

Chronic Kidney Disease in the United States: A Public Policy Imperative

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Background and objectives: In the past decade, a crisis in nephrology has slowly emerged in the areas of both clinical care and public policy. In 2003, the Council of American Kidney Societies (CAKS) identified 19 barriers to improved patient outcomes in chronic kidney disease (CKD).

Design, setting, participants, & measurements: Site visits and in-depth telephone interviews were conducted with 15 nephrologists focusing on current issues with identifying and treating patients with CKD. The qualitative analyses were considered in the context of CAKS-identified barriers to assess the present state of nephrology care and provide a foundation for a more detailed quantitative CKD project potential implications for advancing nephrology-related health policy.

Results: Despite new evidence-based therapies to slow, stop, or reverse the progression of CKD to ESRD as well as premature cardiovascular disease, major systemic barriers continue to limit the implementation of this body of evidence at the level of the nephrology practice. Key factors include under- or uninsurance, unstructured medical care systems, and lack of enabling public policies.

Conclusions: The crisis of nephrology is embedded within the unresolved duress of the ability to provide quality early intervention juxtaposed upon inadequate reimbursement for clinical care and procedures, unfunded mandates for information technology systems, and organizational inconsistencies between nephrology and other specialties. We believe now is the time for the renal community and related stakeholders to unite in an effort to address the clinical, financial, and public policy issues that will enable the delivery of appropriate CKD care to this vulnerable patient population.

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Nephrology faces a crisis that is both clinical and a matter of public policy, one that has developed slowly in the past decade. Clinically, nephrologists today have the evidence and knowledge to slow, stop, or even reverse the progression of chronic kidney disease (CKD) to ESRD, the latter requiring dialysis and/or transplantation, and associated comorbid conditions. This marks a major change in the conceptualization of the principal disease entity of concern to the specialty, but major systemic barriers remain, including lack of enabling public policies, which limit the implementation of this body of evidence.

No better illustration of this crisis can be found than the February 2003 meeting organized by the Council of American Kidney Societies (CAKS), which was subsequently reported as the Chronic Kidney Disease Initiative (1). The meeting came on the heels of the Kidney Disease Outcomes Quality Initiative (K/DOQI) Guidelines on CKD, published in 2002 (2). Forty-eight individuals—nephrologists, primary care physicians (PCP), nurses, physician extenders, payers, representatives of government agencies, dialysis providers, disease management organizations, epidemiologists, academicians, and representa-

tives of professional nephrology societies—identified 19 barriers to improved patient outcomes in CKD.

Many of the barriers are systemic and require significant public policy changes. Several are at the level of site of care and have been tackled by creative nephrology practices. Note that in Table 1, the barriers were identified using a modified Delphi method, whereas the current challenges are based on the authors' site visits and interviews highlighted in this report.

The situation facing CKD is reminiscent of that confronting patients with ESRD in the 1960s, when a laborious search for a policy solution to the absence of reimbursement for dialysis and kidney transplantation took place for years before Congress resolved the issue by enacting the Social Security Amendments of 1972. Today, as then, however, only Congress can cut the Gordian knot that prevents effective care from being provided.

When coverage to virtually all Americans who have permanent kidney failure was enacted in 1972, many nephrologists spoke about the resulting ESRD program as providing a model for national health insurance. Major proposals for national health insurance had been advanced in 1971 and 1972 by the Nixon administration, the Senate Finance Committee chairman, Senator Russell Long, and the American Medical Association. Many observers anticipated broad changes in Nixon's second term, but the not unreasonable hope that the nephrology model would blossom into a broader national health insurance plan

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Table 1. Barriers preventing improved patient outcomes in CKD: The Chronic Kidney Disease Initiative, 2003^a

CAKS Appraisal 2003	Appraisal of Current Situation 2007 to 2008
GFR is not reported by laboratories	Uneven reporting of GFR
Lack of public and patient awareness and concern regarding the risks associated with CKD	Limited progress
Maldistribution and worsening shortage of health care providers	Not getting better, probably getting worse
Lack of coordination between primary care physicians and nephrologists	Some evidence of improvement; much more work to be done
Unwillingness of payers to invest in CKD care	Basic issue at the heart of things
Need for payers to recognize the value of early treatment of CKD	Critical issue that impedes current progress
Absence of a coordinated system of care that includes a delivery system that will reach all patients with CKD	Remains an ideal to be sought in the next decade
Inadequate recognition of cardiovascular disease and complications of decreased GFR as patient outcomes of CKD, rather than ESRD the only complication	Vital clinical issue, for both nephrologists and other specialties
Conceptualization of CKD is very recent and not widely diffused within nephrology, medicine, or the health care system	A fundamental rate-limiting factor
Lack of consensus regarding the importance of CKD	Some progress; need exists for joint statements between nephrology, cardiology, endocrinology, general internal medicine, and family practice specialty organizations
Need for information on variations in care process, outcomes, and best practices	Too little structure to allow systematic data collection
No definition of how the marketing of CKD message should be structured and implemented	Various models exist: Capture model, evangelism model, entrepreneurial model
Inadequate understanding of optimal context for CKD screening, prevention, and treatment	Is a quality nephrology/CKD practice feasible independent of a CKD clinic?
Need for nephrology leadership to unite and speak with a single voice on this issue	Need convening authority, perhaps Institute of Medicine
Lack of convincing cost–benefit data	Critical economic issue
Lack of acceptance of a uniform definition of CKD	Technical issue, largely resolved by K/DOQI guidelines
Lack of understanding of patients who have CKD and for whom interventions will affect outcomes	Growing body of evidence for strengths and limitations of disease-specific interventions on CKD progression and improved timing for pre-ESRD education
Risk of no entity with a broad mandate to sustain these efforts long term	No payer in the game: CMS/Medicare, state Medicaid programs, private insurers
Lack of prospective evidence for effective tests and therapies to prevent complications of CKD	Growing body of evidence allowing early intervention with positive results; clinical opportunity exists; financing is limited

^aAdapted from reference (1). CAKS, Council of American Kidney Societies; CKD, chronic kidney disease; CMS, Centers for Medicare and Medicaid services; K/DOQI, Kidney Disease Outcomes Quality Initiative.

was dashed by Watergate and impeachment. What did happen, however, was that the entitlement to the treatment of kidney failure focused both clinical and policy attention almost exclusively on ESRD. Hemodialysis and, to a lesser extent, kidney transplantation and peritoneal dialysis became the defining

procedure of the specialty. Nephrology became dependent on public policy to a greater extent than perhaps any other medical specialty.

In recent years, however, a quiet revolution has occurred in nephrology, a revolution that has yet to receive adequate at-

tention within the specialty and certainly not by policy makers. It was crystallized by the 2002 publication of the K/DOQI guidelines, basically redefining the diagnosis and treatment of CKD in terms of function rather than disease type and stipulating a progressive CKD model that incorporated ESRD.¹ To be sure, the bulk of the specialty remains occupied with dialysis and kidney transplantation, but quiet though it may be, the framing of the specialty's clinical concern as CKD represents a major change, a major innovation, an unfolding revolution.

It is now clear that nephrology is able to intervene at earlier stages of kidney disease—from stage 3 CKD and onward—to slow, stop, or even reverse the progression to ESRD as well as premature cardiovascular disease. Prevention is no longer an ethereal aspiration but a clinical possibility, and the recognition of the high prevalence of the early stages of CKD provides new opportunities to address modifiable risk factors. The crisis of nephrology, then, lies in an unresolved tension between the ability to provide quality early intervention and the persistent realities of inadequate reimbursement for clinical care and procedures, unfunded mandates for information technology systems, and organizational issues including weak relationships between nephrology and other specialties.

This cluster of CKD-related issues is formidable. The epidemiologic, personal, and financial dimensions are substantial. First, CKD is highly prevalent in the US population, affecting nearly 15%, or 26 million, Americans (3). Second, CKD is now recognized as an important risk factor for premature mortality (4,5). Third, differentiating CKD care from that for ESRD has become a significant policy issue because nearly 500,000 individuals with advanced disease are treated each year with renal replacement therapy (dialysis and kidney transplantation) at a cost of approximately \$35 billion (6). The way forward to continued improvement in clinical outcomes, while restraining costs, is far from clear.

Moreover, the crisis of nephrology is hardly peripheral to American medicine, which essentially ignores the confluence of factors that influence health and well-being and devotes most of its resources toward disease-based medical care that is focused on costly chronic care interventions. Per capita spending on health care of the United States is more than double that of most developed nations, yet it ranks among the lowest in health access and outcomes (7–9). In fact, CKD constitutes a microcosm of one of the deepest problems confronting the US health care system: How to move from a system that is focused almost exclusively on procedure-oriented treatment of chronic disease to a system that strikes a reasonable balance between therapeutic and preventive services. Perhaps the modeling contribution of kidney disease of the US health care system is at hand: If this domain of the medical commons can be fixed, then the lessons for the larger system may become clearer for both clinicians and policy makers.

¹Antecedents to the guidelines included recognition of inadequate preparation of many patients who crashed at the nephrologist's doorstep needing dialysis immediately; the emergence of angiotensin-converting enzyme inhibitors, angiotensin II receptor blockers, and blood glucose control as treatments to slow progression of CKD; and the dramatic appearance of a "second generation" of dialysis patients: The children of early dialysis patients.

In addition to the clinical and policy crises, CKD illustrates one of the most common burdens of inadequate health care in the United States, the deeply unpleasant overrepresentation of underserved and minority individuals who have chronic illness. Within America, there remain marked differences in health outcomes by sociocultural, racial/ethnic, and geographic stratifications (10,11). In the 2007 Shattuck Lecture, Dr. Steven A. Schroeder underlined this point: "Since all of the actionable determinants of health—personal behavior, social factors, health care, and the environment—disproportionately affect the poor, strategies to improve national health rankings must focus on this population" (12).

Consistent with these calls for reducing health disparities, the National Institutes of Health funded a comprehensive center to address disparities in CKD (National Institutes of Health/National Center for research Resources: U54-RR019234) through a partnership among Charles Drew University, the David Geffen School of Medicine at the University of California at Los Angeles (UCLA), and the RAND Corporation.

Materials and Methods

A pilot project conducted through the Health Outcomes and Policy core consisted of a series of telephone interviews with 15 nephrologists to provide some qualitative information for a subsequent CKD project. There were many differences in the perspectives of this group of nephrologists regarding the current issues with identifying and treating patients with CKD and the best areas to focus limited resources to have the greatest impact on outcomes.

Consequently, to gain more qualitative "street-level," experience-based insights into potential barriers and facilitators to the care of patients with CKD, we conducted six site visits and in-depth interviews with CKD providers who practice in distinct health care systems or settings and were representative of the initial group of 15 CKD practices. The site visit interviews focused on understanding strategies for providing quality care, including care for the most vulnerable patients in their communities. Although these six sites clearly do not reflect all of the CKD approaches to CKD care in the United States, we believe that the mix of urban, rural, academic, and integrated health care system represented here does indeed encompass a large fraction of the nephrology practices.

Importantly and very deliberately, these reports describe the realities of CKD care in ways that are more understandable by members of Congress and other policy makers than the medical literature. They highlight issues that cannot be resolved within nephrology alone but that require conscious policy action, especially related to reimbursement, but the major policy issue is not simply one of money. It involves the larger recognition that medical advances now allow nephrologists to intervene at earlier stages of CKD, improving CKD and CKD-related outcomes. Seen in this light, prevention is no longer a lofty aspiration but an achievable clinical reality. When viewed with this perspective, CKD is a microcosm of a much larger health policy challenge.

Results

Case Studies

The six case studies in this series will be presented in full in a RAND monograph. The following provides some background detail on the six sites followed by a depiction from one practice of the six that best illustrates challenges and creative

approaches to addressing eight of the key barriers to improving outcomes for patients with CKD that were identified by the CAKS initiative to illustrate how individual nephrology practices may move this field forward while waiting for the systemic changes to occur to accelerate progress truly.

St. Clair Specialty Physicians, P.C., Detroit, Michigan. St. Clair Specialty Physicians, P.C.,² is a CKD practice that is housed in St. Johns Hospital and Medical Center, an affiliated hospital of Wayne State University School of Medicine. It draws its patients from all of Greater Detroit and its suburbs. The socioeconomics of the patient population is mixed, with a large underserved population.

Associates in Nephrology, Chicago, Illinois, Chronic Kidney Disease Clinic. The Associates in Nephrology (AIN)³ is a single specialty-group nephrology practice that is located in the Chicago metropolitan area and includes 27 nephrologists who care for patients at 34 hemodialysis clinics and two CKD clinics: one on the southwest side of Chicago and the other in a northern suburb. The former cares for the majority of patients with CKD, a predominantly black, inner-city population.

Indiana Medical Associates, Fort Wayne, Indiana. Indiana Medical Associates is a large physician group practice that includes 10 nephrologists. The group has three offices, the main one on the southwest side of Fort Wayne, and its physicians see patients in nine satellite and nine hemodialysis clinics in Northeastern Indiana and Northwestern Ohio. Some of the latter are used as sites for visits for patients with CKD. The patient population is largely middle class and predominately white.

Northwestern University CKD Clinic, Chicago, Illinois. The Northwestern University CKD clinic—called Healthy Living—is an integral part of the Division of Nephrology and Hypertension within the Department of Internal Medicine of the Feinberg School of Medicine, Northwestern University. The clinic is physically located within the academic complex of the medical school and Northwestern Memorial Hospital in downtown Chicago. Although there is a mix of ethnic, racial, and socioeconomic groups, there is a minimal number of underserved patients.

The Mayo Clinic, Jacksonville, Florida. The Mayo Clinic in Jacksonville, Florida, a large multispecialty practice, serves a geographically diverse population through an outpatient and new inpatient campus facility located on the southeastern side of Jacksonville, and formerly St. Luke's Hospital several miles west of I-95, the major north-south interstate highway along the East Coast of the United States. Mayo-Jacksonville, like its Rochester, Minnesota, parent organization, is a major referral treatment center. Because of the referral nature of the population, this is generally a group of patients who have adequate insurance coverage and have attained significant levels of education.

Winthrop University Hospital, Mineola, New York. The Winthrop University Hospital nephrology service consists of a chain of not-for-profit, hospital-owned dialysis units (operated by Winthrop Dialysis Services) and the Division of Nephrology and Hypertension, a part of the Department of Medicine of the hospital. Patients are seen in the nephrology office practices that are associated with these dialysis units. Depending on the location, patients may be underserved or of middle or higher socioeconomic groups and are generally well insured.

Illustrative Practice Approaches to Eight of the Key Barriers to Improving Outcomes for Patients with CKD Identified by the CAKS Initiative

Conceptualization of CKD Is Very Recent and not Widely Diffused within Nephrology, Medicine or the Health Care System. Efforts to provide CKD care are rooted in several recent developments. First, clinicians recognized the effect of poorly prepared patients, those who arrived on the doorstep of the nephrologist needing immediate dialysis. Second, scientific and clinical advances had identified treatments for major comorbidities, especially diabetes and high BP. Third, a second generation of dialysis patients began to appear in clinics, literally the children of early dialysis patients.

These factors led to the differentiation of the CKD practice from that of ESRD, although the initial lack of focus on CKD within the profession created significant challenges to initiation of the CKD component of nephrology. In 1988, the St. Clair Specialty Physicians, P.C., was formed from an existing practice, and its focus was redirected more broadly than just ESRD care to include the care of patients with CKD, also called patients with “early renal insufficiency.” Few practices were focused on CKD in 1988, and even the Michigan state chapter of the National Kidney Foundation (NKF) showed little interest in CKD at that time. What prompted the reorientation toward CKD? More and more patients were presenting with varying degrees of kidney disease, not all of whom were at end stage. Although there were limited early data demonstrating that the course of the CKD was modifiable, emerging therapies/medications that could slow CKD progression and improve comorbidities were becoming available, beginning with angiotensin-converting enzyme (ACE) inhibitors and followed by vitamin D analogs. The practice purchased half of the hospital dialysis business and entered into a joint venture called the St. Johns Dialysis Network. The dialysis program grew from 76 patients to 900 patients in 4 yr and expanded to vascular access centers with profits used to cross-subsidized CKD care.

The strategy of the St. Clair CKD practice was (and remains) one of, first, to identify the at-risk populations and broadly focus on intervention to reverse or forestall progression. If despite therapy or if CKD was identified too late for reasonable intervention, then patients would be prepared for renal replacement treatment, either dialysis or, if appropriate, kidney transplantation.

The practice was molded to provide a community service. Black individuals were disproportionately represented among patients with CKD. The business model that was created encompassed the entire cadre of patients with CKD and ESRD

²This case study is based on an extended site visit interview conducted on April 18, 2007, supplemented by later correspondence, and on a telephone survey interview conducted on April 13, 2006.

³This case study is based on an extended interview conducted during a site visit, May 1, 2007, supplemented by later correspondence and by responses to a telephone survey interview conducted on April 10, 2006.

and all related conditions by providing an integrated, stratified system of care specifically focused on these unique patients' needs. If this approach were successful, then it was hoped that health care providers, health insurers, and health plans would refer more patients to the practice. At the time, such patients tended not to stay enrolled in a single plan for long; therefore, initiation of intensive and often-expensive therapy was not in the fiscal interests of the health plans. In addition, patients with ESRD were only a very small number of their total enrollees.

Need for Information on Variations in Care Process, Outcomes, and Best Practices. Although considerable literature had been published about process and outcomes of care for patients with CKD, it was not until two sets of clinical practice guidelines became available, one from the NKF (K/DOQI, 2002) and later one from the Renal Physician Association, that nephrology practices could begin to standardize and monitor care, but the mere existence of guidelines does not ensure that CKD clinics are following best evidence in care for patients with CKD.

The CKD clinic at Mayo-Jacksonville, however, is an excellent example of how such guidelines can be effectively implemented. The data system uses the K/DOQI guidelines to track stages of CKD as well as progressive estimated GFR, providing the physicians a view of the effectiveness of therapies to slow the progression of CKD. It also uses the field-tested RPA advanced CKD Management Toolkit clinical performance measures for BP, ACE inhibitor or angiotensin II receptor blocker therapy, anemia care, mineral metabolism, metabolic acidosis, lipids, nutrition (albumin, body weight), timing of renal replacement therapy preparation (discussion of modality, referral for arteriovenous fistula, transplant), counseling and rehabilitation, and influenza vaccination.(13,14).

Dr. William Haley, one of the Mayo nephrologists, led the RPA task force that developed the CKD tool kit. In his judgment, the tool kit has been well received: "It has led to improved processes of care, but it has only been in use since 2005, so we don't yet have evidence on outcomes of care. [However,] it has helped with patient satisfaction, and it has helped in engaging allied health professionals. Users of the tool kit believe that it improves outcomes." Many of Haley's patients like the "diary" tool, a "report card" to the patient, which allows them to keep up with their "numbers" as well as their medications. It also explains the goals of care in lay terms (*e.g.*, why diet is important), and it is visual. It is both one-time and ongoing.

Unwillingness of Payers to Invest in CKD Care. There is clearly a lack of adequate reimbursement for CKD care, including financing of physician and nonphysician care, the latter including nurses, nurse practitioners, physician assistants, dietitians, and social workers. This lack has created a disincentive to providing such care in the nephrologists' office and has required creative use of "cross-subsidies," often from the care of patients with ESRD; however, continuing pressure on the composite rate for dialysis, continuing controversy over anemia treatment, and the perverse effects of Medicare's sepa-

ration of reimbursement for Part A and Part B on nephrology office practice has severely limited the prospects for cross-subsidies without providing a clear policy alternative. If anything, such pressure has underlined the imperative to undergird a rational clinical regime with an equally rational reimbursement approach. The recent introduction of G-codes, permitting an analysis of claims data for Medicare patients with CKD by CKD stage, may be a positive first step in permitting an understanding of the costs of CKD care and may lead to more creative approaches to organizing the care to improve outcomes and overall costs of care.

The role of private health insurers remains to be defined for CKD care, including reimbursement for the estimated GFR. Insurers face an economic disincentive, however, because the turnover of covered individuals is sufficiently high to diminish or eliminate their interest in tracking patients; however, the continuing efforts by the executive branch and by Congress to lengthen the period of Medicare as Secondary Payer potentially increases the exposure of private health insurers to ESRD costs and may provide them some economic incentive to give greater attention to CKD.

For Chicago-based AIN, reimbursement is also a key issue that has required creative approaches. AIN believes that nephrologists must be paid for the prevention of CKD. Acute care dialysis in the hospital and long-term dialysis in the dialysis clinic is where a nephrologist generates most income, but from a public health perspective, CKD care should be supported. AIN loses money on its CKD practice, with difficulty meeting the expense of the nurse practitioner, dietitian, social worker, and others. The collaboration with Fresenius Medicare Care (FMC) CKD Services has been very helpful in improving patient care and achieving excellent outcomes in managing hypertension, anemia, and diabetes and improving GFR, more so than the financial balance sheet will justify. These results would not have been achievable without the help of a multidisciplinary team including nurse practitioners, dietitians, and social workers. The real test of the financial viability of the AIN CKD clinic will come when a planned expansion occurs. It remains to be seen whether the financial reward will outweigh the financial risk.

The policies of relevant private health insurers for AIN, including Blue Cross Blue Shield of Illinois, Humana, Cigna, Aetna, Unicare, and United Healthcare, are reasonable regarding physician services but highly restrictive for medication formularies. Illinois Medicaid is a reasonable payer as well, although there are long delays between billing and actual payment.

Lack of Coordination between PCP and Nephrologists. The emergence of CKD care has highlighted the need to establish new relationships between nephrologists and PCP, internists, cardiologists, and endocrinologists. This need has called forth two responses. The first consists of educational efforts of various sorts by nephrologists reaching out to their colleagues in other specialties, efforts that are driven by the needs of nephrologists in private practice. The second response involves education that is internal to the academic or group practice

within which nephrology services are being provided. Both responses, however, require nephrologists to reach out on the basis of a disease entity that is now defined in terms of degree of kidney function.

The new referral patterns that are required for CKD clinics and practices also call forth the need to define working “co-management” relations with other specialties. Crucial to co-management is the need for nephrologists to avoid the impression that they are stealing patients from referring physicians. Clearly, this area deserves continued attention, which could be helped by statements on CKD care developed jointly between the different specialty societies.

A creative approach to this area has been taken by Dr. Fishbane at Winthrop Hospital, who began to lecture across Long Island about CKD. “I lectured on the need for CKD care to primary care doctors. The lectures were 20 to 40 min, usually 20. The lectures and one-on-one visits dealt with the key points in CKD; the major focus was not over-relying on serum creatinine as an estimate of kidney function.”

Dr. Fishbane then teamed up with Dr. Lionel Mailloux, a nephrologist at the North Shore Hospital System, who had a strong educational interest. “We were more effective [as a team] in going to CME meetings,” Fishbane said. “We included a cardiologist. We covered a lot of Long Island. We would give 4 h of talks at dinners, lectures. I would discuss the value of nephrology intervention, and Lionel would talk about cardio-renal function.”

“We did a lot of outreach in 2000 to 2006 to primary care doctors,” Fishbane recalled; “this has been the most important thing we’ve done. I wrongly assumed the doctors would not be receptive, but the Long Island doctors were very receptive. Small decreases in kidney function have been acknowledged, leading to earlier referrals and/or changes in care.

Many CME lectures, for which there are evidenced-based guidelines, were industry sponsored. Many interventions for comorbidities in the later stages of CKD are not the biggest issue for primary care docs,” Fishbane noted. “I try to keep the focus on early CKD recognition and intervention.”

Long Island is famous for patients’ having eight different doctors, according to Fishbane. “The medicalization of people’s lives is extensive.” Consequently, the Winthrop nephrologists work hard on communication to the referring physicians. “We teach the fellows how to talk to the referring docs, how to write a good referral letter,” Fishbane said.

Fishbane articulated one of the major reasons for the extensive outreach efforts: “Cardiology has made tremendous strides in keeping people alive by cardiac interventions: CABG, stents, ACE inhibitors, *etc.*,” he said, “but at some cost, some congestive heart failure (CHF), some kidney disease. This has resulted in a huge change in nephrology in the last 10 yr. Consequently, so much depends on how well I work with the cardiologists. We engage in soft co-management, which requires good communication. The development of RHIO (regional health information organizations) will help. Half my Bethpage practice involves the co-management of CHF.”

Lack of Public and Patient Awareness and Concern Regarding the Risks Associated with CKD/Inadequate Recognition of Cardiovascular Disease and Complications of Decreased GFR as Patient Outcomes of CKD, Rather than ESRD the Only Complication. The risk factors for CKD, unlike blood sugar for patients with diabetes, high BP for many individuals, and elevated cholesterol for those at risk for coronary artery disease, are seldom understood or appreciated by patients. To the extent that these are more prevalent among minority populations, they intersect strongly with lower education and income. Consequently, nephrologists confront the need to educate individuals in at-risk communities about behaviors that can favorably influence the prevention of CKD.

The cases present two distinct strategies for patient outreach and education. The first relies on education of PCP to identify and refer at-risk individuals. The second involves community education: Articles in community newspapers, local television appearances, participation in church health fairs, and enlistment of hairdressers and barbers as first-line providers of information.

The Chicago-based CKD practice of AIN is built on extensive community outreach and educational efforts, which focus on prevention of kidney disease, heart disease, diabetes, and other conditions. Dr. Paul W. Crawford’s distinctive signature has been volunteer work through community organizations, especially black churches. Education of minorities has been in conjunction with the America Kidney Fund in Chicago, Washington, DC, and Atlanta. He was instrumental in founding the Church Based Hypertension Program of the American Heart Association, which initially screened for hypertension and later for urine, creatinine, and metabolic disorders. Through the American Heart Association’s national “Search Your Heart” outreach program, this effort has encouraged more comprehensive health ministries. He has also worked with the National Black Nurses Association, put on health fairs, and participated in the Kidney Mobile Van for Illinois program, sponsored by the NKF of Illinois. Frequent radio and television spots and interviews increase the reach of the practice to reach the community with education regarding AIN.

Part of CKD outreach focuses on other medical specialties. The primary referral source to the AIN CKD clinic is outpatient referrals from PCP. The CKD clinic has strengthened relations with those who refer to it. The focus is on PCP who continue to refer patients late, in stage 4 or 5 CKD. Significant barriers persist, in part caused by the nephrology community itself. PCP have reported that they have sent patients to nephrologists with early CKD, as indicated by NKF-K/DOQI guidelines, only to have the nephrologist question why they had sent the patient. The key is to get PCP and patients to understand CKD care as preventive nephrology, not pre-ESRD nephrology.⁴

⁴This case study is based on an extended site visit interview conducted on May 1, 2007, supplemented by later correspondence, and on a telephone survey interview conducted on April 12, 2006.

In general, relationships with medical subspecialists are better than with PCP. Bidirectional referrals may be an important component of this relationship, particularly with cardiologists. Endocrinologists, however, tend to be less aggressive with diabetes management in patients with CKD, and nephrologists are increasingly managing this important comorbidity.

Absence of a Coordinated System of Care that Includes a Delivery System that Will Reach All Patients with CKD.

The cases make clear that a good deal of care in CKD clinics and practices must be provided by nonphysician personnel—nurses, nurse practitioners, physician assistants—acting on the basis of guideline-based protocols. Consequently, it is necessary to disentangle the issues related to the reimbursement of such personnel, some of which stem from state-to-state policies unrelated to CKD care. The Northwestern CKD clinic and the outpatient dialysis unit are housed in a new building within the university's downtown Chicago campus, making all renal medical services—CKD, kidney transplantation, and dialysis—available within this academic complex.

In an issue of *Seminars in Nephrology* published in 2002, Ghossein *et al.* (15) described the Northwestern clinic organization as follows: “The pre-ESRD team was established with a staff of nephrologists, a physician assistant, nurses, a nutritionist, and access to renal social workers. Each member of the team focuses on different aspects of the comprehensive care with the main objectives being (1) treating the complications of CKD including anemia and renal osteodystrophy; (2) providing nutritional support; (3) identifying and managing comorbidities; (4) preparing for transplantation; and (5) preparing for dialysis.” An electronic medical record (EMR) was launched in 2004 and has been used to help track the established patients with CKD. The primary reason for referral to the clinic is for CKD education, management of a CKD complication, or overall renal care. Once the patient has been referred to the clinic, he or she is seen on a regular basis by the physician assistant.

Use of Information Technology. In 1991, the Institute of Medicine issued its first report on the computer-based patient record, which was updated in 1997 (16,17). What is remarkable is that EMR and information systems still appear in a rudimentary stage of development nearly two decades later. In the CKD world, information systems for ESRD are not adequate for an office-based CKD practice. The six cases reveal a wide divergence between sophisticated and developing systems, few comprehensive systems are on the market, and the economics of building and maintaining adequate systems have yet to be clarified.

At Mayo-Jacksonville, by contrast, the CKD clinic uses PowerNotes, a function of its EMR, which allows it to collect a set of relevant discrete, standardized data at each visit. In addition, all CKD clinic patients are entered into a database designed by Mayo Staff (StudyTrax), which allows the clinic to track outcomes such as mortality, hospitalizations, patient satisfaction, anemia, and BP control. The Nephrology PowerNotes were developed in late 2002. A templated visit note is incorporated into the medical record; patient data are imported directly from the EMR to the note, which

includes the various domains of CKD care: BP, hematology (hemoglobin, iron, ferritin), kidney function (the laboratory estimate of GFR), mineral metabolism, and nutrition. Follow-up is also part of the electronic system, which uses a “point and click” approach. Visit data can be documented very quickly, without transcription, and are immediately available. K/DOQI and RPA clinical practice guidelines are embedded in the CKD domains of the PowerNotes that provide reminders to address goals of care at the time of each visit. The database enables the group to follow the cohort of patients with CKD prospectively, aggregate and analyze data, and provide feedback reports on quality metrics. This information technology system facilitates systematic care, adherence to guideline-based checklists, and effective management of joint doctor–nurse relations.

Interactions with Large Dialysis Organizations. The dominance of ESRD care in the United States by generally for-profit, large dialysis organizations (LDO) creates an incentive for them to view CKD as a feeder stream to dialysis care. The incentive may be weak or nonexistent for them to view slowing progression to ESRD as in their corporate financial interest. This tension, a consequence of public policy, needs to be acknowledged realistically in efforts to respond to the new clinical opportunities afforded by emerging CKD care.

A major issue regarding CKD care involves the relation of a clinic or practice to the LDO. Indiana Medical Associates of Fort Wayne has been part of two LDO: From 1996 to 2006, it was affiliated with the Renal Care Group (RCG) followed by FMC subsequent to its purchase of RCG in April of 2006. RCG began the process of identifying practices that were involved in CKD care and with the help of Frank Maddux, MD, improved the CKD information system. FMC has embraced the CKD process and is encouraging practices to enhance and develop their CKD programs.

Conclusions

Finally, we asked each of the six groups to provide five key recommendations for improving CKD care that could be the focus of future public policy and clinical practice efforts. It is remarkable that in the 5 yr since the Chronic Kidney Disease Initiative was announced, only minor incremental progress has been made on these, and the current recommendations of the six case study programs that are included in this series are very similar to those made in 2003. The categories of recommendations are shown in Table 2, with more detail provided in each case study in the RAND monograph. In our view, now is the time that the renal community and all stakeholders should come together and address the clinical, financial, and public policy issues that will enable appropriate CKD care to be delivered to this vulnerable patient population.

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Table 2. Recommendations for improving CKD care, 2008^a

Recommendation	Key Strategies
Economic/reimbursement	<p>Improve reimbursement for office-based CKD care</p> <p>Eliminate financial disincentives for practicing preventive nephrology</p> <p>Reimburse a multidisciplinary team</p> <p>Find ways to finance CKD clinics that currently lose money</p> <p>Review reimbursement needs and adjust to pay services provided</p> <p>Amend E&M reimbursement to allow “modifiers” for management of comorbidities</p> <p>Direct public funding at federal, state, and local government levels to CKD in high-risk populations</p> <p>Create “empowerment zones” for long-term care</p>
Patient referral	<p>Improve the nephrologist–non-nephrologist interaction</p> <p>Modify standard of care to include earlier referral to a nephrologist who is active in preventing CKD progression</p> <p>Use hospital credentialing mechanisms or society certification to identify CKD-trained nephrologists</p>
Screening	<p>Require all government-sponsored health care systems to report eGFR</p> <p>Encourage all health insurers and health plans to reimburse eGFR</p>
Education	<p>Convey to patients and physicians that CKD can often be stabilized, even in advanced stages</p> <p>Reimburse for patient education</p> <p>Reimburse for end-of-life education</p>
Practice organization	<p>Improve integration of care across venues and domains of care</p> <p>Encourage provision of care in a CKD clinic with a multidisciplinary team</p> <p>Encourage/require the CKD clinic to provide comprehensive care</p> <p>Develop an organized process that has buy-in from all</p>
Use of clinical practice guidelines	<p>Embrace K/DOQI guidelines, which have made management easier and more uniform</p> <p>Use guidelines to provide consistent care</p>
Need for IT	<p>Obtain and maintain an electronic record for ready use</p> <p>Collect, analyze, and use data to understand and improve practice outcomes</p>
Nephrologist accountability	<p>Promote a sense of responsibility among nephrologists to improve and participate in CKD care before initiation of dialysis</p> <p>Encourage nephrologists to become more accessible and available</p> <p>Require accountability for outcomes by nephrologists, and encourage nephrologists to embrace accountability</p>
Research	<p>Promote health services research to improve outcomes</p> <p>Promote translational research that tangibly links basic science studies and clinical trials to cost-effective relevance for CKD care</p>

^aeGFR, estimated GFR; E&M, evaluation and management; IT, information technology.

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Disclosures

Dr. Nissenson has recently assumed the role of Chief Medical Officer, DaVita Inc.

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