The Importance of Prognostication in the Patient-Centered Care of Chronic Kidney Disease and ESRD Patients

By Alvin H. Moss, MD

A foremost goal of American medicine for the 21st century is to improve the quality of health care is individualized, patient-centered care. The recommended means to achieve this care is shared decision-making, a conversation process in which the physician communicates information to the patient about diagnosis, prognosis, and treatment options and the patient communicates to the physician about his or her history, values, and treatment preferences. Together, the two share responsibility in reaching a common understanding of the patient’s preferred treatment course. This process has been called “the pinnacle of patient-centered care” (1).

Patient-specific estimate of prognosis

For patients to be able to participate in shared decision-making and express their preferences, they need to know their overall condition, their treatment options, and their prognosis. The clinical practice guideline Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis, 2nd Ed., recommends that each patient be given a patient-specific estimate of prognosis as part of the informed consent process for shared decision-making (2). This guideline recognizes that neither a clinician nor a prognostic score can predict with absolute certainty how well a particular patient will do with or without dialysis. However, evidence-based factors have been determined to be valuable in predicting prognosis in chronic kidney disease (CKD) and ESRD patients. Validated prognostic scores for ESRD patients have been constructed on the basis of the evidence to improve the accuracy of predictions of prognosis and to facilitate a patient-centered approach (3, 4).

Physician ethical obligation to disclose prognosis

Physicians have an ethical obligation to disclose prognosis to assist their patients in decision-making (5), to know their prognosis (6). Prediction of prognosis assists the nephrologist in recommending dialysis to patients with a good prognosis who are likely to benefit from it, and a conservative, nondialytic pathway to patients with a poor prognosis, for whom dialysis is unlikely to be a benefit. Physicians may be hesitant to conjecture a diagnosis because of considerable clinical uncertainty, but in such situations, patients may want to incorporate their extramedical values into the decision-making, and they appreciate physician candor about uncertainty.

In one study of 62 dialysis patients, no patient reported a discussion of prognosis with his or her nephrologist, and patient and physician estimates of prognosis were profoundly discordant (κ=0.08). In this study, 66% of nephrologists said they would not disclose prognosis, even if their patients requested it. This is of concern from a patient-centered care perspective, because more than half of patients indicated a preference for comfort-focused care if they knew they were seriously ill (7). The authors concluded that interventions are needed to help nephrologists more effectively communicate with their dialysis patients about prognosis.

The advancing science of prognostication

The science of prognostication for patients with CKD and ESRD is advancing. There are several validated prognostic tools to predict 6-month to 1-year survival with an accuracy C-statistic of 0.75 to 0.80 (4). One is an integrated prognostic tool that combines a subjective response to the surprise question—would you be surprised if this patient died in the next 6 months?—with objective variables to obtain 6- and 12-month predictions of survival with a C statistic of 0.80 (Figure 1) (3).

The systematic literature review for the clinical practice guideline on shared decision-making identified four statistically significant independent predictors of poor prognosis in dialysis patients: age, comorbidities, impaired nutrition, and impaired functional status (2). Since then, other factors, such as frailty, cognitive impairment, self-reported appetite, and independence in the ability to transfer, have been identified as potentially helpful variables that might improve the accuracy of prognostic scores if integrated into them (4).

The future of prognostication in the care of kidney patients

Validated prognostic scores with a high degree of accuracy can help calibrate nephrologists’ estimate of prognosis. They are not meant to replace the shared decision-making process. The decision about dialysis is to be on the basis of the medical indications for it—the balance of benefits to burdens—and the patient’s preferences. Estimates of prognosis can help in the assessment of the likely benefits versus burdens calculus. In the future, as dialysis decisions become more patient-centered, other outcomes important to patients beyond survival, such as predicted quality of life with or without dialysis, need to be incorporated into prognostic scores. Patients are being included in those framing the research agenda for the treatment of CKD and ESRD (8). There is reason to be optimistic that the future of treatment of patients with kidney disease will be more patient-centered and that patients will report more satisfaction with their experience of care.

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Abbreviation: HU = hemodialysis.

References