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PERITONEAL DIALYSIS TRIALS OFTEN DO NOT ASSESS PRIORITIES MOST IMPORTANT TO PATIENTS

Highlight

- Patients on peritoneal dialysis and their caregivers give high priority to clinical outcomes (such as infection and mortality) and many patient-reported outcomes (particularly fatigue and flexibility with time), which are absent in most trials in peritoneal dialysis.

Washington, DC (December 20, 2018) — Patients on peritoneal dialysis and their caregivers give high priority to outcomes that are absent from the majority of clinical trials in peritoneal dialysis, according to a study appearing in an upcoming issue of the *Clinical Journal of the American Society of Nephrology (CJASN)*. The findings point to the need to focus the selection of outcomes towards those that are important to patients on peritoneal dialysis and their caregivers to support decisions about their own health.

Clinical trials typically assess patients' outcomes based on their responsiveness to an intervention, rather than examining outcomes that are directly meaningful to patients. The increasing recognition of the mismatch between the priorities of patients and investigators has prompted efforts to ensure that patient-centered outcomes are identified and integrated into research.

To identify priorities for outcomes in kidney failure patients on peritoneal dialysis and their caregivers, Karine Manera, MIPH (University of Sydney and The Children's Hospital at Westmead, in Australia) and her colleagues conducted focus groups with 81 patients and 45 caregivers from Australia, the United States, and Hong Kong. The 10 highest ranked outcomes were peritoneal dialysis infection, mortality, fatigue, flexibility with time, blood pressure, peritoneal dialysis failure, ability to travel, sleep, ability to work, and impact on family. These outcomes could be summarized as focusing on health, maintaining lifestyle, and self-management. Interestingly, mortality was ranked first in Australia, second in Hong Kong, and 15th in the United States.

"Research often only reports outcomes that are chosen by researchers and doctors, but may not report findings that are important to patients or their families. This study helps uncover which outcomes and findings are important for patients and their families to know

about, so that research can become more relevant to its end-users and ultimately help patients and their families make informed decisions about their treatment,” said Manera.

In an accompanying Patient Voice editorial, Jonathan Haydak of the Georgia Institute of Technology College of Engineering, who is a peritoneal dialysis patient, noted that it is easy for patient concerns to get lost in the sea of medical opinions that surround a topic such as kidney disease. “This is one of the reasons that I am personally involved with the American Association of Kidney Patients - patients need to take charge of their destiny, band together and aspire bring about the change they want,” he wrote. “While it is perhaps not the norm, something as simple as a conversation about values of different outcomes between patients and nephrologists can make for a more successful experience.”

Study co-authors include David W. Johnson, MBBS, FRACP, FASN, PhD, DMed (Res) Jonathan C. Craig, MBChB, DipCH, FRACP, M Med (Clin Epi), PhD, Jenny I. Shen, MD, Lorena Ruiz, Angela Yee Moon Wang, MBBS, MD, PhD, MRCP (UK), FRCP (Lond/Edin), FHKCP, FHKAM, FASN, Terence Yip, MBBS, MRCP, FHKCP, FHKAM (Med), Samuel KS Fung, MBBS, FHKCP, FHKAM (Med), FRCPI, FRCP, Edin, Matthew Tong, MBBS, MRCP, FHKCP, FHKAM (Med), FHKAM (Nephrology), Achilles Lee, MBChB, MRCP, FHKCP, FHKAM (Med), Yeoungjee Cho, MBBS, FRACP, PhD, Andrea K Viecelli, MD, Benedicte Sautenet, MD, Armando Teixeira-Pinto, PhD, Edwina A. Brown, BMBCh, Gillian Brunier, MN, Jie Dong, MBBS, Tony Dunning, Rajnish Mehrotra, MD, MS, Sarala Naicker, MBChB, PhD, FRCP, MRCP(UK), Roberto Pecoits-Filho, MD, PhD, FACP, FASN, Jeffrey Perl, MD, FRCP(C), SM, Martin Wilkie, BSc, MBChB, MD, FRCP, and Allison Tong, BMedSc, MPH, PhD

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The article, entitled “Patient and Caregiver Priorities for Outcomes in Peritoneal Dialysis: Multinational Nominal Group Technique Study,” will appear online at <http://cjasn.asnjournals.org/> on December 20, 2018, doi: 10.2215/CJN.05380518.

The editorial, entitled “Patient Priorities for Research Involving Peritoneal Dialysis,” will appear online at <http://cjasn.asnjournals.org/> on December 20, 2018.

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