



PRESS RELEASE

ASN Contacts:

Christine Feheley (202) 640-4638 | cfeheley@asn-online.org

Tracy Hampton thampton@nasw.org

DO FAMILY MEMBERS UNDERSTAND THE END-OF-LIFE WISHES OF PATIENTS ON CHRONIC DIALYSIS?

Study uncovers need for improved communication.

Highlights

- Most surveyed family members of patients with kidney failure on long-term dialysis reported they had spoken with the patient about their end-of-life wishes but not about stopping dialysis or initiating hospice.
- Most family members also lacked a detailed understanding of patients' perspectives on other aspects of end-of-life care.

Washington, DC (September 10, 2021) — Patients with kidney failure who are on long-term dialysis often rely on family members or friends to make critical treatment decisions towards the end of life. A study in *CJASN* examines whether such close contacts have a good understanding of these patients' wishes.

The study conducted by Fahad Saeed, MD (University of Rochester Medical Center) and his colleagues included 172 family members of people undergoing maintenance dialysis. The team ascertained their level of involvement in each patient's care and prior discussions about care preferences. The investigators also compared patient and family member responses to questions about end-of-life care.

"Perhaps the most striking finding was how hard it was to enroll family members in the study. Many patients were unwilling to provide the names of family members who we could contact, and approximately 10% of patients indicated that they did not have a family member or friend to list," said Dr. Saeed

Not surprisingly, the family members who did enroll were relatively involved in each patient's care, and many lived with the patient. Most family members indicated that they had spoken with the patient about treatment preferences, but fewer than one-third had spoken about whether they would want hospice or would want to stop dialysis if they were to become sicker.

Family members had a fair understanding of patients' wishes pertaining to CPR but much more limited insights into how patients would respond to a range of questions about other

aspects of end-of-life care including whether they would want to receive mechanical ventilation, the value placed on life prolongation, preferred place of death, and prognostic expectations.

“When we talked with family members of people on dialysis, most did not have a clear idea of what patients would want if they were seriously ill or dying,” said Dr. Saeed. “Because family are often in the position of making important medical decisions for people undergoing dialysis when they become seriously ill, these findings show how important it is for patients to discuss their wishes with those close to them and for clinicians and health systems to find ways to support these conversations.”

Study co-authors include Catherine R. Butler, MD, MA, Carlyn Clark, MSW, Kristen O’Loughlin, MA, MS, Ruth A. Engelberg, PhD, Paul L. Hebert, PhD, Danielle Lavalley, PharmD, Elizabeth K. Vig, MD, Manjula Kurella Tamura, MD, MPH, J. Randall Curtis, MD, and Ann M. O’Hare, MD, MA.

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The article, titled “Family Members’ Understanding of the End-of-Life Wishes of People Undergoing Maintenance Dialysis,” will appear online at <http://cjasn.asnjournals.org/> on September 10, 2021, doi: 10.2215/CJN.04860421.

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