

Education and End of Life in Chronic Kidney Disease: Disparities in Black and White

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More than a half million patients are being treated for ESRD in the United States (1). Estimates suggest that more than 23 million people in the United States have earlier stage chronic kidney disease (CKD) (2). More than one third of US dialysis patients are black, a three-fold overrepresentation (1,3–6). The mortality of dialysis patients with ESRD is approximately 21% annually (1). In contrast to the course of other chronic illnesses in the United States, black dialysis patients enjoy improved survival compared with white patients (1,5). This paradoxical difference is unexplained by socioeconomic status or currently identified biological factors. A reasonable hypothesis would suggest psychosocial factors underlie this dramatic disparity (7).

A typical assertion in the introduction to many a press release, grant proposal, and article contains words to the effect that “the mortality rate of hemodialysis patients is unacceptably high.” For those who have served as health care workers since the 1970s, this type of statement must be taken with a grain of nephrologic salt. Before 1973, before the formulation of the administrative term “end-stage renal disease” (and before the genesis of “chronic kidney disease”), a diagnosis of uremia represented a death sentence for the patient (8,9). Enactment of a US federal entitlement for care for patients with ESRD allowed a large number of people to extend their lives, to perform useful employment, to participate in social activities, or to prepare for death. Those early, pioneering patients included few elderly patients or people with diabetes—techniques were too primitive to allow tolerable treatment for such individuals (or so it was thought). The institution of Medicare coverage removed many disparities in ESRD care (10). Since the enactment of HR-73, advances in dialytic technique, such as measurement of and increase in dosage of dialysis, improvement in

dialyzer design, volume control, bicarbonate dialysate, and on-line monitoring methods (11,12), have enhanced treatment, and the population has grown enormously (1). The fastest growth in the program has been in the elderly population, a group with special needs and shortened survival (1).

Quality of life is determined subjectively (13,14). Different query methods, however, yield different results and interpretations. Curiously, using satisfaction-with-life measures, elderly hemodialysis (HD) patients have been shown to have superior quality of life compared with younger patients (15). In some ways, this is understandable. A life dependent on machines, nurses, technicians, and continuous treatment for up to 15 h/wk, outside the home, not including transportation barriers, presents burdens that might be perceived as overwhelming. For many elderly patients, dialysis, as burdensome as it is, provides a meaningful, if relatively short, extension of life. Interestingly, the perception of quality of life of black HD patients exceeds that of comparison groups (16–18). Quality of life and psychosocial factors have been shown in several studies to predict survival, independent of medical and treatment parameters (7,16,19). Once again, the reasons for these observations remain undetermined.

Life on dialysis poses some extraordinary challenges to quality of life. Binik *et al.* (20) identified, almost 30 years ago, that pain was an important but unappreciated experience for HD patients. Work by Davison (21) and others has extended this research and again documented these facts more recently and demonstrated that improvements in HD therapy have not been accompanied by meaningful diminution in patients’ perception of pain (22). Survival on dialysis is demanding, and the threat of death is real, apparent, and always looming. The psychological toll that living in this condition exacts for such a prolonged period is salient for patients with ESRD. People respond to stress and mortal threat in disparate ways. Some people are “active copers”—on the lookout for information and things that they can do to help themselves. Others are “avoidance copers”—trying their best to dodge negative messages and exerting mental effort not to think about their predicament. Patients who use many types of coping styles might endorse an item that queries about the advantage of increased involvement and care from the treatment team. The extent that the participants would actually use any offered services, however, may

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depend on their style of coping. Avoidance copers may choose not to receive additional prognostic information (23).

HD patients with ESRD primarily die of cardiovascular and infectious diseases (1). Although the focus of much research interest, these biological factors presently seem intractable, and the major mortality risk factors do not seem to be modifiable. Alternatively, 8% of the deaths of HD patients annually are attributed to withdrawal from dialysis (1). Almost one eighth of deaths of dialysis patients who are older than 75 years annually are attributed to withdrawal (1). A dramatic disparity is that black patients are approximately one third as likely to withdraw from dialysis as white patients (1). Psychosocial parameters are acknowledged to be important in decisions to withdraw from dialysis (24,25), and these have the potential to be modified (7). Social support may be important in mediating outcomes, including withdrawal decisions and improved survival (26). Nephrologists may be an important source of social support for dialysis patients, with effects perhaps more influential than those elicited by the more ubiquitously present dialysis nursing and technical staff (27).

It should be noted that the issues related to quality of life, pain, and outcomes, including those regarding palliative care, are quite different for patients with early-stage CKD compared with patients with ESRD (6,7). Research regarding such factors deserves to be finely grained and focused. Many patients with CKD will die rather than progress to ESRD (28). The educational needs of those who will not progress are necessarily different from those required by people who will start ESRD therapy. A truly amazing, perhaps surprising, yet incredibly important finding of the article published in this issue of *CJASN* is that more than 60% of the sample evaluated by Davison “regretted their decision to start dialysis” (29). Several possibilities can explain this remarkable finding, which has important implications for policymakers as well as practitioners. In light of Davison’s results, however, it is important to acknowledge that denial is a powerful weapon in the psychological armamentarium of patient coping. The modal answer of patients in our CKD clinic to a question regarding when they thought they were going to start dialysis was, “Never,” regardless of functional status, stage of disease, or level of renal function (30, and unpublished data). As Davison points out, the meaning of some questionnaire items is unclear. Did the patients with CKD at George Washington think they were never going to progress to ESRD, or could they never envision consenting to begin dialysis treatment? It seems that many patients, before the absolute necessity of making a choice between certain death and a fraught life on dialysis, would perhaps favor the former path. Of course, many may choose ESRD therapy later in the course of their illness (31). At such an emotionally laden time, the patient education provided by the nephrologist and the dialysis staff would seem to be crucial.

The article by Davison (29) serves as a clarion call to the broader nephrology community to be more sensitive to the end-of-life preferences of patients with CKD and ESRD. Certain design characteristics of the study, however, may limit the generalizability of its results. First, although the author describes piloting the questionnaire, it is unclear how certain

questions were understood by the participants, because there is limited discussion of criterion validity. The very high rate of respondents who endorsed regretting starting dialysis may be partially due to a different interpretation of the question. Perhaps participants interpreted the question as regretting the course of events that led them to require dialysis, not that they would have preferred death over the course that they had chosen. Second, the impact of experimental demand characteristics, a common problem in research that uses questionnaires (32), on the responses is unclear. It is possible the way in which the questions were framed inadvertently encouraged the participants to endorse increased need for the items that the questionnaires evaluated. As an example, only 22.3% of the population acknowledged knowing what a hospice is at the beginning of the questionnaire, but by its end, 28.8% preferred to die at one. Third, combining the various groups of populations with CKD makes the results more difficult to interpret, especially without an understanding of the experience of illness and the illness severity of the populations (7,15,30,31). Finally, this Canadian study population does not match the broader US population in its racial and ethnic diversity, and there may well be a different set of needs and perceptions in different patient populations. Critical potential differences in responses to such items, perhaps based on the physician–patient relationship or trust (33), may underlie (and shed light on) differences in CKD outcomes and ESRD disparities.

The findings presented in this issue of *CJASN* (29) are important, probing the patient experience regarding starting and receiving an intrusive but life-saving therapy. As with most studies, the research poses further questions. The psychometric aspects of the investigative approach must be enhanced, the life situation and signal events of patients assessed should be standardized and clarified, and populations of different backgrounds and ethnicities ought to be evaluated to provide clearer pictures of needs of patients with CKD regarding end-of-life care. Behavioral and psychosocial studies of various, contrasting populations can provide important insights into biological mechanisms that underlie differences in outcomes between groups.

Palliative care, with all that it entails (34–36), is undoubtedly important for patients with a mortal illness. Understanding prognoses is also critical for patients and families who are starting to deal with a chronic illness and its burdensome treatments. Providing prognosis is a fundamental duty of physicians. Care to improve the quality of life of patients with ESRD for each day of their lives is as important as optimizing their nutritional status or dosage of dialysis. Identifying patients in need and having appropriate resources available is only part of the solution. Encouraging patients to use referrals and to seek additional help is often also required.

The article by Davison (29) serves to highlight the lack of knowledge that the professional community has of end-of-life preferences and needs of patients with ESRD. It is not sufficient for the treatment team to be working only toward preserving life, but as patients become more ill, it is appropriate to help support patients’ contemplation and facilitation of their end-of-life wishes. While we labor to increase the quantity of life for

our patients, we must be cognizant of its quality as well. Both education of patients and families, as well as physicians and dialysis staff, will surely facilitate this goal.

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Disclosures

None.

References

1. US Renal Data System: *USRDS 2009 Annual Data Report: Atlas of End-Stage Renal Disease in the United States*, Bethesda, National Institute of Diabetes and Digestive and Kidney Diseases, 2009
2. Coresh J, Selvin E, Stevens LA, Manzi J, Kusek JW, Eggers P, Van Lente F, Levey AS: Prevalence of chronic kidney disease in the United States. *JAMA* 298: 2038–2047, 2007
3. Norris K, Nissenson AR: Race, gender, and socioeconomic disparities in CKD in the United States. *J Am Soc Nephrol* 19: 1261–1270, 2008
4. Norris KC, Agodoa LY: Unraveling the racial disparities associated with kidney disease. *Kidney Int* 68: 914–924, 2005
5. Powe NR, Melamed ML: Racial disparities in the optimal delivery of chronic kidney disease care. *Med Clin North Am* 89: 475–488, 2005
6. Powe NR: Let's get serious about racial and ethnic disparities. *J Am Soc Nephrol* 19: 1271–1275, 2008
7. Cukor D, Cohen SD, Peterson RA, Kimmel PL: Psychosocial aspects of chronic disease: ESRD as a paradigmatic illness. *J Am Soc Nephrol* 18: 3042–3055, 2007
8. Maher JF, Nolph KD, Bryan CW: Prognosis of advanced chronic renal failure: 1. Unpredictability of survival and reversibility. *Ann Intern Med* 81: 43–47, 1974
9. Merrill JP, Hampers CL: Uremia I. *N Engl J Med* 282: 953–961, 1970
10. Evans RW, Blagg CR, Bryan FA Jr: Implications for health care policy: A social and demographic profile of hemodialysis patients in the United States. *JAMA* 245: 487–491, 1981
11. Gotch F: What is important in dialysis? Efficiency: Blood flow, KoA and Kt/V? *Contrib Nephrol* 161: 168–177, 2008
12. Himmelfarb J: Success and challenge in dialysis therapy. *N Engl J Med* 347: 2068–2070, 2002
13. Kimmel PL: Just whose quality of life is it, anyway? *Kidney Int* 57[Suppl 74]: S113–S120, 2000
14. Finkelstein FO, Wuerth D, Finkelstein SH: Health related quality of life and the CKD patient: Challenges for the nephrology community. *Kidney Int* 76: 946–952, 2009
15. Kimmel PL, Peterson RA, Weihs KL, Simmens SJ, Boyle DH, Cruz I, Umana WO, Alleyne S, Veis JH: Aspects of quality of life in hemodialysis patients. *J Am Soc Nephrol* 6: 1418–1426, 1995
16. Lopes AA, Lopes AA, Bragg-Gresham JL, Satayathum S, McCullough K, Pifer T, Goodkin DA, Mapes DL, Young EW, Wolfe RA, Held PJ, Port FK, Worldwide Dialysis Outcomes and Practice Patterns Study Committee: Health-related quality of life and associated outcomes among hemodialysis patients of different ethnicities in the United States: The Dialysis Outcomes and Practice Patterns Study (DOPPS). *Am J Kidney Dis* 41: 605–615, 2003
17. Unruh M, Miskulin D, Yan G, Hays RD, Benz R, Kusek JW, Meyer KB, HEMO Study Group: Racial differences in health-related quality of life among hemodialysis patients. *Kidney Int* 65: 1482–1491, 2004
18. Kimmel PL, Emont SL, Newmann JM, Danko H, Moss AH: ESRD patient quality of life: Symptoms, spiritual beliefs, psychosocial factors, and ethnicity. *Am J Kidney Dis* 42: 713–721, 2003
19. Mapes DL, Lopes AA, Satayathum S, McCullough KP, Goodkin DA, Locatelli F, Fukuhara S, Young EW, Kurokawa K, Saito A, Bommer J, Wolfe RA, Held PJ, Port FK: Health-related quality of life as a predictor of mortality and hospitalization: The Dialysis Outcomes and Practice Patterns Study (DOPPS). *Kidney Int* 64: 339–349, 2003
20. Binik YM, Baker AG, Kalogeropoulos D, Devins GM, Guttman RD, Hollomby DJ, Barré PE, Hutchison T, Prud'Homme M, McMullen L: Pain, control over treatment, and compliance in dialysis and transplant patients. *Kidney Int* 21: 840–848, 1982
21. Davison SN: Chronic kidney disease: Psychosocial impact of chronic pain. *Geriatrics* 62: 17–23, 2007
22. Unruh M, Benz R, Greene T, Yan G, Beddhu S, DeVita M, Dwyer JT, Kimmel PL, Kusek JW, Martin A, Rehm-McGillcuddy J, Teehan BP, Meyer KB, HEMO Study Group: Effects of hemodialysis dose and membrane flux on health-related quality of life in the HEMO Study. *Kidney Int* 66: 355–366, 2004
23. Roth S, Cohen LJ: Approach, avoidance, and coping with stress. *Am Psychol* 41: 813–819, 1986
24. Kurella M, Kimmel PL, Young BS, Chertow GM: Suicide in the United States end-stage renal disease program. *J Am Soc Nephrol* 16: 774–781, 2005
25. Cohen LM, Bostwick JM, Mirot A, Garb J, Braden G, Germain M: A psychiatric perspective of dialysis discontinuation. *J Palliat Med* 10: 1262–1265, 2007
26. Cohen SD, Sharma T, Acquaviva K, Peterson RA, Patel SS, Kimmel PL: Social support and chronic kidney disease: An update. *Adv Chronic Kidney Dis* 14: 335–344, 2007
27. Kovac JA, Patel SS, Peterson RA, Kimmel PL: Patient satisfaction with care and behavioral compliance in end-stage renal disease patients treated with hemodialysis. *Am J Kidney Dis* 39: 1236–1244, 2002
28. Hsu CY, Vittinghoff E, Lin F, Shlipak MG: The incidence of end-stage renal disease is increasing faster than the prevalence of chronic renal insufficiency. *Ann Intern Med* 141: 95–101, 2004
29. Davison S: End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol* 5: 000–000, 2010
30. Shidler NR, Peterson RA, Kimmel PL: Quality of life and psychosocial relationships in patients with chronic renal insufficiency. *Am J Kidney Dis* 32: 557–566, 1998
31. Kimmel PL: Towards a developmental view of end stage renal disease. *Am J Kidney Dis* 15: 191–193, 1990
32. Orne MT, Whitehouse WG: Demand characteristics. In: *Encyclopedia of Psychology*, edited by Kazdin AE, Washington, DC, American Psychological Association and Oxford Press, 2000, pp 469–470
33. Cooper-Patrick L, Gallo JJ, Gonzales JJ, Vu HT, Powe NR,

- Nelson C, Ford DE: Race, gender, and partnership in the patient-physician relationship. *JAMA* 282: 583–589, 1999
34. Holley JL: Palliative care in end-stage renal disease: Illness trajectories, communication, and hospice use. *Adv Chronic Kidney Dis* 14: 402–408, 2007
35. Moss AH, Holley JL, Davison SN, Dart RA, Germain MJ, Cohen L, Swartz RD: Palliative care. *Am J Kidney Dis* 43: 172–173, 2004
36. Cohen LM, Moss AH, Weisbord SD, Germain MJ: Renal palliative care. *J Palliat Med* 9: 977–992, 2006

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