

Older patients feel they have little say in choosing dialysis, study says

August 30 2016, by Kalimah Redd Knight

Starting dialysis treatment for end-stage renal disease (ESRD) should be a shared decision made by an informed patient based on discussions with a physician and family members. However, many older dialysis patients say they feel voiceless in the decision-making process and are unaware of more conservative management approaches that could help them avoid initiating a treatment that reduces their quality of life, according to a study led by Tufts University researchers.

The study, published online in *Nephrology Dialysis Transplantation* in advance of print, also found that patients who perceived they did not have a choice in starting dialysis reported low satisfaction with the treatment, despite acknowledging its life-extending benefits.

The research coincides with the recent increase of attention to poor end-of-life care in the United States. The study's link between the process of decision-making and satisfaction with treatment choices affirms the need to prioritize better understanding of shared decision-making in the older patient population.

The findings also highlights how decisions about dialysis initiation are made by members of the growing dialysis population in the United States, which has increased nearly 60 percent between 2000 and 2012, most dramatically among those aged 75 and older, according to the U.S. Renal Data System's 2014 Annual Data Report. The study also demonstrates that patients who actively engage in decision-making are more satisfied with their outcomes, according to researchers.

"For some patients, dialysis may be the best treatment that aligns with their preferences and goals. But our study found that many of our respondents did not know that starting dialysis was voluntary and that they had a different option," said Keren Ladin, Ph.D., first author on the paper. Ladin is an assistant professor in the Department of Occupational Therapy at the Graduate School of Arts and Sciences and the Department of Public Health and Community Medicine at Tufts University School of Medicine. "Patient-centered care requires better communication between patients and providers, including better understanding how potential treatments may affect patients' goals of care and lifestyle preferences."

Recent studies show that for elderly ESRD patients, dialysis and conservative management are similarly effective at extending life, although dialysis significantly impacts quality of life. Consequently, the decision to start dialysis for elderly patients should be driven by their priorities and personal goals, said Ladin.

The study found that key decision-making factors for patients include: independence, ability to travel, social participation, not burdening loved ones, continuing meaningful activities, and avoiding pain and fatigue.

The qualitative study, which focused on 31 patients in greater Boston age 65 and older with an average age of 78, found multiple barriers to shared decision-making, including:

- A perception among patients that dialysis was necessary to prevent imminent death;
- A perception among patients that the decision to begin dialysis was solely up to their physicians;
- A lack of communication of important prognostic information for the patient from a doctor; and
- A patient's deference to the views of clinicians and family

members who often override a patient's expressed preferences, fueled by a desire to be a "good patient."

As a result, most patients who said they felt less engaged in the [decision-making process](#) reported feeling dissatisfied with their treatment outcomes. Many focused on unexpected setbacks from dialysis and expressed feelings of distress about the impact of the treatment on their independence and overall energy.

By contrast, the research found that patients reported actively making choices between peritoneal [dialysis](#) and hemodialysis. In this process, most patients reported their choice involved careful research and conversations with clinicians and [family members](#).

Ladin said the research illustrates the value of delivering the highest quality care while respecting patient autonomy.

"While we cannot cure ESRD at this point, we can help [patients](#) achieve their goals and live out their last state of life according to their wishes," said Ladin.

More information: Keren Ladin, Naomi Lin, Emily Hahn, Gregory Zhang, Susan Koch-Weser, Daniel E. Weiner, "Engagement in decision-making and patient satisfaction: a qualitative study of older patients' perceptions of dialysis initiation and modality decisions," *Nephrology Dialysis Transplantation*, published online August 30 in advance of print, [DOI: 10.1093/ndt/gfw307](https://doi.org/10.1093/ndt/gfw307)

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