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National Kidney Disease Education Program

THOMAS H. HOSTETTER and MIMI LISING
National Kidney Disease Education Program, National Institutes of Health, Bethesda, Maryland.

Abstract. The National Kidney Disease Education Program (NDKEP) is a program of the National Institute of Diabetes and Digestive and Kidney Diseases at the National Institutes of Health. It seeks to increase awareness of CKD among high risk groups and primary care providers. The NKDEP is a response to the rapidly escalating incidence of ESRD in the United States in the face of new treatment to prevent and mitigate CKD. The hope is that awareness will lead to action, testing, and treatment.

The impetus for a National Kidney Disease Education Program (NDKEP) derives from three observations. First, the number of people with ESRD is increasing such that it now represents a significant public health burden. Second, clinically valid approaches for detecting, preventing, and slowing the progression to ESRD are widely available. Third, these approaches are sparsely used in practice.

In 2000, approximately 100,000 people were projected to develop ESRD. Adding these people to the prevalent ESRD population yielded a total of about 380,000. Of these, approximately 80,000 were alive with a functioning renal transplant; the remainder were on dialysis. The number of people developing ESRD has doubled each decade for the last two decades with annual increases of 6 to 8%. The projections suggest that over 600,000 people will have ESRD by the year 2010. Because transplantation rates have remained plateaued at around 13,000/yr, the projected 175,000 people developing ESRD in 2010 will essentially all be maintained on one form of dialysis or another (1). Currently, the incidence of ESRD exceeds the death rate from any cancer except lung cancer. Furthermore, with annual mortality for patients on dialysis in the range of 20%, more people die with treated uremia than with any cancer, except for lung cancer. If current trends continue, by 2010, the toll of ESRD will exceed that of lung cancer (2).

This burden of disease is paralleled by the enormous cost for delivering ESRD care. The total costs of treating people for ESRD in 1999 were $17.9 billion. This figure includes not only the cost of dialysis, or transplant care, but also the associated medical expenditures incurred by this large patient group. Furthermore, the Centers for Medicare and Medicaid Services (CMS) expends approximately 6% of its entire budget on reimbursements for people with ESRD, whereas those people represent less than 1% of the CMS beneficiaries. For comparison, the total cost of caring for the ESRD population in 1999 was $17.9 billion dollars, whereas the total budget for the entire National Institutes of Health (NIH) that year was $15.6 billion. By almost any measure the load of ESRD is staggering (1). Moreover, it is increasing at a rapid rate such that if these trends persist, the human and financial toll will be overwhelming in the next decade.

Effective therapeutic approaches exist which could in some cases prevent ESRD, and in many others, slow its progression. The diseases largely contributing to the ESRD populations are diabetes, mainly type 2 diabetes, and hypertension. Type 2 diabetes seems to be preventable in a large segment of the population at risk (3). Furthermore, the microvascular complications of diabetes for both type 1 and type 2 can be mitigated by careful glycemic therapy (4,5). Although substantial data are lacking, prevention of ESRD due to hypertension is likely also possible, simply by observing current guidelines for the care of primary hypertension. However, most patients destined for ESRD are not detected until kidney damage appears. Indeed, in many cases the disease is at a very advanced phase. Even with clinically detectable injury, effective approaches exist. For example, in recent trials of angiotensin receptor blocker therapy in overtly proteinuric patients with type 2 diabetes who had already lost about 50% of renal function, ESRD was delayed by approximately 2 yr (6). More benefits could be expected at early phases of the disease.

Over the last decade, multiple studies have demonstrated benefits of BP control in patients with kidney disease of both type 2 and type 1 diabetes (6). Treatment of such patients with angiotensin-converting enzyme (ACE) inhibitors and angiotensin receptor blockers (ARB) slows the progression of their disease. The same has been shown for other progressive renal diseases including hypertensive nephrosclerosis (7). Although the exact levels of BP required to achieve optimal results have been less clear than the value of ACE inhibitors and ARB, a consensus has developed that targets less than the standard 140/90 mmHg are desirable in these patients. Furthermore, assiduous glycemic control blunts the advance of renal complications in patients who already have evidence of kidney damage due to diabetes (4). The value of dietary protein restriction has been confirmed in several meta-analyses of trials using this dietary manipulation (8). Of note, education for

Correspondence to Dr. Thomas H. Hostetter, National Institute of Diabetes and Digestive and Kidney Diseases, NIH, 6707 Democracy Blvd., MSC 5458, Bethesda, MD 20892-5458. Phone: 301-594-8864; Fax: 301-480-3510; E-mail: HostetterT@extra.niddk.nih.gov

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diabetes and nutritional counseling for renal insufficiency are reimbursed by Medicare. Unfortunately, none of these therapies can reverse established renal disease. However, delaying the onset of ESRD is clearly worthwhile. Cost-effective analyses support the economic desirability of early therapy (9). Furthermore, ACE inhibition and BP control will likely preserve other aspects of cardiovascular health. Thus, we do have treatment regimens that are safe, relatively simple, and if not perfect, quite effective.

The clinical delivery of the known therapy for preventing or slowing progression of ESRD is sadly inadequate. Many patients who fall into the high risk groups of hypertension, diabetes, or families of people with ESRD do not undergo simple screening with serum creatinine properly interpreted, and urine protein assessments. More distressing are the data that patients who have had these tests are often not prescribed the cardinal components of the accepted therapeutic regimen. For example, only about one-third of diabetic patients discharged from hospitals who had proteinuria or elevated serum creatinine were placed on ACE inhibitors (9). An even smaller percentage of those who had hypertension and evidence of renal damage were discharged with prescriptions for ACE inhibitors.

Recognizing the magnitude of the problem, the availability of therapy, and deficiency of its use, the Council of American Kidney Societies commissioned a feasibility study for a kidney disease education program in 1999. The report suggested that the current situation would profit by such a federally supported effort. A meeting of experts in public health and kidney disease convened at the campus of the NIH in the summer of 2000 and ratified the value of an education program. They emphasized that it should be patient and primary care provider oriented. In the winter of 2000 to 2001, a director and associate director to the program were appointed. Meetings held during 2001 surveyed the situation with regard to professional performance in treating progressive renal disease, and the methods for routine and populations at high risk for ESRD. A large public meeting convened in Bethesda in June 2001 and developed a strategic plan. The first meeting of the Steering Committee of the NKDEP took place in September 2001. The Steering Committee comprises approximately 25 representatives of organizations interested in the problem. Industries with products and services for patients with CKD met at another meeting in the fall of 2001 and provided advice and expertise to the program's planning.

The strategic plan calls for activation of people at high risk to seek testing and treatment. Those at risk include people with diabetes, hypertension, or close relatives of these with ESRD. The risks in these categories are markedly amplified in African-American, Native-American, and Hispanic groups. Thus, the strategic plan emphasizes targeting these medical conditions within those communities. Second, the strategic plan calls for developing messages for primary care providers. The number of people with substantial kidney impairment and/or persistent proteinuria approaches 20 million individuals. The magnitude of this population requires that primary care providers be engaged in addressing this problem. Thus, development of straightforward targets for therapy and screening are a goal of the NKDEP.

Currently, three working groups have been organized to address components of the strategic plan. First, a group composed of experts in nephrology, primary care, and laboratory medicine will develop simple goals for BP therapy and laboratory screening for kidney disease. It is anticipated that these targets will distill guidelines and evidence-based efforts of multiple other organizations, including the National Kidney Foundation, the Joint National Commission on Hypertension, and the American Diabetes Association. The second working group, comprising people in organizations engaged in health education, particularly for African Americans, have begun to lay out a pilot program for public awareness. These pilot programs will target African Americans at risk for kidney disease in four areas of the country—Baltimore, Atlanta, Cleveland, and Jackson. The third working group is charged with evaluating the efficacy of these pilot programs.

As the messages for the public and providers develop, and are brought forward and evaluated, ever broader national application will follow. A key element in the success of the program will be collaboration with groups already interested in the progression of kidney disease, including nonprofit professional organizations as well as a number of industry partners whose businesses focus on this patient population. Furthermore, continuing collaboration with other education programs such as those at the NIH, will be essential in gaining maximal advantage from the NKDEP.

The problem with progressive kidney disease is a large and increasing one. CKD progresses to ESRD over many years and millions are now moving along this path. Hence, the most important effect of this program—to reduce the incidence of ESRD—will not come quickly. However, the success over the last 25 yr in reducing mortality from cardiovascular disease gives hope that a silent killer can be subdued (10).

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