at Temple University in Philadelphia. Educational level and outside support systems impact adherence to the therapeutic regimen and influence the patient's perception of any side effects and how the transplant is doing in general, he explains. "If the patient is doing well overall and has gone back to work, and then experiences side effects, their perception of those side effects will be different from that of someone who has lots of comorbidities and a poorer quality of life." The take-home message of this study, he says, is that close follow-up, education, and providing appropriate social support throughout the process is critical in helping to maintain quality of life post-transplant, whatever therapeutic regimen the patient is on.

Often, the best way to determine how a patient is doing is simply to ask them, says Kristine S. Schonder, PharmD, clinical pharmacist at the Thomas E. Starzl Transplantation Institute at the University of Pittsburgh School of Medicine. During the month after a transplant, one of the surgeons at her institute asks every patient at every visit, "Was it worth it?" A simple question like that can tell you a lot about how the patient feels about the transplant, and how the medications may be impacting those feelings, she says.

Perhaps someone should be asking that question a year or more after the transplant as well, in an effort to spare patients some of the problems observed by Dr. Liu and her coauthors.

Bottom Line

Some patients find that their quality of life isn't as they hoped or expected it to be after a transplant, and medication side effects may contribute to their disappointment. These are the patients who might benefit from more support from their families and social networks, and should probably be seen more frequently by their providers. "The challenge," says Dr. Friedman, "is how do we get those resources for those patients?" Unfortunately, there aren't any easy answers.

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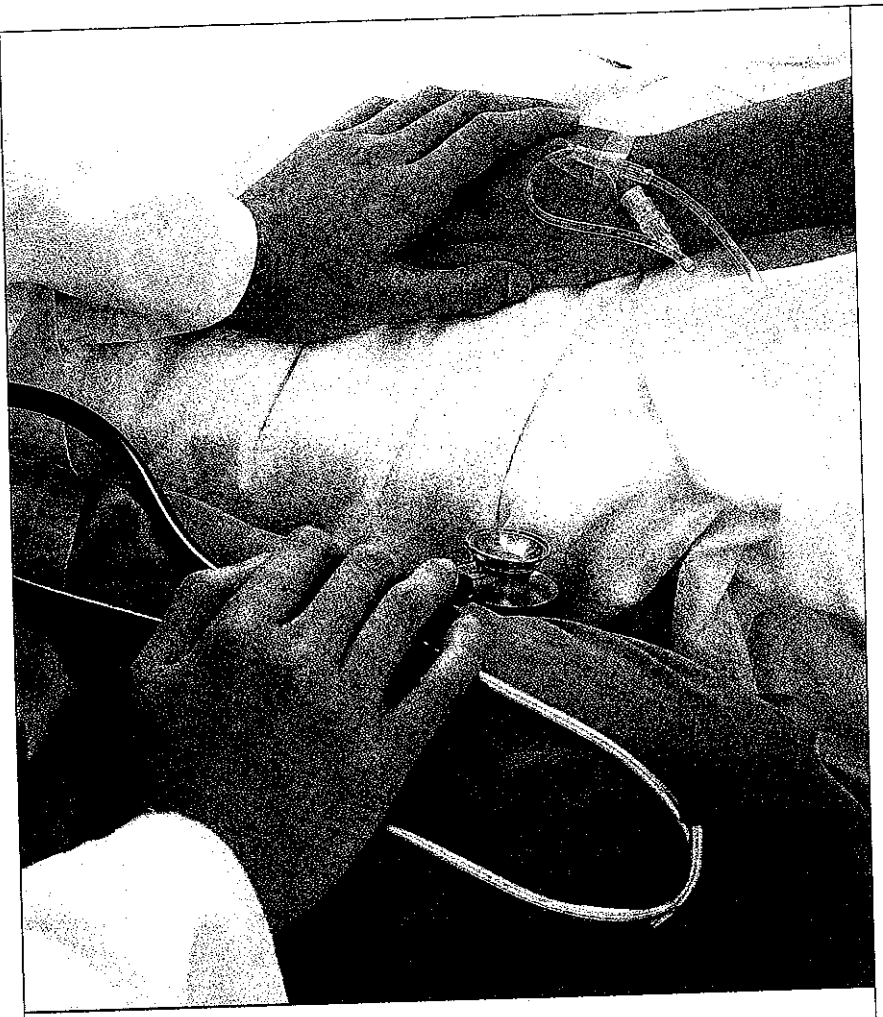

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The "Surprise" Question

Multiple comorbidities and advanced age are becoming increasingly common among patients receiving renal care, and many face a limited life expectancy. How some clinicians are approaching end-of-life issues with their patients

The end-stage renal disease (ESRD) population is getting older and frailer, and patients have ever-longer lists of symptoms and comorbidities at the time they initiate dialysis (*Table I*).[1] This means that nephrologists and nephrology nurses will be increasingly required to engage in end-of-life discussions—including conversations regarding palliative and hospice care—with patients and patients' families. Nephrology training programs worldwide are acknowledging this reality by adding more instruction on these issues to their curricula.[2]

But despite this growing attention, real change has been slow. Of nearly 600 patients in Canada with chronic kidney disease (CKD) in stages 4 and 5 who were surveyed between January and April 2008, more than half (61%) said they regretted their decision to start dialysis, and fewer than 10% could recall talking with their doctors about end-of-life issues within the previous 12 months.[3]

Misconceptions

Nephrologists may be reluctant to initiate these conversations partly because it simply isn't a part of their training, says Edwina Brown, MD, FRCP, professor of renal medicine at Imperial College London (U.K.). Also, she says, there is a tendency to look at specific events in isolation and not as part of a trajectory.

"Nephrologists are 'doers,' so they find it difficult not to actively treat," she says. And it is often easier to look at a phosphate level than to discuss end-of-life issues, she adds.

Clinicians may also harbor the misconception that palliative care is something that should begin just before death, "and not something that we should all practice as part of holistic care in all patients, with increasing emphasis on symptom control and psychosocial support as [the] end of life approaches," says Dr. Brown. Some physicians believe that patients find these discussions depressing and may lose hope, although evidence in the literature does not support this, she notes.

Identifying Appropriate Patients

Despite ever-improving treatment regimens that continue to extend patients' lives, patients with kidney disease are an increasingly aging population—one that has a higher mortality rate than that of many patients with cancer, says Lewis Cohen, MD, a nephrologist with Baystate Medical Center in Springfield, Mass. Hoping to increase the use of hospice services among people with ESRD, Dr. Cohen, along with Michael Germain, MD, also a Baystate nephrologist, and several other coauthors developed a tool to give nephrologists an easy way to identify patients with a life expectancy of six months or less (the definition Medicare uses to determine eligibility for hospice care). "We looked at all the different predictors out there. No one's really looked that closely at six-month mortality in dialysis patients before," says Dr. Germain.

> Some physicians believe patients will find discussions about end-of-life care depressing, but the literature doesn't support this.

Dr. Cohen, Dr. Germain, and colleagues Robin Ruthazer, MPH, and Alvin H. Moss, MD, used prospective data from 512 patients undergoing hemodialysis at five centers to develop the tool.[4] Most of the predictors were taken from the Charlson Comorbidity Scale, a list of 19 conditions weighted according to their relationship to one-year mortality, particularly among elderly cancer patients.[5] To this they added what they call the "surprise" question: "Would you be surprised if your patient died within the next six months?" The question was not a sufficient predictor by itself, but when combined with the other factors, Dr. Germain says they ended up with a clinically applicable instrument for the first time.

The instrument contains just five items: advanced age, presence of dementia, presence of peripheral vascular disease, low serum albumin, and a negative answer to the "surprise question."[4] The authors validated it two years later in another patient cohort. "It's a pretty accurate predictor of six-month mortality," Dr. Germain maintains. "As it stands, it's a practical tool that clinicians can use."

Bottom Line

There are signs that the renal community is starting to acknowledge the importance of end-of-life care: The American Society of Nephrology now includes a podcast about it on its website, and some hospital centers are developing special programs, like the Renal End of Life Initiative at St. Paul's Hospital-Providence Health Care in Vancouver, British Columbia, which has very specific goals. This is an encouraging trend that may improve the quality of care delivered to the very sickest people with kidney disease.

Table I: Comorbidities for prevalent hemodialysis patients, by age.

COMORBID CONDITION	18-44 Yrs	45-64 Yrs	65-74 Yrs	>74 Yrs
Coronary artery disease	14.7%	33.1%	43.7%	52.0%
Congestive heart failure	19.8%	25.2%	33.9%	43.2%
Other cardiac disease	18.6%	28.9%	39.2%	48.7%
Hypertension	73.7%	71.5%	74.9%	74.0%
Cerebrovascular disease	5.6%	13.2%	20.7%	22.5%
Peripheral vascular disease	7.1%	19.4%	28.0%	29.1%
Diabetes	15.7%	34.8%	41.7%	31.1%
Pulmonary disease	3.8%	7.2%	12.5%	15.1%
Cancer (other than skin)	2.5%	6.4%	10.5%	15.4%
Neurologic disorders	9.9%	5.4%	8.7%	13.9%

Adapted from: McKevitt, PM, Bommer J, Bragg-Gresham JL, et al.[6]

Access the mortality prediction tool at **www.nephron.com.** Click on **"Hemodialysis Mortality Predictor—Surprise Question"** under the "CKD EPI Calculator" section.

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