

Supportive Care: Meeting the Needs of Patients with Advanced Chronic Kidney Disease

Sara N. Davison* and Alvin H. Moss^{†‡}

Clin J Am Soc Nephrol 11: 1879–1880, 2016. doi: 10.2215/CJN.06800616

Introduction

Over the last several decades, despite advances in predialysis care and dialysis technology, people with advanced CKD continue to have a high symptom burden, shortened life expectancy, and substantial physical, emotional, and spiritual suffering (1). Unfortunately, most nephrologists are not trained to address this multifactorial suffering (2), and consequently, many patients on dialysis experience significant unmet supportive care needs (3–5). Kidney supportive care is aimed directly at relieving this suffering, and training in primary supportive care for clinicians treating patients with CKD is an urgent priority (6).

The first article in this Moving Points in Nephrology feature provides a framework for understanding what kidney supportive care is and how it integrates patient-centered care into standard nephrological care (7). Supportive care is patient centered, because it identifies what matters most to patients, and it is respectful of patients by providing treatments that align with their values and preferences (1). Supportive care includes symptom assessment and management, patient-specific estimates of prognosis, shared decision making for informed consent, advance care planning, and referral to hospice as appropriate (7,8).

Supportive care aims at improving the quality of life (QOL) of any patient with a life-limiting illness, such as CKD, throughout the continuum of illness. Kidney supportive care, therefore, is not restricted to withholding dialysis (*i.e.*, comprehensive conservative care of patients with advanced CKD) or withdrawal of dialysis. Kidney supportive care is about doing things differently to provide the best care possible, which includes enhancing QOL through meticulous symptom management and ensuring that patients' values guide clinical decisions after those values have been learned in the process of shared decision making (1). Supportive care can be provided together with therapies intended to prolong life, such as dialysis. Because it is still a commonly held view by both patients and health care providers that palliative care and terminal care are synonymous (9–11), the term kidney supportive care is replacing the term kidney palliative care (8). The concepts, however, remain consistent with the World Health Organization definition of palliative care (12). As a nephrology community,

we need to educate patients and care providers on the appropriate role of kidney supportive care.

Recognizing that there are no clinical standards to inform how supportive care can best be delivered to people with CKD, Kidney Disease Improving Global Outcomes in partnership with the International Society of Nephrology held the first consensus forum on kidney supportive care in December of 2013. The overall aim was to focus the nephrology community on issues related to the international application of palliative medicine to patients with CKD with the ultimate goal of working toward global guidelines for the implementation of kidney supportive care. This resulted in a roadmap to help improve the QOL and standard of care for all patients worldwide with advanced CKD (8).

Since this conference, there has been a substantial shift in the clinical and research priorities of many involved with the care of people with CKD (13,14), resulting in increased knowledge translation and policy changes internationally (15). It has also been a time of great reflection. Both of these points are highlighted by the articles in this Moving Points in Nephrology feature that discusses several of the main aspects of kidney supportive care, such as appropriate prognostication (16), aligning treatment with a patient's goals through culturally sensitive shared decision making and advance care planning (17), patient-centered and palliative dialysis (7), symptom control (7), and comprehensive conservative (nondialysis) care of patients with advanced CKD (18). They not only illustrate the advancements in the field but also highlight key knowledge gaps and future directions for research. As researchers develop strategies to optimize the integration of kidney supportive care into standard nephrological care, Morton *et al.* (19) emphasize the importance of evaluating the effect on outcomes most important to patients and caregivers, such as QOL, symptom management, physical and cognitive function, the ability to live independently, and survival, in addition to health care services utilization and costs. They note that kidney supportive care has the potential to reduce the high costs associated with unwanted hospitalization and intensive medical treatments (19).

In many ways, the field of kidney supportive care is leading the way for the integration of supportive care principles into the treatment of patients with other chronic nonmalignant diseases. Even in developing

*Division of Nephrology and Immunology, Department of Medicine, University of Alberta, Edmonton, Alberta, Canada; and †Sections of Nephrology and ‡Supportive Care, West Virginia University School of Medicine, Morgantown, West Virginia

Correspondence:

Dr. Sara N. Davison, 11-107 Clinical Sciences Building, Edmonton, AB, Canada T6G 2G3. Email: sara.davison@ualberta.ca

countries, people are increasingly dying with chronic nonmalignant disease, often after a prolonged period of vulnerability and suffering. Although a shift to a more patient-centered approach to both clinical care and research is absolutely critical for maximizing the QOL of patients with CKD, there remain key knowledge gaps. A lack of data should not be used to justify inaction when it is clear that the burden of patients with CKD is substantial and that the status quo is unacceptable. However, there is an urgent need to expand the research agenda to provide evidence to improve health outcomes for these patients.

International collaboration will aid in advancing effective and efficient models of integrated kidney supportive care by contextualizing multiple health system characteristics and identifying best practices and models for supportive care that will have the greatest applicability and relevance globally. It will better enable us to discover which interventions are applicable regardless of the configuration of local health services and which are responsive to local health care systems. International collaboration also enables a better understanding of different cultures and religions at the end of life. Many supportive care interventions to improve outcomes for patients with advanced CKD may be shared across countries, even if the configuration and coordination of these services into integrated models of care will vary according to local health care provision.

As we move forward, we need to understand what contributes to the suffering of our patients with CKD so that we can respond appropriately to it. This will require substantial patient engagement from setting clinical and research agendas to working collaboratively on the solutions. Clinical innovations, evaluation strategies, and quality metrics will all need to reflect the needs of our patients. We need to listen to our patients and allow them to teach us, so that we can partner with them in their care and treat them the way they want to be treated. In this manner, supportive care will add to standard nephrological treatment in a patient-centered approach that is the key element of the new system to improve health care quality in the 21st century (20).

Acknowledgments

S.N.D. has research funded by the Canadian Institutes of Health Research, funding reference numbers 89801, 126151, 126193, and Alberta Innovates: Health Solutions, number 201400400.

Disclosures

None.

References

1. Davison SN, Levin A, Moss AH, Jha V, Brown EA, Brennan F, Murtagh FE, Naicker S, Germain MJ, O'Donoghue DJ, Morton RL, Obrador GT; Kidney Disease: Improving Global Outcomes: Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: Developing a roadmap to improving quality care. *Kidney Int* 88: 447–459, 2015
2. Combs SA, Culp S, Matlock DD, Kutner JS, Holley JL, Moss AH: Update on end-of-life care training during nephrology fellowship: A cross-sectional national survey of fellows. *Am J Kidney Dis* 65: 233–239, 2015
3. Culp S, Lupu D, Arenella C, Armistead N, Moss AH: Unmet supportive care needs in U.S. dialysis centers and lack of knowledge of available resources to address them. *J Pain Symptom Manage* 51: 756–761.e2, 2016
4. Davison SN: End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol* 5: 195–204, 2010
5. Davison SN, Jhangri GS: Existential and supportive care needs among patients with chronic kidney disease. *J Pain Symptom Manage* 40: 838–843, 2010
6. Quill TE, Abernethy AP: Generalist plus specialist palliative care—creating a more sustainable model. *N Engl J Med* 368: 1173–1175, 2013
7. Davison SN, Jassal SV: Supportive care: Integration of patient-centered kidney care to manage symptoms and geriatric syndromes. *Clin J Am Soc Nephrol* 11: 1882–1891, 2016
8. Davison SN, Levin A, Moss AH, Jha V, Brown EA, Brennan F, Murtagh FE, Naicker S, Germain MJ, O'Donoghue DJ, Morton RL, Obrador GT; Kidney Disease: Improving Global Outcomes: Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: Developing a roadmap to improving quality care. *Kidney Int* 88: 447–459, 2015
9. Payne S, Sheldon F, Jarrett N, Large S, Smith P, Davis CL, Turner P, George S: Differences in understanding of specialist palliative care amongst service providers and commissioners in South London. *Palliat Med* 16: 395–402, 2002
10. Davison SN, Jhangri GS, Koffman J: Knowledge of and attitudes towards palliative care and hospice services among patients with advanced chronic kidney disease. *BMJ Support Palliat Care* 6: 66–74, 2016
11. Dalal S, Palla S, Hui D, Nguyen L, Chacko R, Li Z, Fadul N, Scott C, Thornton V, Coldman B, Amin Y, Bruera E: Association between a name change from palliative to supportive care and the timing of patient referrals at a comprehensive cancer center. *Oncologist* 16: 105–111, 2011
12. World Health Organization: WHO Definition of Palliative Care, 2008. Available at: <http://www.who.int/cancer/palliative/definition/en/>. Accessed April 5, 2016
13. Manns B, Hemmelgarn B, Lillie E, Dip SC, Cyr A, Gladish M, Large C, Silverman H, Toth B, Wolfs W, Laupacis A: Setting research priorities for patients on or nearing dialysis. *Clin J Am Soc Nephrol* 9: 1813–1821, 2014
14. Tong A, Chando S, Crowe S, Manns B, Winkelmayer WC, Hemmelgarn B, Craig JC: Research priority setting in kidney disease: A systematic review. *Am J Kidney Dis* 65: 674–683, 2015
15. Centers for Medicare and Medicaid Services: ESRD Quality Incentive Program. Available at: <https://www.cms.gov/Medicare/Quality-Initiatives-patient-Assessment-Instruments/ESRDQIP/>. Accessed July 20, 2016
16. Couchoud C, Hemmelgarn B, Kotanko P, Germain MJ, Moranne O, Davison SN: Supportive care: Time to change our prognostic tools and their use in CKD. *Clin J Am Soc Nephrol* 11: 1892–1901, 2016
17. Brown EA, Bekker HL, Davison SN, Koffman J, Schell JO: Supportive care: Communication strategies to improve cultural competence in shared decision making. *Clin J Am Soc Nephrol* 11: 1902–1908, 2016
18. Murtagh FEM, Burns A, Moranne O, Morton RL, Naicker S: Supportive care: Comprehensive conservative care in end-stage kidney disease. *Clin J Am Soc Nephrol* 11: 1909–1914, 2016
19. Morton RL, Tamura KM, Coast J, Davison SN: Supportive care: Economic considerations in advanced kidney disease. *Clin J Am Soc Nephrol* 11: 1915–1920, 2016
20. U.S. IoM: *Crossing the Quality Chasm: A New Health System for the 21st Century*, Washington, DC, National Academy Press, 2001