

# Patients with end-stage kidney disease have different expectations than their doctors

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In any given year, 400,000 Americans suffering from end-stage kidney disease will undergo dialysis, and as many as 20 to 25 percent of those dialysis patients will die, a statistic comparable to many types of cancer. But while cancer doctors may be more accustomed to talking with patients about the likely course of their disease, a new study from Beth Israel Deaconess Medical Center finds that doctors who treat patients with kidney failure are reluctant to discuss a difficult prognosis, and their patients are likely to have distorted expectations about their own probable outcomes.

The results of the study appear online, May 27th in *JAMA Internal Medicine*.

"Our study suggests that we may not be serving these patients as well as we could. These missed opportunities and [misperceptions](#) may actually be influencing patients' goals of care," says lead author Melissa W. Wachterman, MD, MPH, MSc, who conducted the research while a fellow in BIDMC's Division of General Medicine and Primary Care. "Giving seriously-ill patients a realistic sense of their own illness can be important so they can make informed medical and [life decisions](#) moving forward."

The researchers interviewed 62 seriously-ill patients from two Boston area dialysis centers whose predicted one-year mortality, based on two validated prognostic models, was at least 20 percent. They found that patients were significantly more optimistic than their doctors about one

and five year survival. "Overall, 81 percent of patients thought they had at least a 90 percent chance of being alive in one year, whereas nephrologists were this optimistic for only 25 percent of patients," the authors write.

"The nephrologists in our study reported they had not shared estimates of prognosis with their patients," says Wachterman, who is now a palliative care physician with the Veterans Affairs Boston Healthcare System. In fact, given the hypothetical scenario where patients asked their nephrologists for an estimate of their prognosis, over half the time the doctors reported that they would tell the patient they could not give an estimate.

The disconnect was also apparent when the researchers asked patients and doctors about the possibility of kidney transplantation.

"We know that getting a kidney transplant improves one's prognosis," says Wachterman. "But our findings showed that over a third of the time patients and nephrologists were not on the same page about whether the patient is even a transplant candidate. The patients thought they were candidates and nephrologists said they were not."

Wachterman thinks that nephrologists may not want to talk about prognosis because they are concerned that they will take away patients' hope. She also thinks it may help [doctors](#) to know that when patients were asked to think about if they were to have less time, would they want to focus on quality of life or living longer, more than half stated that they would "choose care focused on relieving pain and discomfort, even if it meant not living as long."

"It's hard to give a patient a difficult prognosis, but in the long-term, having that information may actually help bring patients a greater sense of hope and facilitate peace and closure because it enables them to plan

for what to do with the time they have left," says Wachterman.

"The way we talk about this is not easy, but it's important," says senior author Ellen McCarthy, PhD, MPH, an epidemiologist at BIDMC, the Assistant Dean for Diversity and Community Partnership and an Associate Professor of Medicine at Harvard Medical School. "We might start by asking [patients](#) if they want to know their [prognosis](#). And then look for the kinds of resources, such as palliative care, that are available, which can add a much needed extra layer of support."

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