

Shifting to the chronic care model may save lives

—Paula Stec Alt, MBA • Dori Schatell, MS

The scale at the dialysis center records some bad news—a fluid gain of more than 10 kg. Today, the extra fluid will mean an uncomfortable treatment (with cramping, hypotension, headache, nausea). It might be tempting to skip the next treatment. Over time, repeated fluid buildup will contribute to left ventricular hypertrophy and shortened life expectancy.

This unhappy scenario is all too familiar, repeated on every shift, in every dialysis center in the nation. Why? The easy answer is “noncompliance.” A better, more thoughtful response demands a closer look at our flawed system of care. We are using an acute health care model to provide care for a chronic health condition. And this approach fails our patients.

An estimated 45% of Americans experience chronic disease, which is linked to seven of every 10 deaths and accounts for 76% of doctor visits and 75% of health care costs.¹ Yet Western medical clinicians are trained in an acute health care model, and patients are socialized in it as well.

The chronic care model

We can better shift to a chronic care model by transforming a system that is essentially reactive—responding mainly when a person is symptomatic—to one that is proactive and focused on keeping a person as healthy as possible.²

The chronic care model, developed by the MacColl Institute for Healthcare Innovation in 1999 and updated in 2003, identified the essential elements of a health care system designed to encourage high-quality chronic disease care: community, the health system, self-management sup-

port, delivery system design, decision support, and clinical information systems.³

Perhaps the best way to understand the chronic care model is to contrast its four key differences with the acute one now in place (see Table 1).⁴

Duration of disease: Appendicitis can’t last for a lifetime—but CKD does just that.

Patient’s role: Patients with an acute disease need only to seek good care and comply with a treatment plan.

ease, by definition have no cure. Rather, treatment goals are managing symptoms and adapting to change for an optimal quality of life.

Staff’s role: Professionals who treat acute conditions provide medical care. When treating chronic disease, providing care is necessary but not sufficient—it is also staff’s role to prepare patients for their extensive and vital self-management role.

Table 1: Contrast between acute and chronic illness⁴

	Acute Illness	Chronic Illness
Duration of disease	Short	Long-term—may be lifelong
Goal of treatment	Cure—return to normal life	<ul style="list-style-type: none"> ▶ Adapt to a changed life ▶ Manage day-to-day symptoms
Patient’s role	Comply with the treatment plan	Self-manage treatments, diet, medications, etc.
Staff’s role	Provide medical care	<ul style="list-style-type: none"> ▶ Provide medical care ▶ Prepare patients to self-manage

But with chronic conditions like CKD, patients must learn to self-manage, taking on a full-time “job” that requires both extensive knowledge and skill. This job is vastly more complex than simple compliance.

Goal of treatment: In an acute model, when a patient presents with an illness (e.g., appendicitis), the goal is a cure. But chronic illnesses, like chronic kidney dis-

Practical implications

The difference between acute and chronic care models is the difference between giving patients a fish versus teaching them to fish. Using the chronic care model clarifies the need to provide effective, ongoing self-management education. With a chronic illness, patient education is not just nice to have—it is fundamental to long-term survival.

The content and depth of patient education are also guided by the vision of the chronic care model. Providing brief facts is not enough. Patient education must teach patients how to self-manage as full partners in their own care. Good

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CKD education will focus on the benefits to the patient of self-management, with tips for undertaking specific tasks. Support strategies like goal setting, action planning, problem solving, and following up, are also vital.³

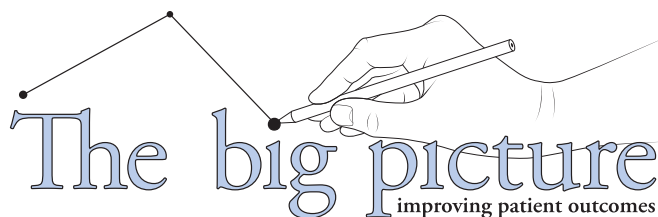
Self-management: The good, the bad, and the ugly

With or without our help, people with CKD are self-managing. Even when kidney failure is treated with standard in-center hemodialysis—the most medically supervised treatment we have—a patient is under direct staff supervision for only about 8% of the time (see Fig. 1). The other 92% of the time, he or she is self-managing (for better or worse) with every bite of food, every drink, every medication taken or skipped.

Our interdialytic weight gain example illustrates not “non-compliance,” but rather a systemic failure to provide patients with the tools, motivation, and skills they need to self-manage well. Teaching patients how and why to take care of themselves and providing the tools they need to succeed is essential.⁴

Saving lives

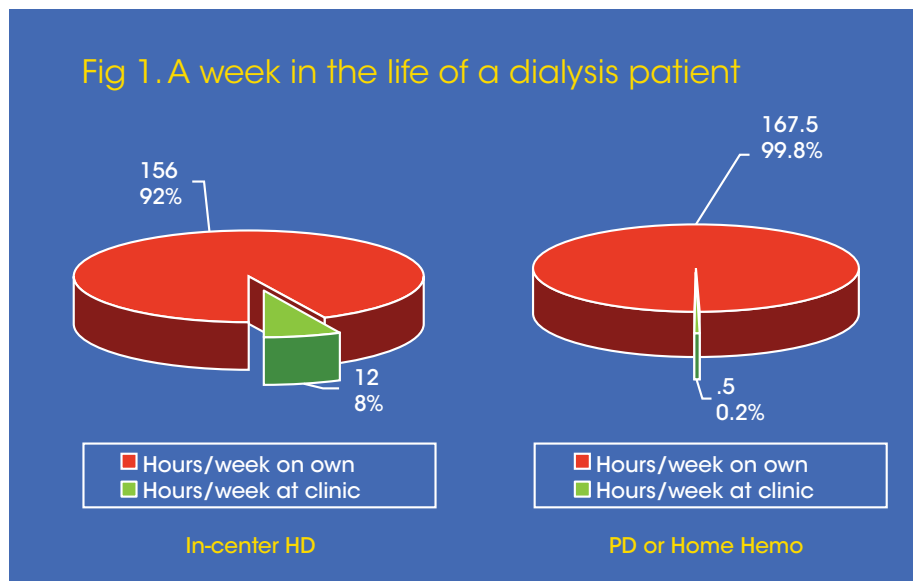
Switching from an acute to a chronic care model would have positive—even lifesaving—results in CKD. Two research groups have found that patient education is actually more effective than early nephrologist referral for slowing progression of CKD,⁵ ensuring a planned (rather than emergent) dialysis start,⁶ and significantly improving long-term survival.^{7,8} Multiple studies have found that when predialysis CKD patients receive modality education, 45% to 60% will choose a home treatment.⁹⁻¹⁶ Currently, peritoneal dialysis and home hemodialysis are the only modalities that require patient training about dialysis itself. A comprehensive review found that patient-centered, chronic disease self-management programs do, in fact, “simultaneously improve disease control, patient satisfaction, and guideline adherence.”¹⁷



To achieve the improved outcomes using the chronic care model, we need to change the way we provide CKD care.¹⁸ We must emphasize predialysis and dialysis education, and ensure that it is designed to empower patients to self-manage. Professionals who rethink their roles as care providers will put more focus on coaching and guidance in patients’ skill development. The best care in the world cannot produce optimal results unless those who receive the care—our patients—learn how to take on the task of successfully managing their own health.

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NKDEP's look at the chronic care model

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Chronic kidney disease is a significant public health problem in the United States. Millions of Americans have diabetes or high blood pressure, the two leading risk factors for CKD. An estimated 26 million have CKD or albuminuria; recent data show that more than 485,000 people are on dialysis or living with a kidney transplant. In 2004, kidney failure cost the health care system approximately \$32.5 billion.

The National Kidney Disease Education Program (NKDEP)—an initiative of the National Institute of Diabetes and Digestive and Kidney Diseases, one of the National Institutes of Health—was established to improve the detection and management of kidney disease. Our top priority is improving the capacity of health care providers, especially those in primary care settings, to help them better identify and care for CKD patients.

We look to the chronic care model (CCM) to guide our efforts. We believe it offers a strong framework for identifying the system-level changes that engage both providers and patients in improving CKD detection and management.



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NKDEP works across the CCM's four key areas: self-management support; delivery system design; decision support; and clinical information systems. Through tailored materials and outreach programs, we help patients assess their risk for CKD and learn how to keep their kidneys healthy. A pilot program with a network of community health centers aims to identify best practices for care delivery. A growing array of provider-education materials—including a robust new website under development—helps providers better understand and make decisions about CKD management. Our community health center network and Laboratory Working Group are working to adapt clinical information systems to improve CKD diagnosis and monitoring.

One example that spans several of these areas is our efforts to promote use of estimated glomerular filtration rate (eGFR) to measure kidney function. NKDEP produces materials that educate both providers and patients about eGFR, encourages laboratories to automatically report eGFR, and is exploring ways to modify electronic health record systems to prompt for eGFR and track it over time. These complementary projects help foster more “productive interactions” between providers and patients around this critical but poorly understood diagnostic and monitoring tool.

The chronic care model is particularly useful in guiding NKDEP's outreach to primary care providers, who see the vast majority of at-risk patients, as well as undiagnosed patients. Yet due to a perception that CKD is a complex “specialist disease,” primary care providers may miss opportunities for the early diagnosis and treatment that can keep kidneys healthier longer.

A key tenet of the CCM is integrating specialty expertise and primary care. For CKD, this means giving primary care providers the training and tools that can help them detect and treat early stages of the disease. While nephrologists and renal clinics are clearly needed to manage diagnostic or therapeutic challenges, as well as rapidly progressing and advanced cases of CKD, there is plenty that can be done in a primary care setting.

The CCM helps point the way, but it means nothing without the committed professionals who bring it to life. To succeed, NKDEP must work in close partnership with the renal community, public health advocates, professional associations, and all those who work to empower patients, support providers, and improve chronic care. **N**

For more information and free resources on CKD, visit www.nkdep.nih.gov.