Health–Related Quality of Life in CKD—Advancing Patient-Centered Research to Transform Patient Care

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Patients’ experiences and quality of life are increasingly recognized as important domains of health for providers to identify, understand, and improve. Improvement in the quality of life related to human health as well as the length of life are the paramount goals of health care. Patients not only wish to compress morbidity, such as that associated with kidney or other chronic diseases, into the last moments of life, but they also seek to maintain optimal physical and mental health function as long as possible. Healthcare providers who are patient-centered recognize these desires and partner through shared decision making with patients to achieve them.

Patient experience and health–related quality of life (HRQoL) have been studied for over a decade in patients with ESRD (1–7). The study by Porter et al. (8) in this issue of the Clinical Journal of the American Society of Nephrology examines the factors and outcomes associated with poor HRQoL in patients with mild to moderate CKD. This is an analysis of data collected in the Chronic Renal Insufficiency Cohort (CRIC) Study, a multicenter cohort study designed to study the natural history and outcomes of a diverse group of persons with CKD in the United States. The study has many strengths. First, it is prospective, with ongoing follow-up that allowed possible examination of how HRQoL may influence short-, intermediate-, and long-term outcomes. Second, the CRIC Study and its derivative, the Hispanic CRIC Study, enrolled nearly 4000 patients from eight centers throughout the United States (California, Illinois, Louisiana, Maryland, Michigan, Ohio, and Pennsylvania), and a large number of black and Hispanic patients was included (9). Third, the CRIC Study carefully assessed kidney function and kidney damage and collected a wide range of phenotypic data in additional to HRQoL. Fourth, HRQoL was measured using the Kidney Disease and Quality of Life questionnaire, a standardized instrument in which generic as well as disease–specific HRQoL measures are embedded that have been validated in patients with more severe kidney disease. Fifth, the study also collected data on important health consequences, including progression of kidney disease, cardiovascular disease, and death.

Porter et al. (8) examined the characteristics associated with poor HRQoL and the relation between HRQoL and important clinical outcomes. The study found that being younger or a woman is a risk factor for having poor HRQoL. Also, having low education, diabetes, vascular disease, heart failure, obesity, or low kidney function portends poorer HRQoL. Importantly, over time, aspects of low HRQoL were associated with a higher risk of cardiovascular disease (physical health, effects, and symptoms) or death (physical and mental health, effects, and symptoms) but not with CKD progression.

This is not the first study describing HRQoL in patients with CKD (10–12). However, it is probably the largest and most diverse to date. As such, the independent contribution of CKD to a patient’s HRQoL is of interest. The CRIC Study only included patients with CKD. As such, there is no direct control group recruited in the same way or at the same time to which patients without kidney disease but with diabetes or hypertension (almost one half of participants in the CRIC Study had diabetes and more than two thirds had hypertension) can be compared. Nevertheless, the results show that physical function in patients with CKD seems more depressed than mental function compared with general United States population age norms, a similar finding to that in studies of patients with end stage kidney failure, and the multivariate analysis indicates that HRQoL is inversely related to the level of kidney function but not proteinuria.

The results regarding characteristics associated with HRQoL cry out for more insight about the underlying physiology of HRQoL in CKD. What is the pathway by which younger age, women, and low education affect different domains of HRQoL? How does HRQoL change over time? The CRIC Study was scheduled to collect not only baseline but also, repeated annual collections of HRQoL (7). Examining the trajectories of HRQoL in participants with different characteristics might provide a more comprehensive picture of prognosis for specific types of patients with CKD and could provide insight into interventions to improve HRQoL (4).

The associations of HRQoL and their effect sizes with cardiovascular events and deaths from all causes are striking. However, we need to better understand the mechanism by which HRQoL affects these outcomes. For example, might poor HRQoL influence physical and mental functioning through attainment of medical care, adherence to medications, patient expectations, dietary practices, physical activity, or other behaviors? Are persons with different trajectories of health-related quality of life in chronic kidney disease...
specific HRQoL domains (moving from high HRQoL to lower HRQoL or moving from low HRQoL to higher HRQoL) more or less prone to certain outcomes? How do different domains of HRQoL or symptoms (e.g., stress and sleep [13]) relate to specific types of cardiovascular events reported (myocardial infarction, heart failure, stroke, atrial fibrillation, or peripheral vascular disease interventions and hospitalizations) or specified causes (such as cardiovascular, infectious, and suicide) of death. Are relations of all HRQoL domains to each outcome entirely linear, or are there thresholds above which relations are different? Future studies as well as additional analyses of baseline and repeated follow-up measures from the CRIC Study could considerably advance scientific knowledge in these areas.

The clinical implications of this study are central to improving care. Given the prevalence of CKD (14), decrements in HRQoL, and consequences of poor HRQoL in patients with CKD, we need to learn how to best communicate to patients how HRQoL affects prognosis and more importantly, what we can do or tell them to prevent poor outcomes. We also need to use this information to understand how patients adapt to their illness over time and their care experiences. Undoubtedly, a better understanding and improvement will require input from not only physicians but also, a variety of other health professionals, such as social workers, physical therapists, occupational therapists, nurses, nutritionists, and behavioral counselors. For example, we might need to address disability, social isolation, unhealthy behaviors, and much more. Developing patient-centered interventions will require a deeper dive into the physiology of HRQoL informed by more rich data and potentially fueled by collection of HRQoL assessments electronically as an integral part of routine practice (15,16). Such widespread collection of HRQoL data to transform patient experience was envisaged by Paul Ellwood (17) in his Shattuck lecture almost three decades ago. It is time to fulfill this vision.

References


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See related article, “Predictors and Outcomes of Health–Related Quality of Life in Adults with CKD,” on pages 1154–1162.