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Chronic Kidney Disease—
A Quiet Revolution in Nephrology

Six Case Studies

Richard A. Rettig, Roberto B. Vargas, Keith C. Norris,
Allen R. Nissenson

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Summary

For nearly 40 years, public policy has defined kidney disease primarily by its terminus—end-stage renal disease (ESRD). Recently, however, the disease entity of concern has been redefined as chronic kidney disease (CKD), a progressive disease that culminates in ESRD and that in most instances can be effectively treated in its earlier stages. Prevention is thus a possibility: Clinical interventions at earlier stages of CKD can effectively slow, stop, or, in some cases, reverse the progress to ESRD.

The possibility of preventing early-stage CKD from developing into kidney failure represents a still-unfolding area of innovation in nephrology. For medicine, CKD represents a challenge in moving from a chronic disease treatment model to a model that balances the relationship between prevention and care. For policy, the key issues involve the reimbursement of care, i.e., who will pay for the range of care associated with the expanded understanding of CKD.

There is a need for both practitioners and decisionmakers to better understand the CKD clinical practices capable of managing CKD throughout the disease continuum and of improving patient outcomes for kidney disease in the United States. This study represents an initial step in developing that understanding. Our Comprehensive Center for Health Disparities—Chronic Kidney Disease (CCHD–CKD) team, composed of researchers at Charles Drew University, the David Geffen School of Medicine at UCLA, and the RAND Corporation, has been conducting health services research within the CCHD’s Health Policy and Outcomes Core, including this 2006–2007 study. The findings from this study offer descriptive examples of what leading nephrology practices around the United States are doing to address the challenges of CKD and provide the basis for a set of policy and clinical recommendations about how to advance the treatment of CKD.

A “Quiet Revolution” in Nephrology

In 1972, Congress extended Medicare entitlement to all individuals with a diagnosis of permanent kidney failure who needed dialysis or kidney transplantation to avoid death. This legislation led to a dramatic growth in the patient population, especially among the elderly, along with a corresponding rise in expenditures for treatment of the growing patient population. The increase in the patient population also revealed marked disparities in both the incidence and prevalence of ESRD among minority populations. The emergence of disparities did not represent a sudden increase in the number of cases of CKD among minorities; instead, the Medicare benefit gave providers an incentive to find and treat all patients, bringing many previously undiagnosed cases out into the open. In addition, Medicare began to document the changing
demographics of the ESRD patient population, thus providing data that had previously been lacking.

Today, a quiet revolution is occurring in nephrology. The nature of the revolution was crystallized by the 2002 publication of the Kidney Disease Outcomes Quality Initiative (KDOQI) guidelines for the diagnosis and treatment of CKD, which described a progressive five-stage CKD model that incorporated ESRD as the final component of the overall model but provided direction for the early detection and treatment of CKD. Hence, the diagnosis of CKD has become relatively simple (for both nephrologists and non-nephrologists) through a process known as estimation of glomerular filtration rate (or eGFR), which, though not a direct measure of kidney function, estimates the ability of the kidneys to filter cellular toxins.

The framing of the disease as CKD shifts the focus from ESRD and represents a major change and innovation that is still unfolding. But this revolution has yet to receive adequate attention within nephrology and by policymakers, and some significant barriers remain to improved care for CKD patients. Key among these is the fact that treatment for ESRD is paid for through Medicare, but early treatment of CKD is not. Other barriers include a lack of coordination between primary care physicians (PCPs) and nephrologists, a lack of public awareness regarding CKD, a lack of consensus among health care providers concerning the importance of CKD, and the need for data concerning the effectiveness of different tests and therapies for CKD.

Findings from Our Research

In 2006, we undertook a series of 15 telephone interviews, which were followed in 2007 by site visits to six CKD clinics or practices, to obtain an in-depth understanding of how diverse groups of leading nephrology practices around the United States are confronting the challenges of CKD. These findings offer descriptive examples of CKD practices and specific policy recommendations intended to improve patient outcomes for kidney disease in the United States.

Our telephone interviews raised several key themes concerning CKD practices today, many of which were later echoed in the case studies. Most practices we interviewed favored early intervention, although several expressed ambivalence, and a few thought the payoff was greater when treatments were started in later stages of CKD. The practices identified a number of problems and challenges in treating CKD patients, including limited reimbursement, lack of patient awareness of CKD, and difficulty in identifying CKD patients and in creating patient histories from multiple sources. Relations between nephrologists and other medical specialists—PCPs (internists, family practitioners), cardiologists, and endocrinologists—elicited a good deal of comment. In general, nephrologists felt that patients were being referred for CKD care too late, although respondents also noted a recent trend toward earlier referrals. The practices we interviewed organized CKD care in a variety of ways: Some lacked any formal approach to CKD care, others emphasized CKD but lacked a clear organization, and others had established clinics specifically focused on CKD.

* In February 2003, the Council of American Kidney Societies (CAKS) identified 19 barriers to improved patient outcomes in CKD, including specific aspects of both the delivery and financing of care for CKD.
The case studies provide details about these findings and shed light in particular on several of the challenges faced by CKD clinics, as well as some of the ways in which clinics are addressing these challenges. Specifically, these findings include:

**Reimbursement.** The major barrier to clinic operations involved limitations on reimbursement of CKD. All six of the CKD clinics and practices in the case studies face financial challenges in providing CKD care, especially to support the multidisciplinary staff of nurses and other health professionals needed for a comprehensive practice.

**Patient Referral.** All CKD clinics and practices in the study have confronted the need to reach out to PCPs, cardiologists, and endocrinologists to ensure the predictable referral of patients for CKD care before patients need immediate dialysis. There was concern among nephrologists that PCPs were reluctant to refer for fear of losing patients, but this concern was tempered in academic and integrated CKD clinics by targeted efforts to comanage CKD with PCPs.

**Patient Screening.** The ability to screen potential CKD patients varied across clinics but was generally limited by weak referral patterns in nonintegrated health systems and limited public awareness of the need for early-stage care. The use of eGFR and community outreach programs was cited as a factor in increasing early-stage referrals.

**Patient and Provider Education.** The need to educate both patients and PCPs was seen as critical, both to increase patient awareness of CKD and to ensure that physicians know the early indications of CKD. All CKD clinics engaged in some educational efforts, including presentations, public service announcements, and provider education.

**Practice Organization.** Clinic organization remains quite varied and in flux. The structures of the clinics in our case studies varied greatly. Some nephrology divisions of large multispecialty group practices had carved out a CKD clinic within that context, while in others the CKD effort was an extension of a clinical base in ESRD.

**Use of Clinical Practice Guidelines.** Guidance is increasingly available through continuously updated clinical practice guidelines (CPGs). All CKD clinics in our study used CPGs as a first-order means to identify patients, organize practices, and build data systems. All of the clinics visited adapted the guidelines for local and patient-specific purposes.

**Health Information Technology.** The use of health information technology (HIT) can facilitate CKD care. The six CKD clinics varied greatly in the stage of development of their HIT systems. Some have purchased off-the-shelf products, while others have developed their own. One site received financial assistance from a state and federal government effort to encourage the transition to electronic medical records.

**CKD Disparities.** Unfortunately, the racial and ethnic disparities prevalent in the ESRD population appear also in the CKD population, but, without reimbursement, referral patterns and levels of patient knowledge often go undetected. In our case studies, sites that served predominantly minority and underserved communities had patients presenting at much younger ages and with more advanced disease. In response, they employed targeted community outreach and educational programs.

The case studies also highlighted a number of benefits that flow from CKD clinics, including the advantages of early treatment, success in using the estimation of GFR for early referrals, and the increasing possibility of preemptive kidney transplantation.
Policy Recommendations

On the basis of the telephone interviews and the six case studies, we developed a set of policy and clinical recommendations about how to advance the treatment of chronic kidney disease. The following set of recommendations provides a blueprint for reengineering CKD in the United States:

- Appropriate reimbursement needs to be available to screen at-risk populations and to enable ongoing care by physicians as CKD is diagnosed and progresses.
- Patient referral, the other critical resource, requires negotiations between nephrologists and other providers and specialists at the local clinic or practice level, as well as at the level of the pertinent professional societies.
- Screening patients for CKD by eGFR should be made obligatory by Medicare and state Medicaid agencies, and private insurers should be strongly encouraged to pay for such screening.
- Education is critical. Both patients and providers need to be educated about the prevalence of CKD, who is at risk, who should be treated, and which treatments are effective in slowing the progression of the disease, as well as treating its complications and those associated with comorbid conditions that are present.
- CKD clinical practice needs to integrate the efforts of PCPs, cardiologists, endocrinologists, nephrologists, and nonphysician care providers to optimize clinical outcomes. Coordinated care management, relying on available best medical evidence, needs to drive clinical decisions and practice.
- Available clinical practice guidelines, such as the Kidney Disease Outcomes Quality Initiative (KDOQI) guidelines published by the National Kidney Foundation (NKF) and the Renal Physicians Association (RPA) guidelines, need to be integrated into actual clinical practice.
- Consistent with current health reform efforts, robust HIT is essential to track and evaluate care across various delivery sites.
- Nephrologists and other providers need to be held accountable for the outcomes of their patients.
- Substantial investments in translational and health services research are needed to better understand how to prevent CKD, treat it when it occurs, and carry out these activities efficiently and effectively.

The crisis of nephrology lies in an unresolved tension between the specialty’s increasing ability to do the right thing clinically (by providing effective preventive care) and the persistent realities of major barriers to doing so, including inadequate reimbursement, weak working relations between nephrology and other specialties, organizational impediments, ineffective clinical procedures, and a lack of HIT systems. To the extent that our observations identify models of improved access to CKD care for all individuals as well as efforts targeted at minority populations, this work may help eliminate disparities in kidney disease outcomes. Action on CKD policy will equip clinicians with the basic tools to respond to such factors.