



American Academy of
Hospice and Palliative Medicine

AAHPM Comments submitted to the National Quality Forum on
National Voluntary Consensus Standards for End Stage Renal Disease
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National Voluntary Consensus Standards for End Stage Renal Disease

The American Academy of Hospice and Palliative Medicine supports the eleven new measures, particularly noting that they are a step forward because they include pediatric patients in measures of dialysis adequacy and complications. However, even with these new measures, the list of NQF-endorsed measures for ESRD is still lacking in measures that robustly address the palliative care needs of ESRD patients as outlined in current guidelines.ⁱ We strongly recommend that NQF note this gap and develop a strategy for addressing it in future work.

Ample evidence shows that ESRD has a high mortality rateⁱⁱ, multiorgan dysfunction syndromeⁱⁱⁱ, symptom burden,^{iv v vi} and incidence of depression^{vii} and that life-threatening complications and sudden death are common occurrences for both pediatric^{viii ix x} and adult patient populations.^{xi} Furthermore, end-of-life decisions are frequently made after the patient has lost decisional capacity.^{xii} Current clinical guidelines for shared-decision making concerning withdrawal of dialysis in both adults and children specify using advance care planning, integrating palliative care, and addressing symptoms and disease burden.¹ Quality measures that address these areas are needed so that clinical settings can assess their progress in delivering the care that meets the guidelines. To address both the high symptom burden and the high mortality rate, quality care of patients with ESRD should include:

1. assessment and treatment of common symptoms including (in order of prevalence) fatigue, insomnia, cramping, pruritus (itching), neuropathic pain, depression, nausea and vomiting;
2. advance care planning on at least an annual basis, including prognosis and goals of care, appointment of health care proxy, living will, resuscitation wishes; discussion of circumstances under which the patient would want dialysis stopped, and where the patient would like to spend the last days of life;

3. assessment of multiple quality of life domains, as measured in the KDQOL-36—currently endorsed by the NQF, but only for adults
4. utilization of a holistic interdisciplinary team to address quality of life needs and concerns that may be identified by the KDQOL-36 or other means
5. appropriate utilization of hospice and palliative care for patients who stop dialysis and as concurrent care along with dialysis for patients who have poor prognosis such as advanced cancer.

The current and proposed measures target the adequacy of dialysis and assessment of complications (anemia, hypercalcemia, hospitalization and bacteremia). However, none of the 11 recommended measures, nor any of the rest of the 32 measures that were initially considered, address any essential domains of palliative care (e.g. quality of life, advance care planning, symptom assessment or management, or bereavement support.)

Among the 25 quality measures already endorsed in 2008, only four address a domain of palliative care. However, these are limited. They exclude pediatric patients, and they do not address many areas of palliative care. The existing measures applicable to palliative care needs are:

- 0324 Patient education awareness –facility level (excludes patients <18 years old and calls for a documented discussion at least once every 12-month reporting year about renal replacement modalities including hemodialysis, peritoneal dialysis, home hemodialysis, transplants and identification of potential living donors, and no renal replacement therapy.)
- 0320 Patient education awareness-individual clinician level (same as above)
- 0260 Assessment of Health-Related Quality of Life (Physical and Mental Functioning)-facility level (excludes patients < 18 years old and calls for patients to complete a Kidney Disease Quality of Life KDQOL-36 document at least once a year that includes symptoms, functioning and other QOL domains important for palliative care.)
- 0258 Consumer Assessment of Healthcare Providers and Systems (CAHPS) In-center Hemodialysis Survey-facility level (excludes patients < 18 years old and measures responses to 57 questions about quality of care provided to patients at in-center hemodialysis units-including communication and information received.)

These 11 new standards are a step forward because they include pediatric patients in measures of dialysis adequacy and complications, but they do not address the gap that exists from the exclusion of pediatric patients from the four existing measures with

relevance to palliative care outlined above. We recommend that future work include measures that address *the* palliative care aspects of the applicable ESRD guidelines.

- i Renal Physicians Association (RPA). Shared decision-making in the appropriate initiation of withdrawal from dialysis. 2nd ed. Rockville (MD): Renal Physicians Association (RPA); 2010 Oct.
- ii Data from the Prospective Pediatric Continuous Renal Replacement Therapy (ppCRRT) Registry Group revealed 58% survival, with worse prognosis for patients with liver failure/transplant (31%), pulmonary disease/transplant (45%) and stem cell transplant (45%). (Symons JM, Chua AN, Somers MJ 2007)
- iii Goldstein SL, Somers MJG, Baum M a, Symons JM, Brophy PD, Blowey D, et al. Pediatric patients with multi organ dysfunction syndrome receiving continuous renal replacement therapy. *Kidney international*. 2005 Feb ;67(2):653-8.
- iv Poppel DM, Cohen LM, Germain MJ, The Renal Palliative Care Initiative. *J Pal Med*, 2003; 6:321-326
- v Strid, et al. The prevalence of gastrointestinal symptoms in patients with chronic renal failure is increased and associated with impaired psychological general well-being. *Nephrol Dial Transplant*, 2002; 17:1434-1439
- vi Fukuhara, et al, Health-related quality of life among dialysis patients on three continents: the Dialysis Outcomes and Practice Patterns Study. *Kidney Int*, 2003; 64:1903-1910
- vii Lopes, et al, Depression as a predictor of mortality and hospitalization among hemodialysis patients in the United States and Europe. *Kidney Int*, 2002; 62:199-207
- viii Symons JM, Chua AN, Somers MJ et al. Demographic characteristics of pediatric continuous renal replacement therapy: a report of the prospective pediatric continuous renal replacement therapy registry. *Clin J Am Soc Nephrol*. 2007 Jul;2(4):732-8.
- ix Flores FX, Brophy PD, Symons JM, Fortenberry JD, Chua AN, Alexander SR, et al. Continuous renal replacement therapy (CRRT) after stem cell transplantation. A report from the prospective pediatric CRRT Registry Group. [Internet]. *Pediatric nephrology* (Berlin, Germany). 2008 Apr ;23(4):625-30.
- x Rajasekaran S, Jones DP, Avent Y, Shaffer ML, Elbahlawan L, Henderson N, et al. Outcomes of hematopoietic stem cell transplant patients who received continuous renal replacement therapy in a pediatric oncology intensive care unit. [Internet]. *Pediatric critical care medicine*. 2010 Nov ;11(6):699-706.
- xi Herzog, Cardiac arrest in dialysis patients: approaches to alter an abysmal outcome. *Kidney Int*, 2003; 63:S197-200
- xii Cohen, et al, Dialysis discontinuation and palliative care. *AJKD*, 2000; 36:140-144