

RENAL PALLIATIVE CARE INITIATIVE  
BAYSTATE HEALTH SYSTEM

*Springfield, Massachusetts*

**I**t all started with a single consult. Nephrologist Michael Germain, MD, had a patient who decided to stop dialysis treatments. “We were shocked,” says Germain. “She was young and medically stable at the moment, but she had been through so many complications and treatments that she said she’d had enough. She wanted us to let her die peacefully. We didn’t know what to do. We called for a psychiatric consult.”

Lewis Cohen, MD, consulted on the case — but he didn’t stop there. As a faculty scholar on the Project on Death in America, his interest was piqued, so he collaborated with a regional, interdisciplinary research group to examine how people make the decision to stop dialysis and die. It was the first study of its kind in the United States, and the results were disturbing. “One in eight was a bad death,” says Cohen. “That horrified us. We started thinking, ‘Why? What could we do better for these patients?’”

The result is a pioneering effort to apply the principles of palliative care to the practice of nephrology — a discipline that has traditionally focused on prolonging the lives of people with end-stage renal disease. The Renal Palliative Care Initiative (RPCI) asserts that improving survival need not overshadow relieving suffering and responding to end-of-life considerations. The potential national impact is significant: 300,000 patients nationwide are on dialysis and more than 60,000 end-stage renal disease patients die each year.

Now in its fifth year of operation, RPCI, which has been funded in part by the Robert Wood Johnson Foundation, has been remarkably successful in developing innovative practice interventions and catalyzing change. It serves Baystate



Health System’s acute renal unit, renal transplant unit, and hospital-based dialysis unit. It also involves another nearby hospital-based dialysis center and patients who attend seven free-standing dialysis clinics in the region. Interdisciplinary teams of renal clinicians have undergone intensive training in palliative care and have a new set of tools to use as they work with end-of-life patients. The most visible are treatment protocols for common symptoms, such as pain, itching, fatigue, and sleeplessness.

“They make a profound difference for physicians like me,” says Germain. “We can offer a different dimension of care. We have options where before, we felt helpless. At first, many doctors were skeptical — they thought having a conversation about the end of life wasn’t their role. But now that they’ve seen RPCI in action, they’re convinced. It’s a whole change of direction.”

RPCI also holds morbidity and mortality conferences — a format rarely used by dialysis clinics. Staff reviews the circumstances of terminal care, determines whether dialysis should have been discontinued, and attempts to quantify the quality of how patients died.

A third innovation is an annual renal memorial service, rare for families of renal patients. “This service is the centerpiece of RPCI’s effort to provide continuity of care and to support the often-ignored bereavement needs of patients’ loved ones,” says Cohen. “This is where we fulfill the most precious vision of RPCI.”

RPCI’s success has prompted the system to expand palliative-care education and services. The impact is evident in residency education, transplant programs, and its system’s new cancer center.

RPCI is changing minds and practices outside Baystate Health System, too. It has sparked intense, nationwide curiosity and interest among nephrologists and other palliative care programs. Staff members are publishing widely, and they continue to actively collaborate in a variety of research investigations. In addition, RPCI continues to work with proprietary dialysis clinics to enhance standards of care.

“Until recently, most renal patients and their families were left largely unprepared for death. Now, we’re watching the medical model transform itself,” says Cohen. “This is a most welcome and valuable change.”



INNOVATION HIGHLIGHTS

**PALLIATIVE CARE FOR RENAL PATIENTS**

**RENAL MEMORIAL SERVICE**

**GROUNDBREAKING RESEARCH AND TREATMENT PROTOCOLS**