symptom detection for in-center dialysis versus home-based dialysis modalities?

5. What are barriers to symptom reporting from a patient's perspective (e.g., cultural, social factors) or symptom detection by healthcare providers (e.g., bias in pain treatment during opioid crisis)?

Breakout Group 2: Reducing Burden of Physical Symptoms

These symptoms include but are not limited to: 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, among others

1. 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?
2. 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?
3. Which physical symptoms are amenable to improvement with modification of the dialysis (HD or PD) regimen/ prescription?
4. Which physical symptoms are best managed by non-pharmacologic treatments?
5. Which physical symptoms are best managed by pharmacologic treatments?
6. Are there physical symptoms that are best managed by a combination of non-pharmacologic and pharmacologic treatment?
7. What are important considerations for developing and evaluating new treatments for physical symptoms?
8. What are important considerations for low/middle-income countries?
9. How can we manage the physical impact of COVID-19 pandemic (or other disasters) on patients on hemodialysis?



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. How can we better account for existing comorbidities or mental state? Is there a listing of patient mitigating factors (cultural, social) to physical/psychological symptom detection to look out for?
3. How much does cognitive dysfunction impact psychological symptoms?
4. Are there psychological symptoms amenable to improvement with modification of the dialysis (HD or PD) regimen/prescription?
5. Which psychological symptoms are best managed by—
 - a. Non-pharmacologic treatments?
 - b. Pharmacologic treatments?
 - c. A combination of non-pharmacologic and pharmacologic treatments?
6. What are important considerations for low/middle-income countries?
7. How can we manage the psychological impact of COVID-19 pandemic (or other disasters) on patients on hemodialysis?

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?
 - a. For example, 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, dietitians, physiotherapists
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, efficiencies
 - c. Consider the benefits to patients (quantitative and qualitative)
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, other forums
4. What are the unique considerations for low/middle income countries?
 - a. Limited dialysis sessions per week
 - b. Access to prescribed medicines
 - c. Available personnel and role of family and community members
5. How do solutions differ for overcoming barriers to symptom detection for in-center dialysis versus home-based dialysis modalities?