



Global Action. Local Change.

KDIGO Controversies Conference on Supportive / Palliative Care in CKD

**December 6-8, 2013
Mexico City, Mexico**

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 to ask conference participants to determine what needs to be done in this area to improve patient care and outcomes. Sometimes the recommendations from these conferences lead to KDIGO guideline efforts and other times they highlight areas for which additional research is needed to produce evidence that might lead to guidelines in the future.

NEEDS ASSESSMENT

Chronic, non-malignant diseases are a major public health and economic burden. The public health and economic burden of chronic, non-cancer related diseases is particularly high in the last years of life. Traditional models of supportive/palliative care focus primarily on patients with cancer in the last 1-6 months of life. Patients with chronic illnesses such as advanced CKD have tremendous disability, symptom burden and the requirement for quality supportive/palliative care that typically extends beyond the last year of life. Models of care, which limit access to supportive care services, will not serve adequately the needs of patients dying with CKD.

Benefits of life-sustaining treatment, such as dialysis, for elderly and frail patients with

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high co-morbidity are often minimal. For some, dialysis does not provide a substantial survival benefit. In fact, elderly patients with co-morbid conditions managed with early supportive care and no chronic dialysis may live as long as patients who elect to start dialysis therapy. In oncology, receiving early palliative care has recently been associated with better quality of life, fewer emergency department visits and hospitalizations, less aggressive care at the end of life, and surprisingly, longer survival. These observations suggest that for some patients, a supportive care approach may be more appropriate. Conservative care programs that integrate early palliative care are slowly being developed, primarily in the UK and Canada.

The development of a system of integrated supportive/palliative care is urgently required to provide quality care for those with long-term chronic illnesses such as advanced CKD in which multiple co-morbidities among older people will dominate palliative care in the future. To achieve international, multidisciplinary, transparent and unbiased analysis, KDIGO will bring together experts from around the world to attend a Controversies Conference on Supportive/Palliative Care in CKD.

CONFERENCE OVERVIEW

Renal Palliative Care experts Drs. Sara Davison (University of Alberta, Canada) and Gregorio Obrador (Universidad Panamericana School of Medicine, Mexico) will co-chair this conference. The Controversies Conference will: a) summarize the state of knowledge of renal palliative care; b) discuss what recommendations can be derived from the available knowledge; and c) assess what needs to be undertaken in the future to improve the evidence-base for clinical management. 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.

Invited participants and speakers will include the leading worldwide experts in supportive care, including nephrologists, palliative specialists, epidemiologists, and representatives of other disciplines to give the broadest views possible on the subject. The conference output will include publication of a position statement that will help guide KDIGO and others on additional research and ultimately the development of clinical practice guidelines.

KDIGO anticipates that this conference will have a prominent role in increasing the

international uptake of supportive/palliative care services for patients with advanced CKD. International collaboration will aid in advancing effective and efficient models of integrated renal palliative care by contextualizing multiple health system characteristics and identifying best practices and models for supportive/palliative care that will have the greatest applicability and global relevance. International collaboration also enables a better understanding of different cultures and religions at the end of life, both for indigenous populations and for those who have migrated to other countries. This is especially challenging given the considerably higher rate of CKD in non-Caucasian populations. KDIGO anticipates that the specific supportive/palliative care interventions to improve outcomes for patients with advanced CKD may be shared across countries, while the configuration and coordination of these interventions into integrated 'models of care' will vary according to local healthcare provision.

We recognize that renal supportive care includes patients with AKI and renal transplant, but for the purposes of this conference we have limited the scope to patients with CKD. For a detailed listing of topics to be addressed in this conference, please see Appendix: Scope of Coverage.

APPENDIX: SCOPE OF COVERAGE

- A. Symptom Assessment, Epidemiology and Management
 - Symptom assessment tools
 - Pruritus
 - Fatigue, weakness/lethargy
 - Pain
 - Anorexia, nausea, vomiting, constipation, diarrhea
 - Sleep disturbances, restless leg syndrome, cramps, agitation, and miscellaneous dialysis related symptoms (e.g., headache)
 - Depression, anxiety (and other mental illnesses) and sexual dysfunction
 - Physical function and quality of life
 - Consequences of symptoms on resource utilization and healthcare costs
 - Challenges from developing countries
 - Clinical practice guidelines/policies and models of care from around the world

- B. Prognosis
 - Epidemiology and large database studies
 - Novel prognostic approaches and tools/scoring systems

- C. Advance Care Planning and Shared-Decision Making
 - Advance care planning
 - Decision-making
 - Impact of advance care planning on outcomes
 - Operational aspects of advance care planning

- D. Initiation, Withholding, and Withdrawal of Dialysis
 - Impact of culture and religion on withholding and withdrawal
 - Healthcare provision after withdrawal in countries with palliative care services

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- Healthcare provision after withdrawal in countries with no organized palliative care services
- Cost-effectiveness of dialysis and palliative care
- Provision of patient education and involvement in decisions affecting dialysis choice, withholding, and withdrawal
- Ethics around "forced" withdrawal or withholding of dialysis because of non- medical factors
- Healthcare funding and system impact on dialysis initiation and withholding in emerging economies
- Variations in pre-ESRD care and dialysis initiation, withholding, and withdrawal in developed economies

E. Conservative Care

- Need for and availability of conservative care in low, middle and high income countries
- Costs and/or cost-effectiveness of conservative care, including overall healthcare costs and resource utilization
- Comparative evidence on survival between conservative care and dialysis
- Evidence on models of conservative care and what constitutes as “best practice” in conservative care for low, middle and high income countries
- Perspectives on conservative care: patient, family and professional

The conference will focus predominantly on advanced CKD (whether treated with dialysis or managed conservatively). Although beyond the scope of this conference, it is recognized that issues relevant to acute kidney injury and transplant will also acquire attention in future endeavors.