Effect of End-of-Life Care Planning Discussions on Hospice Use among Patients Receiving Dialysis for Kidney Failure

 Principal investigator
 Lewis Mitchel Cohen, MD
 Mark Unruh, MD
 Organization
 Baystate Medical Center

What was the research about?
Many people with kidney failure receive dialysis to remove toxins from the blood because the kidneys can no longer do so. But they may still be at high risk of dying. Talking about end-of-life care options with a doctor can help patients with kidney failure get the care they want in their last years. For example, patients often want to focus on quality of life or dying at home. For these patients, doctors may suggest hospice care. Hospice care focuses on keeping the best possible quality of life near the end of life. But only one in four dying patients on dialysis gets hospice care.

In this study, the research team tested a program to train kidney doctors and social workers in how to discuss and plan for end-of-life care with patients on dialysis and their families. Social workers in the program also took an eight-hour training on topics such as legal and cultural aspects of end-of-life care. Each patient and his or her family members met with a social worker and a kidney doctor for one hour to plan end-of-life care. Then the social worker followed up with the patient as needed.

The research team looked to see if more patients on dialysis used hospice after talking with their doctor about their goals for end-of-life care. The team also compared patients’ quality of life before and after the program.

What were the results?
Of the patients who died during the study,

- 52 percent died in a hospital
- 29 percent died at home
- 19 percent died in a nursing home

Of these patients, 48 percent stopped dialysis before death and 43 percent used hospice. The percentage of patients who used hospice at study clinics was the same before and after the program.

Of all patients in the study,

- 75 percent had a healthcare proxy, or a person to make decisions on the patient’s behalf if needed
- 63 percent had doctors’ orders that stated their wishes for life-sustaining treatment
- 22 percent had a living will

After the program, patients’ depression, pain, dialysis symptoms, and physical and emotional health didn’t change.
Who was in the study?
The study included 125 patients with about six months to live who got care at 18 dialysis clinics in Massachusetts and New Mexico. Of these, 46 percent were white, 14 percent were black, 12 percent were American Indian, and 28 percent were other or unknown races. The average age was 69, and 51 percent were men.

What did the research team do?
The research team measured hospice use for all patients who got care at study clinics between 2010 and 2017. Then, the team compared results for 125 patients before and after the program to see how many used hospice. The team also followed patients who got the program to see

- How many carried out end-of-life planning tasks
- Where patients died
- Their quality of life

Patients, family members, and social workers helped design and recruit for the study.

What were the limits of the study?
The study didn't compare patients who were in the program with those who weren't during the same period. Thus, it isn't possible to know if the program caused the results.

Future research could further explore programs that promote end-of-life planning. Such research could compare patients who get this type of program to patients who don't. Future studies could also look at how to best fit the program into clinic routine.

How can people use the results?
Researchers can use these results to advance research on ways to prepare patients on dialysis, families, social workers, and clinicians to discuss end-of-life care.

To learn more about this project, visit www.pcori.org/CohenUnruh188.