

Peritoneal dialysis trials often do not assess priorities most important to patients

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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, MPH (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."

More information: "Patient and Caregiver Priorities for Outcomes in Peritoneal Dialysis: Multinational Nominal Group Technique Study," *Clinical Journal of the American Society of Nephrology* (2018). [DOI: 10.2215/CJN.05380518](#)

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