

The Critical Renal Challenge: Finding Godot, Not Waiting for Him: Screening, Early Detection and Treatment of Precursors of Chronic Kidney Disease

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U.S. demographic, social and medical trends are converging and threaten to reach a crescendo in the incidence and prevalence of chronic kidney disease (CKD), particularly affecting those in the later years of life. Government and medical resources are ill prepared to deal with the implications of this phenomenon and demographic population changes. It is imperative that existing programs be expanded and new approaches be developed to intervene earlier in the disease processes that precede CKD. Early childhood education, early screening and treatment of chronic conditions and more effective interventions in minority communities are critically needed. Waiting for kidneys to fail is not an option; there is no choice but to intervene sooner and better than ever before.

INTRODUCTION

A literary reference to Samuel Beckett's *Waiting for Godot* (1954) is particularly appropriate to our global kidney community. In many arenas, and in the not so distant past, professionals, patients and families were frozen in a seemingly passive role as renal disease progressed to the point that kidneys failed and either dialysis or transplant was needed.

Over time, however, state programs, voluntary agencies and treatment facilities have made significant strides in pre-dialysis education, care and planning. These have included the development of a wide range of printed and video educational materials and stage 5 chronic kidney disease (CKD) educational meetings for patients and family members. Programs such as the First Things First seminar at the Washington University Renal Clinic address the education and care needs of early-stage kidney patients, some of whom will never reach stage 5. However, despite increasing efforts to provide optimal care and planning, including early access placement for pre-dialysis patients, findings from the Dialysis Outcome and Practice Patterns Study demonstrate that only 54% of patients have a permanent access in place to initiate dialysis (Pisoni et al., 2002). It is clear that new perspectives and new initiatives are needed in the full continuum of care, from identifying individuals at risk for renal disease to comprehensive and timely planning for patients approaching kidney failure. Indeed, it is the position of this paper that the clinical approach must be significantly more proactive in the process of earlier detection, education and intervention into the diseases that lead to CKD. Godot must be found!

Community screening programs for many conditions (e.g., hypertension, sickle cell disease and diabetes) have been in place for decades. The goal of these programs was the early identification of various conditions so that individuals might pursue care and treatment. Programs have been conducted in such arenas as

workplaces, schools, churches and community health fairs. In early programs, links to care providers and follow-up to determine if these health problems were being effectively treated were often missing. Consequently, medical conditions requiring control and treatment—and the possibility of preventing medical complications—were not comprehensively addressed.

A Kidney Disease Outcomes Quality Initiative practice guideline recommends that individuals found at increased risk for CKD should be further evaluated and those who have CKD should be treated (National Kidney Foundation [NKF], 2002). Following screening with intervention as necessary implies that patients will need to be educated about their treatment and care.

LITERATURE AND DATA REVIEW

Data trends demonstrate a significant increase over time in the incidence of reported End Stage Renal Disease (ESRD) cases (U.S. Renal Data System [USRDS], 2006). Between 1993 and 2003, the yearly incidence increased from a total of 64,492 patients in 1993 to 87,121 patients in 1998, and to 102,567 patients in 2003 (USRDS, 2006).

Particularly striking is the increase in incidence of ESRD patients over the age of 75: there were 11,335 in 1993, 19,432 in 1998 and that population cohort increased to 26,292 by 2003 (USRDS, 2006). This increasing incidence reflects the changing demographics of the United States as a whole. Average life expectancy is increasing dramatically and in some states, the age cohort of 85 years and over is one of the largest growing cohorts in the population pyramid.

The U.S. Census Bureau projects that between 2000 and 2050, not only will the population grow, but also the population will age. Looking only at the 65 to 84 U.S. age cohort alone, the growth is in the magnitude of 30,794,000 (2000) to 65,844,000 (2050). Perhaps most striking is the growth of the 85+ cohort, which

increases from 4,267,000 (2000) to 20,861,000 (2050); (U.S. Census Bureau, 2004). Because we recognize the age-loading characteristic of CKD, the implications are clear: kidney failure in the overall population will continue to increase and possibly accelerate.

Continuing the analysis by the use of percentages instead of actual numbers more clearly illustrates the phenomenon. A striking comparison between 2000 and 2050 is the proportion of the population over the age of 65: 12.4% in 2000 versus 20.7% in 2050. One-fifth of the U.S. total population will be over age 65 by 2050 (U.S. Census Bureau, 2004). USRDS and U.S. census data agree that as America's population grows and ages, it will be in lockstep with the increase in the societal burden of ESRD.

To scientifically examine reasons for these increases, we must address the precursor co-morbidities that result in eventual kidney failure, and the population groups that are disparately affected by these processes. Diabetes and hypertension continue to be predominant etiologies for the development of stage 5 CKD, accounting for 73,649 patients in 2003, or approximately 72% of the total incidence; diabetes alone accounted for 43% of the incident cases in that year (USRDS, 2006).

USRDS data demonstrate that the incidence of reported ESRD is particularly high in the African American population. In 2003, 29% of the total 102,567 incident cases were African American. Because the African American population accounts for approximately 11 to 12% of the total population, this disproportionate burden (a factor of 2.4) of serious chronic illness is dramatic. Also remarkable is that 13% of the incident cases in 2003 are Hispanic. Although anecdotal reports over the past year or so indicate that incidence rates in general have leveled out somewhat, we are left with the reality that more patients present themselves for ESRD and CKD care every year (USRDS, 2006).

More males than females experience ESRD, and the 2003 data show a 54 to 46% male–female split. One bright statistic demographically is that the age cohort 0 to 19 years of age shows only a 22% increase from 1993 to 2003, numbering 1,093 cases in 1993 to 1,337 in 2003. This compares to the 232% increase in the 75+ age cohort over the same time frame (USRDS, 2006).

Evidence of the burden of these diseases is clear. In Missouri, for example, emergency room (ER) visits for hypertension and diabetes, comparing Caucasians to African Americans, are illustrative. For essential hypertension, Caucasians made 1.1 ER visits per 1,000 population compared to 4.5 ER visits per 1,000 population

for African Americans. A similar discrepancy occurs for patients who have diabetes with complications: 0.7 visits per 1,000 population for Caucasians and 2.9 visits per 1,000 population for African Americans (Reed, 2004). Granted, a portion of this racial ER visit disparity may be due to the different incidence of these chronic illnesses in the minority populations, but contributing factors may also be found in differential access to primary health care and differential economic capabilities to buy healthful food and needed medications.

Illustrating the epidemiology of ESRD among African Americans, Martins et al. (2002, p. 1) noted that

although disparities and outcomes among African Americans compared to whites with respect to cardiovascular disease, cancer, diabetes, infant mortality, and other health standards have been well described, these disparities are most dramatic with respect with kidney diseases.

ESRD for African Americans occurs at approximately four times the rate of Caucasians (National Kidney Disease Education Program, 2005). Health practitioners may find it harder to achieve blood pressure control in African American patients and different combinations of medications may be required. Interplay of many factors, including environmental, genetic and economic, contributes to the racial incidence differences in both CKD and ESRD, and a complete understanding is not known at this time. Not only do African Americans have a higher incidence of diabetes than Caucasians, diabetes and hypertension together in the same patient take a higher toll on renal functioning than just one disease by itself. Wright et al. pointed out that “African Americans are six times more likely to develop ESRD from hypertension than whites” (2002, p. 2421).

States vary in terms of their epidemiologic surveillance of chronic conditions. In Missouri, health disparities are followed not only by state offices but by projects funded by the Missouri Foundation for Health. In Missouri from 1998 to 2002, death rates from diabetes were 23.2% per 100,000 for Caucasians (as reflected on death certificates) compared to 35.1% per 100,000 in the Hispanic population, while the death rate for African Americans was 49.9% per 100,000 (Reed, 2004).

For now, we need to focus on what can be done with tools at hand. We must focus on better use of pharmacological agents and better control of blood sugar levels and strive to provide better and more consistent primary health care access.

Crossing clinical lines on an important issue, a small study (103 subjects) in the VA Health System

reported that African Americans rated their physicians as less communicative and consequently less trustworthy (Gordon et al., 2006).

Finally, an important factor in this phenomenon of diabetes, hypertension and CKD is the epidemic of obesity. Jeffrey Koplan, former Director of the Centers for Disease Control and Prevention (CDC), stated that “obesity is as dramatic as anything I’ve seen in public health. It is the health problem of the 21st century” (NKF of Kansas and Western Missouri, 2006). Efforts to reduce obesity should include both adults and children.

Consider obesity rankings for the state of Missouri as an example. Missouri does not rank well. The national average for overweight children ages 10 to 17 is 15%, and while Missouri’s rank of 16% is only 1% higher, only 9 states have more than 16% obese children (Henry J. Kaiser Family Foundation, 2003). Missouri’s adults fare no better; Missourians 18 and over have an obesity rate of 24.9%, which is slightly higher than the U.S. rate of 23.2% (Hitti, 2005). Stated another way, one-fourth of adult Missourians are obese.

The CDC defines childhood obesity as the term used to refer to children and youth between the ages of 2 and 18 years who have body mass indexes (BMIs) equal to or greater than the 95th percentile of the age- and gender-specific BMI chart (Missouri Department of Health and Senior Services, 2005). Nationwide, more than 9 million children over 6 years of age are classified as obese while many millions more are overweight and at risk for becoming obese if they or their parents do not aggressively change their lifestyles (NKF of Kansas and Western Missouri, 2006). In a population-based study, approximately 60% of obese children 5 to 10 years old had at least one cardiovascular disease risk factor (e.g., elevated total cholesterol, triglycerides, insulin or blood pressure), while 25% had two or more risk factors (NKF of Kansas and Western Missouri, 2006).

Unless the current epidemic of obesity in the United States is dramatically altered, a resulting epidemic of kidney disease must be anticipated. Therefore, preventing obesity can be expected to reduce, among other conditions, the potential of kidney disease. Obesity, diabetes, high blood pressure and the early onset of these factors in childhood further stress the need for early interventional approaches, rather than passively “waiting for Godot.”

In summary, this review clearly indicates that the incidence of ESRD is increasing dramatically over time, the U.S. population is aging markedly and the looming entry of the baby boomer cohort on the health care sys-

tem will be significant. In addition, CKD and its precursor diseases, diabetes and hypertension, are significantly more frequent in African Americans and Hispanics than Caucasians. For example, in Missouri, death rates from diabetes alone are double in African Americans than Caucasians, with Hispanics in between; there are multifactorial aspects to the disparate rate of incidence in minority populations and the confounding influence of obesity makes the problem worse. Finally, as in our earlier example of African Americans’ and physicians’ communication, there are indications that the health care system does not serve minority populations as well or as efficiently as it does the Caucasian population. Given these data and demographic characteristics, we are faced with daunting challenges for the future, as more citizens live longer lives with increasing numbers of related chronic medical conditions. The remainder of this article explores different approaches in addressing these trends, current interventional programs and suggestions for further interventions.

BACKGROUND ON INTERVENTION APPROACHES

In recent years, various programs for patients at risk for CKD have been developed. These programs, often funded by state and volunteer agencies, have attempted to not only screen individuals but also follow up with them to encourage and facilitate medical intervention. One of the early programs in the 1980s, entitled “Community Screening and Intervention for Type II Diabetics at Risk for Renal Disease,” was funded by the Missouri Kidney Program. The goal of this program was to link community health clinic diabetic patients, as identified with microalbuminuria, with renal specialists at a major university medical center.

More recently, the NKF developed the Kidney Early Evaluation Program (KEEP) Program (2005), a national community-based program to identify patients with risk factors for CKD. The Missouri Kidney Program has also funded a screening and follow-up program. Both of these ongoing programs are described in the following paragraphs.

Identifying individuals at risk for CKD and referring them to care providers is an extremely important issue. Controlling conditions such as hypertension and diabetes early in their course holds the promise of preventing or delaying complications, including CKD. Identifying patients with early CKD and securing specialty care with nephrologists, in turn, allows for intervention and, if needed, timely planning for later stages of CKD and dialytic and/or kidney transplant planning.

Waterman and Whitlock (2003) collaborated with the Missouri Kidney Program to analyze data obtained from a major study funded by a CDC Reach 2010 grant. This grant afforded a statewide analysis of members of select minority and majority communities within the state to analyze knowledge and attitudes regarding diabetes and organ donation.

Research modalities included telephone surveys and in-person focus interviews in target communities around the state. It was felt that the degree and quality of input from the participants was quite high. One overall conclusion was that Caucasians, African Americans and Hispanics differ in their knowledge and attitudes about diabetes and organ donation. There is no doubt that sensitivity to the differences and needs of these communities is essential to increase knowledge, improve attitudes and promote healthy behaviors. Tailored health education directed at correcting misinformation must be accessible to minority communities and must be expressed in culturally competent ways. The study concluded that future research should focus on learning more about the socioeconomic differences within and between racial communities that affect the groups' perception of diabetes and kidney disease. In addition, significant education must be targeted to young people, as they have a better chance of learning positive habits early, whereas older people have more difficulty changing unhealthy diets and lifestyle habits.

Partial findings concluded that, compared with Caucasians, African Americans and Hispanics agreed that they needed more education about diabetes in their home communities. They tended to have less understanding of the relationships between smoking, exercise and diabetes, or that dialysis and kidney failure could be complications of diabetes. There was also less understanding that complications of diabetes could be preventable.

Patients' willingness to donate organs across racial groups was high. Eighty-nine percent of respondents reported they would consider donating one of their kidneys to a family member. However, African Americans were less likely to donate their organs when they died or through living donation as compared to Caucasians (Waterman & Whitlock, 2003).

The national KEEP project, mentioned earlier, is sponsored by the NKF. Entry criteria for inclusion in the project included a known history of diabetes or hypertension, or a family history of diabetes, hypertension or kidney disease. KEEP's initial program, surveying 900 individuals in 21 cities, showed that CKD was more

common than anticipated (NKF, 2005). By 2005, 37,155 individuals had met the criteria and were included in the report.

Significant results included that 52% of participants reported hypertension, 16% reported cardiovascular disease and 25% (versus 6.4% in the general population) reported diabetes. This extensive report noted that obesity is a common problem in those screened (NKF, 2005).

Another example of a screening program is the Early Intervention Program, in operation since 2001 (NKF, 2005). Conceptualized and run by the NKF of Kansas and Western Missouri, and partially funded by the Missouri Kidney Program, the Early Intervention Project has screened more than 9,700 total subjects. Data have been collected on these subjects and analysis is currently in progress.

Methodologically, outreach efforts are made through health, community, church and workplace groups in Western Missouri, Kansas City, and to a lesser extent, Southwest Missouri. A team works with persons who desire screening to measure blood pressure, microalbuminuria and glucose levels and results are reported on-site to the participants.

Preliminary analysis of the data indicates that, consistently, 51 to 53% of the 9,700+ patients screened possess one or more high-risk factors for developing kidney disease. This rate is similar to some of the KEEP results and reinforces the incidence and prevalence of these chronic health problems in the general population and particularly in minority communities. To the extent that these risk factors are generally detected in persons who were unaware of their health status prior to the screening should be of special concern to professionals in the renal community. An integral part of this program is a referral and follow-up process that encourages patients to follow up with health care providers and then monitor by telephone their actual performance in receiving the recommended health care.

In this ongoing project, increased efforts will be concentrated on extended program expansion into Southwest Missouri, especially in light of the growing concentrations of Hispanics and African Americans in that area.

Another important intervention program has begun in the Kansas City area, conceived and sponsored by the NKF of Kansas and Western Missouri (2006). Echoing the findings from the Reach 2010 project (CDC, 2007), the focus in the Kansas City program is on the issue of childhood obesity via a program called KID POWER.

The program was developed through collaboration among local public and private medical, social and educational institutions. Because of the connections among kidney disease, high blood pressure and diabetes, the program uses a two-pronged educational and motivational approach to decrease childhood obesity. In addition to continuing medical educational courses for primary care providers on the assessment and treatment of childhood obesity, the KID POWER program focuses on healthy nutrition and activity challenges for children 8 to 13, popularly referred to as “tweens.”

KID POWER is a motivational program that educates tweens on the benefits of healthy lifestyles. The overall goal of KID POWER is to develop and maintain healthy nutrition and activity habits in tweens with the ultimate aim of reducing the incidence of the 2 major causes of preventable kidney disease, high blood pressure and type 2 diabetes.

KID POWER consists of 3 main components:

1. A calendar
2. The curriculum
3. Training and coordination of site directors.

This approach is also designed to ensure that parents or guardians of the young participants understand and continue to reinforce the basics of the program, via an adult module that is provided as a part of the “graduation ceremony” at the end of each session. The nutrition course was designed by a registered dietitian who specializes in working with children. KID POWER combines culturally-sensitive nutritional education, physical activities, cooking classes and incentives that increase potential for nutritional and lifestyle modification. Recipes, snack and meal preparation ideas incorporate lower-calorie versions of culturally-appropriate foods that the children’s families are accustomed to eating. By spring 2006, 19 sites were serving 918 tweens participating in KID POWER. Of the participants, 56% were male and 44% female. The average age was 10.9 years. All but 2 of the 19 sites hosted parties with healthy snack demonstrations. The curriculum materials include colorful newspaper-type publications and much effort is made to disseminate these in area public school settings to try and focus increased attention on healthy behaviors (NKF of Kansas and Western Missouri, 2006).

In terms of program outcomes, tween participation in nutrition and physical activity behavior is measured by a self-report tool called Check Your Health. This 13-item questionnaire assesses behaviors directly addressed by the curriculum such as eating 5 fruits and vegetables per day, spending at least 1 hour a day in motion,

eating breakfast and watching less television. Participants complete this questionnaire at the beginning and at the end of the 12-week program. The results indicated a statistically significant improvement in nutrition and physical activity.

Tween participants in selected sites underwent additional measures of nutrition and physical activity behavior at the beginning and end of the 12-week program. These measures included a 24-hour dietary recall, heart rate monitoring during moderate physical activity and the PACE + physical activity questionnaire as used by the KID POWER program. The results of the dietary recall were difficult to interpret due to many incomplete records, but indicated that sugar drinks should be a focus of increased education for subsequent KID POWER challenges. The results of the heart rate monitoring suggested improved physical fitness in KID POWER participants by the end of 12 weeks and the results of the PACE + indicated that participants were being physically active for an hour longer more days a week at the end of period than at the beginning.

Finally we will discuss a 6-state program, Care Improvement Plus, that is developing innovative team approaches to dealing with selective chronic diseases and conditions, which offers specialized care for Medicare beneficiaries (Care Improvement Plus, 2006). This new approach is designed to comprehensively cover individuals living with diabetes, heart failure and ESRD. Essentially, it combines traditional Medicare Parts A, B and D coverages, using a case management model. Traditionally, health plans and insurance companies have focused their efforts on helping members with health problems after they arise. These new specialized care plans take a more preventive approach and use disease management technologies and other services to attempt to prevent further health deterioration.

Research has shown that disease management can help improve health outcomes such as:

- A reduction in blood pressure can reduce heart attacks, strokes and deaths from cardiovascular disease.
- Improving blood sugar control of people with diabetes reduces their risk of developing complications such as eye, kidney and nerve disease.
- Regular eye exams and timely treatment can prevent diabetes-related blindness.
- Regular foot examinations and monitoring can prevent diabetes-related amputation (Care Improvement Plus, 2006).

Health care industry experts recognize the potential for these specialized care plans and other disease management-focused initiatives to address the looming

Medicare budget crisis. As documented earlier in this paper, with the aging of the American population, the first cohort of the baby boomers will become eligible for Medicare in 2011. It is predicted that their medical costs will completely overwhelm federal and state budgets (Care Improvement Plus, 2006). Medicare leaders hope that offering plans specifically geared toward meeting the needs of people with chronic health problems will lead to better health outcomes for those people and lower costs for the health care system overall.

Nonetheless, it is important to acknowledge that while this is positive for Medicare beneficiaries, these beneficiaries have Medicare coverage either because of severely impaired health status prior to 65 or the attainment of age 65. By that time, the ravages of chronic disease have begun or have taken their toll on the individual patient.

Therefore, our culture must develop the same kind of disease management and specialized care programs for younger populations. Echoing the sentiments in earlier sections of this article, we must follow the lead of innovative programs such as Care Improvement Plus and experiment with this team-based model in younger patients with chronic care conditions in those stages in their lives where we can still impact and prevent the serious health consequences of diabetes, hypertension and obesity.

In summary, innovative programs are being undertaken at national, state and local levels. KEEP and the Early Identification Programs are examples of efforts aimed primarily at adults with the primary focus of early detection and referral for treatment of high-risk factors. A salient point is that a significant number of those screened are found to have health conditions of which they were not aware. Hopefully, with early intervention combined with follow-up, progression of kidney disease or loss of kidney function can be positively affected.

In addition, agreeing with research findings, particularly in minority communities, it is apparent that interventions into the lives of young people can be effective. Other evidence-based ideas include finding ways to interface with Parents As Teachers and Head Start programs to see if diet, exercise and lifestyle education can be made part of these early educational programs.

IMPLICATIONS FOR FUTURE PLANNING

It is expected that findings from the Reach 2010 project discussed earlier will be further confirmed in the Kansas City Early Intervention Project. Research strongly sup-

ports the view that education focusing on how people with diabetes should care for themselves, especially stressing the importance of not smoking and getting regular exercise is needed, particularly in minority communities. Focus groups with minority populations in our state revealed that school-based interventions using culturally-sensitive education may offer the best opportunity to devise effective educational strategies. Education about the need for organs in the African American and Hispanic communities is necessary to promote transplantation. Providing additional information in a culturally-sensitive fashion to dispel myths about organ donation may also ease the anxiety people may feel about donating their organs. The need for continuing screening, referral and follow-up is obviously critical, particularly in communities where access to health care is limited. Disease management and team-based care delivery systems in younger populations to better manage patients with obesity, diabetes and hypertension may also help to prevent serious complications and CKD.

CONCLUSION AND IMPLICATIONS FOR PRACTICE

Social workers and the rest of the treatment team have to come to a philosophic understanding that we have to turn our attention to the early detection and treatment of the diseases that underlie CKD. While there is general understanding that the incidence and prevalence of diabetes, hypertension and obesity is significant in the general population, it is even more pronounced in minority communities. Unfortunately, financial or insurance resources to provide early detection services are simply not available at this point in time, nor is the general medical community attuned or organized to deliver comprehensive care to these chronic conditions for patients in all life stages.

Some conclusions are obvious:

1. Education about health, diet and staying fit has to start early in life and become integrated into our early childhood educational system.
2. Screening, referral and education have to become more commonplace.
3. Cultural competency has to become more prevalent if we are to address the special health concerns of our growing minority communities.
4. We have to become involved in the health policy processes of our local, state and national governments to promote adequate funding for early detection and early treatment.

5. We have to become more evidence- and outcomes-based in our everyday professional lives so we can prove what we know from clinical practice.
6. We have to build intellectual bridges with all health professions to shift our collective thinking away from “waiting for kidneys to fail” to strategies for intervention and prevention, particularly with regard to diabetes, hypertension and obesity.
7. We have to become involved with organizations, such as the American Diabetes Association, that focus on precursor diseases.
8. We have to urge state and national policy makers to devise a social/health policy that aggressively uses techniques, such as disease management strategies, if we are to effectively tie care plans together, and use the strength of multidisciplinary teams to effectively serve patients with chronic conditions, particularly in the younger age cohorts.

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