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 threefold 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 paradoxic 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
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 different from those required by people who will start ESRD (28).

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. 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).

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.

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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
33. Cooper-Patrick L, Gallo JJ, Gonzales JJ, Vu HT, Powe NR,


