

A Patient-Centered Vision of Care for ESRD: Dialysis as a Bridging Treatment or as a Final Destination?

Stefaan J. Vandecasteele* and Manjula Kurella Tamura^{†‡}

*Division of Nephrology and Infectious Diseases, AZ Sint-Jan Brugge-Oostende, Bruges, Belgium; [†]Geriatric Research and Education Clinical Center, Veterans Affairs Palo Alto, Palo Alto, California; and [‡]Division of Nephrology, Stanford University School of Medicine, Palo Alto, California

ABSTRACT

The ESRD population is heterogeneous, including patients without severe comorbidity for whom dialysis is a bridge to transplantation or a long-term maintenance treatment, as well as patients with a limited life expectancy as a result of advanced age or severe comorbidity for whom dialysis will be the final treatment destination. The complex medical and social context of this latter group fits poorly in the homogeneous, disease-centered, and process-driven approach of many clinical practice guidelines for dialysis. In this commentary, we argue that the standards of treatment allocated to each individual patient should be defined not merely by his or her disease state, but also by his or her preferences and prognosis. In this more patient-centered approach, three attainable treatment goals with a corresponding therapeutic approach could be defined: (1) dialysis as bridging or long-term maintenance treatment, (2) dialysis as final treatment destination, and (3) active medical management without dialysis. For patients with a better overall prognosis, this approach will emphasize complication prevention and long-term survival. For patients with a limited overall prognosis, strictly disease-centered interventions often impose a treatment burden that does not translate into a proportional improvement in quantity or quality of life. For these patients, a patient-centered approach will place more emphasis on palliative management strategies that are less disease specific.

J Am Soc Nephrol 25: 1647–1651, 2014. doi: 10.1681/ASN.2013101082

The US Congress approved Medicare coverage for ESRD treatment in 1972. Dialysis was expected to bridge patients to renal recovery or transplantation, or to provide an average 9-year increase in life expectancy. Ever since, dialysis gradually evolved toward a first-line treatment option for patients with ESRD, including elderly persons and individuals with debilitating comorbidity. This changing perspective in access fueled a 4-fold increase in ESRD incidence over the last 3 decades, including a 13-fold increase among patients aged >75 years.¹

The heterogeneity of the contemporary ESRD population is not reflected in the prevailing paradigm of ESRD care, which is mainly disease centered and (dialysis) pro-

cess driven. Consequently, the care that is delivered may not be beneficial and may be potentially harmful or impractical for certain subpopulations.² In this commentary, we argue for a more heterogeneous, patient-centered, and attainable goal-directed vision of care for patients with ESRD.

DO ALL PATIENTS WITH ESRD BENEFIT FROM BEST PRACTICE GUIDELINES?

During the past decades, numerous clinical practice guidelines aiming to improve and harmonize dialysis procedures and overall medical care for dialysis

patients were developed. These guidelines are mainly based on epidemiologic data, cohort studies, trials with secondary end points, and expert opinion, rather than on well powered trials with hard end points.³ Although these limitations are acknowledged in the guidelines,³ the guidelines are frequently used as a quality standard applicable to all patients with ESRD, irrespective of their age, prognosis, and individual preferences, and as such are widely endorsed by policy makers and regulatory agencies.

Patients with ESRD experience high levels of mortality, morbidity, and distressing symptoms (Table 1). One-year mortality rates after dialysis initiation range from 10% for patients aged 20–44 years up to 41% for patients aged ≥75 years. Dialysis patients are frequently hospitalized, on average 11.8 days per year.¹ Chronic pain, fatigue, cognitive impairment, and depression are present in up to half of patients with ESRD.^{4,5} There exists, however, considerable heterogeneity in outcome among different patient groups.^{1,6,7} For example, 25% of 70-year-old patients starting dialysis in the United States survive <9 months,

Published online ahead of print. Publication date available at www.jasn.org.

Correspondence: Dr. Stefaan J. Vandecasteele, Division of Nephrology and Infectious Diseases, AZ Sint-Jan Brugge-Oostende, Rudderhove 10, 8000 Brugge, Belgium. Email: Stefaan.Vandecasteele@azbrugge.be

Copyright © 2014 by the American Society of Nephrology

Table 1. Prevalence of ESRD and mortality rates, compared to the general United States population

Age Group	ESRD Adjusted Prevalence per 1,000,000 Population			2004 Cohort Adjusted Probability of Mortality (%) of Incident ESRD Patients, from Day 1						ESRD Adjusted Mortality Rates per 1000 Patient-Years	General Population Mortality Rates per 1000 Patient-Years (Age)
	1980	2009	Increase	6 mo	1 yr	2 yr	3 yr	4 yr	5 yr		
0–19	29.7	85.0	2.9	6	9	17	23	26	30	44.2	0.7 (15–24)
20–44	264.2	929.8	3.5	5	10	18	25	32	37	81.8	1.7 (35–44)
45–64	587.5	3 357.8	5.7	10	17	29	39	48	57	145.4	8.5 (55–64)
65–74	643.3	5 950.2	9.3	18	28	43	56	66	74	238.3	18.8 (65–74)
75+	273.5	5 694.8	20.8	28	41	59	72	81	87	370.3	47.9 (75–84)

Adapted from the US Renal Data System 2011 Annual Data Report.

whereas 25% survive for >4 years. The survival benefit of dialysis treatment may be limited for patients with severe comorbidity or ischemic heart disease.^{6,8}

Clinical trials in dialysis highlight important limitations of existing treatment strategies. The conventional wisdom that dialysis treatment could compensate for native kidney function and thus reduce morbidity and mortality for all patients with ESRD has been tempered by findings from the Initiating Dialysis Early and Late (IDEAL) and Hemodialysis (HEMO) trials.^{9,10} For example, in the IDEAL trial, patients randomized to early start of dialysis, compared with those randomized to late or uremic symptom-triggered start of dialysis, were dialyzed an average of 5.6 months longer at an average expense of \$18,715 per patient, without improvement in mortality, morbidity, or quality of life.⁹ In the HEMO trial, increasing the dosage of thrice-weekly dialysis or the use of high-flux dialyzers had limited, if any, health benefits for the dialysis population as a whole.^{10,11} On the other hand, observational data and two clinical trials suggest that more frequent daily or nocturnal dialysis may improve self-reported quality of life and left ventricular mass, whereas a third trial of frequent nocturnal dialysis failed to find similar results.^{12–14} These potential favorable effects should be balanced against the burdens, risks, and as yet undetermined effects on mortality. Three randomized controlled trials of online hemodiafiltration revealed conflicting results.¹⁵

Similarly, several interventions targeting ESRD-related complications have

produced mixed results. Compared with a strategy of lower hemoglobin targets with restricted use of erythropoietin-stimulating agents, higher hemoglobin targets with more liberal use of erythropoietin-stimulating agents reduce transfusions and modestly improve quality of life, but do not reduce mortality and may increase the risk for stroke. Dietary phosphorous restriction and phosphate binders are difficult for patients to adhere to, and the appropriate intensity of treatment has not been validated in a randomized clinical trial.

Despite evidence of substantial need, there has been less emphasis on palliative and other supportive interventions to address symptom burden, rehabilitation, and end-of-life care in patients with ESRD. Palliative care is defined as care that aims to relieve suffering and improve the quality of life for patients with advanced illnesses and their proxy.^{4,16} This care intends to neither hasten nor postpone death, and should be offered simultaneously with all other medical treatment.^{4,16} Guidelines from the Renal Physicians Association as well as the Kidney Disease Improving Global Outcomes initiative address some of these needs^{3,17}; however, these recommendations have not yet been incorporated into quality indicators.

A PATIENT-CENTERED VISION OF CARE FOR ALL PATIENTS WITH ESRD

When a patient develops ESRD, he or she is confronted with a likely, but not in-

variably, life-threatening disease. Therapy is burdensome, and the best attainable goal is frequently care endeavoring a deferment of morbidity and mortality and an improvement or maintenance of quality of life.^{17,18} Although the risks and burden of many health care interventions are immediate, the benefits may be delayed or may not even materialize for patients with a poor prognosis.^{18–20} Consequently, life expectancy is an important element of the risk/benefit profile of most dialysis-related interventions.^{18–21} Moreover, the most appropriate care for patients with complex multimorbidity, as is the case for many dialysis patients, may differ substantially from the sum of the most appropriate care strategies of each discrete condition.^{17–19,21}

In a patient-centered vision of care, three important elements are combined to determine an “attainable treatment goal” for each individual patient: namely, a thorough knowledge of the patient’s medical condition and treatment options; his or her preferences, expectations, and psychosocial context; and his or her prognosis. We propose to distinguish three attainable treatment goal groups: (1) dialysis as a bridging treatment or long-term maintenance treatment when a bridging or long-term maintenance strategy is no longer feasible and dialysis is intended as short-term support, and (2) active medical management without dialysis. This framework is intended as a means to help clinicians prioritize treatment decisions when the existing evidence base is weak and/or not generalizable to all patients with ESRD,

analogous to a therapeutic framework used for left ventricular assist devices in patients with refractory heart failure. It is important to emphasize that this stratification is not intended to be self-fulfilling, but rather to provide clinicians and patients with therapeutic beacons. A single patient may evolve from one group to another during his or her treatment course as a function of changes in disease state and preferences, as will be the case in a time-limited trial of dialysis, or after a decision to stop dialysis treatment. Some patients may also be willing to trade longer life expectancy for less burdensome treatment that preserves their well-being and quality of life.²¹ Table 2 provides an example of a possible

interpretation of this framework. Ideally, guidelines should suggest the optimal care for each group, on the basis of evidence with clear mortality, morbidity, and quality-of-life end points.¹⁷ In the absence of such data, guidelines might indicate the lag time to benefit for various interventions, so that clinicians can judge whether patients with a more limited prognosis still could expect a benefit. Rates of dialysis withdrawal may approximate a lower bound for the proportion of patients who are candidates for dialysis as a final destination. In the United States, the rate of dialysis withdrawal is between 2% and 9% per year, depending on age, and withdrawals precede approximately 20% of deaths.²²

Consider a 73-year-old woman with oxygen-dependent pulmonary fibrosis, pulmonary hypertension, and advanced heart failure who has been hospitalized multiple times in the past year, culminating in ESRD. Although many patients in these circumstances will choose dialysis in order to increase longevity, some patients may prefer active medical management without dialysis. If she chooses dialysis, the appropriate intensity of dialysis and other medical therapies will depend on the burden of the treatment and whether the intervention is for treatment versus prevention. Some patients may wish to receive interventions with modest or uncertain survival benefit because this may give them hope and the

Table 2. Example of a possible interpretation of an individualized, patient-centered and attainable goal directed approach to care for patients with ESRD

Attainable Treatment Goal	Dialysis as Bridge to Transplantation or Long-Term Maintenance	Dialysis as Final Destination	Active Medical Management without Dialysis
Cure possible	No/(Yes)	No	No
Prognosis	More favourable	Less favourable	Reserved
Patient preferences	Maximize quality of life and longevity	Maximize quality of life +/- longevity	Maximize quality of life +/- longevity
Aim of treatment	Treat and prevent complications Sustain professional and private-life functioning	Treat complications Prevent short-term complications Sustain private-life functioning	Comfort care Hospice referral as appropriate
Start of dialysis	+/- Deferred	Deferred	Never
Vascular access strategy	"Fistula first"	Catheter may be acceptable	No access
Medical supportive interventions			
Routine laboratory testing	Regularly	The minimal necessary	Only if necessary for comfort
Preventive screening exams	Age appropriate screening	Only those with short-term benefits	None
Pill burden	For prevention and symptom control	Mainly for symptom control	For symptom control only
ESA use	To avoid transfusion	To treat symptoms of anemia	If clearly symptomatic
Blood pressure control	Stringent	Sufficient to prevent short term complications (stroke, worsening heart failure)	Sufficient to prevent short term complications (stroke, worsening heart failure)
Glycemia control	Stringent	Sufficient to prevent short term complications	Sufficient to prevent short term complications
Dyslipidemia control	Probably	None	None
Dysphosphatemia control	Maybe	To treat symptoms of pruritus	None unless necessary for symptom control of pruritus
Pain and symptom management	Clinical detection	Proactive and regular screening	Proactive and regular screening
Nursing support	Emphasis on self-care	Self-care with nursing support	More extended nursing support
Psychological support	If necessary	More extended	More extended
Home care support	Emphasis on home dialysis support	Emphasis on caregiver support	Emphasis on hospice support
Physical rehabilitation	Maximal	Maximal	To the extent useful to maintain function without significantly increasing pain

ESA, erythropoiesis-stimulating agent.

impression of control. Other patients in these circumstances may feel the gain in quality and quantity of life with the former treatment approach is small, and may desire minimizing treatment burden as an equally important goal. For example, pulmonary rehabilitation and more frequent dialysis for volume control could produce benefit in the short to intermediate term, but these strategies also carry significant burdens. Conversely, dietary phosphorus restriction and treatment of hyperphosphatemia and secondary hyperparathyroidism are mainly for prevention; these therapies might be relaxed or even discontinued. Conversion of a tunnelled hemodialysis catheter to an arteriovenous graft may reduce risk for infectious complications, but the patient's preferences and limited prognosis should also be factors in the decision-making process. A colonoscopy to assess iron-deficiency anemia in this patient with heme-positive stool is unlikely to improve her longevity or quality of life, whereas higher hemoglobin targets with erythropoietin therapy may alleviate dyspnea.

Consider another 73-year-old active woman without severe comorbidity who develops ESRD after infarction of a solitary kidney. For this patient, dialysis as long-term maintenance treatment, or possibly as a bridge to transplantation, is an attainable goal. Given her favorable prognosis, existing guidelines for dialysis adequacy, vascular access, anemia and mineral bone disease management, and cardiovascular risk reduction are more likely to improve her short- and long-term health outcomes.

CHALLENGES IN ACHIEVING PATIENT-CENTERED CARE FOR PATIENTS WITH ESRD

The proposed patient-centered approach offers a framework for all patients with ESRD to live their lives as fully as possible within the restrictions imposed by their illness and treatment. To achieve this vision of care, several real and perceived barriers must be addressed.²¹

First is the concern that existing prognostic tools are not sufficiently

accurate to permit allocation of patients into the appropriate treatment goal groups. Validated tools to predict prognosis exist for patients receiving dialysis.²³ For patients approaching ESRD, geriatric syndromes such as frailty (defined by three of the following five features: unintentional weight loss, self-reported exhaustion, weakness, slow walking speed, and low physical activity) may help to refine prognostic estimates based on age and comorbidity.⁵ By incorporating patient preferences in addition to predicted prognosis, clinicians can ensure that goals are both attainable and desired by patients. Second is the concern that the goals of treatment are too patient specific to be measurable (and by implication, valuable).²¹ The National Institutes of Health recently identified universal, patient-centered outcome measures that could be objectively measured and routinely recorded in healthcare delivery for patients with multiple chronic conditions. Third, nephrologists need to receive education and training in communication skills to initiate discussions about goal-based care.¹⁷

Finally, well designed trials in patients with limited life expectancy are needed to validate this new model of care. These trials should include patient-centered end points such as functional status, symptom burden, and quality of and satisfaction with life, in addition to mortality. Rather than exploring the effect of single disease-centered interventions, clinically relevant treatment strategies should be compared. For example, a strategy of less stringent BP, glycemic, lipid, and phosphorous control could be compared with a strategy of usual care based on clinical practice guidelines, or usual care could be compared with usual care plus palliative care.

Since its introduction, maintenance dialysis treatment gradually evolved from a means to bridge relatively young and fit patients with ESRD to transplantation, into a universal treatment option for a much more heterogeneous patient population with ESRD, including a growing proportion of elderly patients or patients with multiple and severe comorbidities for

whom dialysis is their final treatment destination. In these latter groups, the burden of dialysis and associated treatments as proposed by current clinical practice guidelines is frequently high, and the evidence supporting its beneficial effects on mortality, morbidity, and quality of life is variable, but sometimes rather weak. This effect may be partially mitigated by integrating the patients' preferences and their overall prognosis into medical decision making. When caring for an individual patient, the question should no longer be "What interventions are available?"; rather, "What treatment goals are attainable and desired for this patient, and how can they be translated into medical care for this individual patient?" This small difference in approach could make a world of difference in the quality of life of many patients with ESRD.

ACKNOWLEDGMENTS

We thank Frederique Vanneville and An De Vriese for their thoughtful comments on earlier versions of this article.

DISCLOSURES

M.K.T. has received honoraria from Satellite Healthcare.

REFERENCES

1. US Renal Data System: *USRDS 2011 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States*, Bethesda, MD, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, 2011
2. American Geriatrics Society Expert Panel on the Care of Older Adults with Multimorbidity: Guiding principles for the care of older adults with multimorbidity: An approach for clinicians. *J Am Geriatr Soc* 60: E1–E25, 2012
3. Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group: KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. *Kidney Int Suppl* 3: 1–150, 2013

4. Davison SN: The ethics of end-of-life care for patients with ESRD. *Clin J Am Soc Nephrol* 7: 2049–2057, 2012
5. McAdams-DeMarco MA, Law A, Salter ML, Boyarsky B, Gimenez L, Jaar BG, Walston JD, Segev DL: Frailty as a novel predictor of mortality and hospitalization in individuals of all ages undergoing hemodialysis. *J Am Geriatr Soc* 61: 896–901, 2013
6. Murtagh FE, Marsh JE, Donohoe P, Ekbal NJ, Sheerin NS, Harris FE: Dialysis or not? A comparative survival study of patients over 75 years with chronic kidney disease stage 5. *Nephrol Dial Transplant* 22: 1955–1962, 2007
7. Kurella Tamura M, Covinsky KE, Chertow GM, Yaffe K, Landefeld CS, McCulloch CE: Functional status of elderly adults before and after initiation of dialysis. *N Engl J Med* 361: 1539–1547, 2009
8. Chandna SM, Da Silva-Gane M, Marshall C, Warwicker P, Greenwood RN, Farrington K: Survival of elderly patients with stage 5 CKD: Comparison of conservative management and renal replacement therapy. *Nephrol Dial Transplant* 26: 1608–1614, 2011
9. Cooper BA, Branley P, Bulfone L, Collins JF, Craig JC, Fraenkel MB, Harris A, Johnson DW, Kesselhut J, Li JJ, Luxton G, Pilmore A, Tiller DJ, Harris DC, Pollock CA; IDEAL Study: A randomized, controlled trial of early versus late initiation of dialysis. *N Engl J Med* 363: 609–619, 2010
10. Eknoyan G, Beck GJ, Cheung AK, Daugirdas JT, Greene T, Kusek JW, Allon M, Bailey J, Delmez JA, Depner TA, Dwyer JT, Levey AS, Levin NW, Milford E, Ornt DB, Rocco MV, Schulman G, Schwab SJ, Teehan BP, Toto R; Hemodialysis (HEMO) Study Group: Effect of dialysis dose and membrane flux in maintenance hemodialysis. *N Engl J Med* 347: 2010–2019, 2002
11. Lowrie EG, Laird NM, Parker TF, Sargent JA: Effect of the hemodialysis prescription of patient morbidity: Report from the National Cooperative Dialysis Study. *N Engl J Med* 305: 1176–1181, 1981
12. Chertow GM, Levin NW, Beck GJ, Depner TA, Eggers PW, Gassman JJ, Gorodetskaya I, Greene T, James S, Larive B, Lindsay RM, Mehta RL, Miller B, Ornt DB, Rajagopalan S, Rastogi A, Rocco MV, Schiller B, Sergeyeva O, Schulman G, Ting GO, Unruh ML, Star RA, Klinger AS; FHN Trial Group: In-center hemodialysis six times per week versus three times per week. *N Engl J Med* 363: 2287–2300, 2010
13. Culleton BF, Walsh M, Klarenbach SW, Mortis G, Scott-Douglas N, Quinn RR, Tonelli M, Donnelly S, Friedrich MG, Kumar A, Mahallati H, Hemmelgarn BR, Manns BJ: Effect of frequent nocturnal hemodialysis vs conventional hemodialysis on left ventricular mass and quality of life: A randomized controlled trial. *JAMA* 298: 1291–1299, 2007
14. Rocco MV, Lockridge RS Jr, Beck GJ, Eggers PW, Gassman JJ, Greene T, Larive B, Chan CT, Chertow GM, Copland M, Hoy CD, Lindsay RM, Levin NW, Ornt DB, Pierratos A, Pipkin MF, Rajagopalan S, Stokes JB, Unruh ML, Star RA, Klinger AS, Klinger A, Eggers P, Briggs J, Hostetter T, Narva A, Star R, Augustine B, Mohr P, Beck G, Fu Z, Gassman J, Greene T, Daugirdas J, Hunsicker L, Larive B, Li M, Mackrell J, Wiggins K, Sherer S, Weiss B, Rajagopalan S, Sanz J, Dellagrottaglie S, Kariisa M, Tran T, West J, Unruh M, Keene R, Schlarb J, Chan C, McGrath-Chong M, Frome R, Higgins H, Ke S, Mandaci O, Owens C, Snell C, Eknoyan G, Appel L, Cheung A, Derse A, Kramer C, Geller N, Grimm R, Henderson L, Prichard S, Roecker E, Rocco M, Miller B, Riley J, Schuessler R, Lockridge R, Pipkin M, Peterson C, Hoy C, Fensterer A, Steigerwald D, Stokes J, Somers D, Hilkin A, Lilli K, Wallace W, Franzwa B, Waterman E, Chan C, McGrath-Chong M, Copland M, Levin A, Sioson L, Cabezon E, Kwan S, Roger D, Lindsay R, Suri R, Champagne J, Bullas R, Garg A, Mazzorato A, Spanner E, Rocco M, Burkart J, Moossavi S, Mauck V, Kaufman T, Pierratos A, Chan W, Regozo K, Kwok S; Frequent Hemodialysis Network (FHN) Trial Group: The effects of frequent nocturnal home hemodialysis: The Frequent Hemodialysis Network Nocturnal Trial. *Kidney Int* 80: 1080–1091, 2011
15. Blankestijn PJ: Has the time now come to more widely accept hemodiafiltration in the United States? *J Am Soc Nephrol* 24: 332–334, 2013
16. Morrison RS, Meier DE: Clinical practice. Palliative care. *N Engl J Med* 350: 2582–2590, 2004
17. Renal Physicians Association: *Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis*, 2nd Ed., Rockville, MD, Renal Physicians Association, 2010
18. Bowling CB, O'Hare AM: Managing older adults with CKD: Individualized versus disease-based approaches. *Am J Kidney Dis* 59: 293–302, 2012
19. Tamura MK, Tan JC, O'Hare AM: Optimizing renal replacement therapy in older adults: A framework for making individualized decisions. *Kidney Int* 82: 261–269, 2012
20. Smith AK, Williams BA, Lo B: Discussing overall prognosis with the very elderly. *N Engl J Med* 365: 2149–2151, 2011
21. Reuben DB, Tinetti ME: Goal-oriented patient care—an alternative health outcomes paradigm. *N Engl J Med* 366: 777–779, 2012
22. Murphy E, Germain MJ, Cairns H, Higgingson IJ, Murtagh FE: International variation in classification of dialysis withdrawal: A systematic review. *Nephrol Dial Transplant* 29: 625–635, 2014
23. Cohen LM, Ruthazer R, Moss AH, Germain MJ: Predicting six-month mortality for patients who are on maintenance hemodialysis. *Clin J Am Soc Nephrol* 5: 72–79, 2010

See related editorial, “Dialysis: Destination or Journey,” on pages 1609–1611.