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STUDIES EXAMINE WAYS TO ASSESS QUALITY OF LIFE IN PATIENTS WITH KIDNEY DISEASE.

Highlight

- Two new studies provide insights on how physicians can effectively and efficiently evaluate patient-reported outcomes and health-related quality of life in individuals with kidney disease.

Washington, DC (March 21, 2019) — In addition to monitoring patients' health through specific clinical tests, physicians should also consider patient-reported outcomes and health-related quality of life, or what patients say about how they feel and what they can do. Two new studies that appear in an upcoming issue of the *Journal of the American Society of Nephrology (JASN)* address ways to do this for patients with chronic kidney disease (CKD).

To gain these perspectives from patients with CKD, physicians often use the Kidney Disease Quality of Life (KDQOL)-36, a survey that asks patients for their views about their health. Despite its widespread use, the KDQOL-36 was developed more than a decade ago and is reported to have some disadvantages.

In a *JASN* study that included 485 patients with CKD, John Ware, Jr., PhD (John Ware Research Group) and his colleagues developed and evaluated an improved and briefer approach to measuring quality of life across the spectrum from early CKD to kidney failure, or end-stage kidney disease (ESKD). The team found that both 6-item and adaptive forms of this Chronic Kidney Disease Quality of Life (CKD-QOL) instrument performed better across multiple tests of validity in head-to-head comparisons with a generic assessment of health-related quality of life called SF-12v2 and with CKD-specific KDQOL-36 measures.

"Quality of life is the most important outcome to patients, and the computer adaptive survey pays attention to a patient's answers, saves time, and doesn't ask questions that are irrelevant to that individual patient," said Dr. Ware. "This research brings us closer to measures of quality of life that are specific to kidney disease and could meaningfully inform the care of individual patients."

In another *JASN* study, a team led by John Peipert, PhD (Northwestern University Feinberg School of Medicine) and Ron Hays PhD (UCLA David Geffen School of Medicine) aimed to increase the KDQOL-36's usefulness for patients with ESKD by providing reference values for the US dialysis population. "These reference values will help give context to individual patients' and groups of patients' KDQOL-36 scores by providing a national norm to compare to," said Dr. Peipert. "In addition, for circumstances where a single, composite KDQOL-36 score is useful, we have provided evidence of the reliability and validity for a summary score derived by combining the 3 KDQOL-36 kidney-targeted scales to create the KDQOL-36 Summary Score."

In an accompanying perspective, Dr. Peipert and Dr. Hays noted that ESKD patients stand to benefit from a variety of new clinical and evaluation opportunities with patient-reported outcomes that will help align care with patients' priorities and open new channels for communication between patients and their doctors. "The burden of disease for ESKD patients is formidable and impacts many aspects of patients' lives," they wrote. "Adopting patient-reported outcome-based approaches to manage ESKD patients' health is a very promising way toward easing this burden."

Dr. Ware's co-authors include Michelle Richardson, PharmD, Klemens Meyer, MD, and Barbara Gandek, PhD.

Dr. Peipert and Dr. Hays' co-authors include Devika Nair, MD, Kristi Klicko, BS, and Dori Schatell, MS.

Disclosures: Dr. Ware reports grants from National Institutes of Health and from Amgen Foundation, during the conduct of the study; and other from John Ware Research Group, outside the submitted work; and being developer and original copyright holder of generic measures used in KDQOL-36 and developer of new CKD-specific measures studied and copyright holder of improved measures developed subsequently. All other authors reported no financial disclosures.

The studies, entitled "Improving CKD-Specific Patient-Reported Measures of Health-Related Quality of Life," and "Kidney Disease Quality of Life 36-Item Short Form Survey (KDQOL-36™) Normative Values for the United States Dialysis Population and New Single Summary Score," will appear online at <http://jasn.asnjournals.org/> on March 21, 2019.

The perspective, entitled, "Expanding the Patient's Voice in Nephrology with Patient-Reported Outcomes," will appear online at <http://jasn.asnjournals.org/> on March 21, 2019.

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