

**AFRICAN AMERICANS' KNOWLEDGE AND BEHAVIOR REGARDING EARLY
DETECTION OF KIDNEY DISEASE**

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ABSTRACT

Background: Kidney disease is an African American public health crisis. The National Kidney Disease Education Program conducted the first survey of African Americans about their knowledge and behaviors related to kidney disease to inform interventions that can address this phenomenon. ***Methods:*** Using random-digit dialing, 2,039 African Americans were surveyed from seven states (GA, MD, OH, MS, LA, MO, TN). ***Results:*** Even though almost half (43.7%) of the African Americans surveyed had a risk factor for kidney disease, only 2.8% reported that kidney disease was a top health concern for them. Less than half of surveyed respondents knew the correct definition of kidney disease (48.6%), knew a test to diagnose kidney disease (39.5%), or knew that African Americans were at higher risk for kidney disease (18.1%). Less than 15% mentioned that kidney disease could be a negative consequence of unmanaged diabetes (13.6%), hypertension (12.1%), or a family history of kidney disease (2.4%). African Americans who were objectively at risk for kidney disease did not always perceive themselves to be at higher risk: 75% of African Americans with risk factors for kidney disease did not perceive themselves to be at higher risk. ***Conclusion:*** This study indicates that kidney disease is not currently perceived as an important health problem for African Americans, that they may not understand fundamental information about kidney disease, and that they are not taking action to prevent kidney disease. These are important findings to consider in planning kidney disease outreach and screening initiatives.

Index words: African American, kidney disease, knowledge, risk factors, hypertension, diabetes, family history

INTRODUCTION

The impact of chronic kidney disease (CKD) and End Stage Renal Disease (ESRD) in the African American community is significant. Life expectancy for African American male ESRD patients is worse than that of African-American colorectal and prostate cancer patients, and for African American females, ESRD has about the same life expectancy as breast cancer.¹ African Americans are 4.2 times more likely than Caucasians to develop ESRD,² and are also more likely to have the primary risk factors for CKD: hypertension, diabetes, and a family history of kidney disease.^{3,4} Researchers agree that African Americans with diabetes, hypertension or a family history of kidney disease should be screened for kidney disease.⁴⁻⁸

The National Kidney Disease Education Program (NKDEP) of the National Institutes of Health was created to increase awareness, detection and treatment of CKD, especially in the African American community. The NKDEP conducted the first large study of African Americans to explore their knowledge and awareness about kidney disease and its risk factors, in order to inform current efforts at helping this population, such as community outreach and screenings. Screenings for kidney disease are increasing nationally, and show promise in identifying individuals with kidney disease and referring such persons for medical care.⁹ This project compliments previous work and can inform future work about kidney disease prevalence using the National Health and Nutrition Examination Surveys,^{10,11} and the work of the African American Study of Kidney Disease and Hypertension.⁸

This study differs from previous research in its unique focus on African American knowledge, attitudes and behaviors related to kidney disease and its risk factors such as diabetes, hypertension and a family history of kidney disease. No large study focusing on these variables has been previously conducted related to kidney disease with this population most at-risk for the

illness. Understanding these factors is important, as knowledge and awareness have been shown to increase the likelihood of health screening participation.^{12,13} Therefore, our study of 2039 African Americans from seven states examined: (1) whether kidney disease is an important health problem for African Americans, (2) whether African Americans understand fundamental information about kidney disease, (3) and whether they are taking action, including getting tested yearly, to learn about and prevent kidney disease.

METHODS

Study Design and Population. Our study used a cross-sectional survey design to ensure a random selection of African American respondents in seven US cities: Atlanta, Georgia; Baltimore, Maryland; Cleveland, Ohio; Jackson, Mississippi; New Orleans, Louisiana; St. Louis, Missouri; and Memphis, Tennessee. These cities were chosen as study sites because of their high proportions of African Americans and for similar demographic characteristics.

Survey Development. The 31-question survey was developed by the NKDEP Evaluation Group, and included questions on respondents' perceptions of the most serious health problems affecting African Americans, their knowledge of kidney disease's risk factors, causes, symptoms, and definition, and whether they had taken specific health promotion behaviors including reading about kidney disease, talking to their physicians about kidney disease, and getting tested for kidney disease yearly. Respondents also reported their medical history, including whether they had diabetes, hypertension, a family history of kidney disease, or kidney disease. The questionnaire was pretested by 11 eligible African Americans to inform project staff on key training issues and assisted in rewording of several response formats. This survey

analysis was approved by Washington University School of Medicine, and the University of Chicago School of Social Service Administration. The questionnaire is available for review from the primary author.

Procedure. Households with a telephone in these cities were chosen from a random-digit dial probability sample drawn in each city. Households meeting eligibility criteria had a working telephone number and included an adult African American who spoke English and was mentally able to complete the survey. To increase the likelihood of encountering an African American household, a race-targeting procedure was used where census tracts with 30% or more density of African American residents were selected. No respondent selection method was used to select the individual interviewed within the household; rather any African American aged 30 years or older was eligible to complete the interview. Trained interviewers administered the 20-minute interview during both day and nighttime hours, and each household was called a minimum of 10 times before stopping.

Statistical Analysis. We present data on respondents' attitudes and behaviors regarding kidney disease descriptively as percentages for categorical variables, and means and standard deviations for continuous variables. To learn more about at-risk African Americans, we divided African Americans into two groups for a secondary analysis: African Americans who had kidney disease or one of its risk factors (diabetes, hypertension, a family history of kidney disease), and those who did not. Chi-square tests of independence were used to compare respondents who were and were not at risk for kidney disease on questions of interest. Chi-square test values were corrected for clustering features of the survey design based on first order Taylor-series methods using THE SAS SURVEYFREQ procedure. An uncorrected alpha level of .05 was used as the threshold of statistical significance for all tests.

RESULTS

We surveyed 2017 of 4311 African Americans (Response Rate = 46.8%). Of these respondents, 1.1% had kidney failure, while 43.7% had a risk factor for kidney disease including hypertension, diabetes, or a family history of kidney disease (Table 1). Respondents were primarily female (72.4%), between the ages of 45-64 (46.3%), and college graduates (37.9%). Respondents with kidney disease risk factors were more likely to be female (75.9% vs. 69.5%, $X^2=10.3$, $p<.05$), between the ages of 45-64 (52% vs. 41.5%, $X^2=101.1$, $p<.001$), and to have a high school education or less (35.4% vs. 27.1%, $X^2=19.3$, $p<.001$) compared with respondents without risk factors.

Top Health Problems in African American Communities. Respondents felt that the top three health problems in the African American community were hypertension (60.8%), diabetes (54.6%), and heart disease (44.9%) (Table 2). Only 2.8% of respondents reported that kidney disease was an important health problem. Patients with kidney disease or one of its risk factors were significantly more likely to be concerned about both hypertension (64.2 vs 58.0, $X^2= 8.1$, $p<.001$) and diabetes (61.0% vs. 49.4%, $X^2= 27.9$, $p<.001$) as health problems. There were no differences in the importance of kidney disease as a health problem for patients with and without kidney disease risk factors (3.2% vs. 2.4%, $p=ns$).

Negative Health Consequences of Diabetes and Hypertension. Almost 100% of patients felt that unmanaged hypertension (99%, 87.4% very likely) and diabetes (98%, 84.5% very likely) could result in serious negative effects to their health. Although there were no differences in the perception that unmanaged diabetes could negatively affect health for patients with and without kidney disease risk factors, patients at risk for kidney disease were less likely to perceive

that unmanaged hypertension would result in negative health effects than patients without risk factors (99.5% vs 98.5%, $X^2=5.6$, $p<.001$).

On average, patients reported 2 potential negative effects of unmanaged diabetes ($SD=0.94$) and 1.8 negative effects ($SD=0.72$) for unmanaged hypertension. The top four perceived negative effects reported for diabetes were limb amputation (39.6%), blindness (35.4%), premature death (19.7%), and kidney disease (16.9%). Respondents at risk for kidney disease were more likely to believe that blindness (38.3% vs. 33.0%, $X^2=6.1$, $p<.014$) and kidney disease (23.5% vs. 11.6%, $X^2=50.3$, $p<.001$) would be negative consequences of unmanaged diabetes than patients who were not at risk. The top four perceived negative effects reported for hypertension were stroke (63.9%), heart attack (47.2%), premature death (18.4%), and kidney failure (7.5%). Respondents at risk for kidney disease were more likely to believe that stroke (70.5% vs. 58.5%, $X^2=31.2$, $p<.001$), heart attack (52.1% vs. 43.4%, $X^2=15.1$, $p<.001$) and kidney failure (9.6% vs. 5.8%, $X^2=10.3$, $p=.001$) were negative consequences of unmanaged hypertension than patients who were not at risk.

Knowledge about Kidney Disease. African Americans' knowledge about kidney disease was low (Table 3). Only 48.6% of all respondents knew that kidney disease is a reduction in kidney function and less than 20% knew that having diabetes (13.6%), hypertension (12.1%), or a family history of kidney disease (2.4%) were risk factors for getting kidney disease. Forty percent of respondents knew at least one test to diagnose kidney disease, most commonly naming general blood tests (24.3%), urine tests (22.7%) and blood pressure tests (2.4%). (More on testing still coming.) Respondents with risk factors for kidney disease were significantly more likely to know that a urine test would diagnose kidney disease (25.2% vs. 20.7%, $X^2=5.5$, $p<.05$).

Sixty-six percent of respondents knew one or more things that a physician might suggest to slow or prevent kidney disease. The top three most common actions to prevent kidney disease mentioned were having a healthy diet (33.7%), drinking lots of water (26.5%), and exercising regularly (15.1%). Few people mentioned controlling hypertension (11.6%), controlling diabetes (9.6%), avoiding soda (4.7%), losing weight (3%), watching for protein in their urine (0.7%), and eating less protein (0.5%) as potential ways to prevent kidney disease.

Attitudes and Behaviors Regarding Kidney Disease. In examining their attitudes about kidney disease specifically, on average, respondents felt that kidney disease was both preventable (6.8, SD=2.4) and treatable (7.5, SD=2.2). There were no significant differences in perceived preventability and treatability of kidney disease for patients with and without risk factors for it. However, African Americans with objective risk factors for kidney disease were less likely to perceive that they had a high risk of getting kidney disease (22.3% vs. 43.8%, $X^2=153.5$, $p<.001$) than respondents without risk factors (Table 4).

Overall, some African Americans were learning about kidney disease (28.6%) and talking to their physicians (9.1%) and family and friends (12.9%) about it (Table 5). While less than one-third of patients with risk factors for kidney disease were taking action to learn about kidney disease, they were significantly more patients with risk factors reading information about kidney disease (31.3% vs. 26.4%, $X^2=6.0$, $p<.014$) and talking to their physicians (13.3% vs. 5.7%, $X^2=34.2$, $p<.001$) and family members and friends (14.7% vs. 11.3%, $X^2=4.2$, $p<.03$) about it, compared to patients without risk factors.

Only 37.4% of African Americans had ever been tested specifically for kidney disease, 23.5% in the last year and 13.9% more than one year ago. However, patients with risk factors

for kidney disease were significantly more likely to be tested than patients without risk factors (33.8% vs. 15.5% in last year, 16.6% vs. 11.8% more than one year ago, $X^2=114.8$, $p<.001$).

DISCUSSION

Our analyses confirmed that kidney disease is a public health crisis for African Americans. In a seven-state survey of over 2000 African Americans, almost half of the respondents had a risk factor for kidney disease. Although over half of African Americans identified two of the risk factors for kidney disease (hypertension and diabetes) as health problems, awareness of the importance of kidney disease was almost zero. Despite the fact that almost 90% of the sample had heard about kidney disease in general, less than 3% reported that kidney disease was a top health concern for them.

Specific knowledge about kidney disease was low. Half of the survey respondents did not know the correct definition of kidney disease. Less than 20% understood the risk factors for kidney disease, how kidney disease is diagnosed, or how to prevent it. The majority of African Americans who were objectively at risk for kidney disease due to having a family history of kidney disease, diabetes, or hypertension did not perceive themselves to be at higher risk. Although African Americans with kidney disease risk factors were more likely to believe that their risk for kidney disease was higher than other people (25% vs. 8%), 75% of African Americans at higher risk did not perceive themselves to be so.

Encouragingly, African Americans generally believed that kidney disease is both preventable and treatable. However, the prevalence of testing for kidney disease is extremely low; nearly 50% of the African Americans with risk factors and 63% of all survey respondents had never been tested for kidney disease. Less than 20% of the surveyed respondents were tested for kidney disease annually. Early detection of kidney disease and CKD medical care (such as

diabetes and hypertension management) can delay progression to ESRD,¹³⁻¹⁷ significantly decrease patient mortality and morbidity,^{18,19} reduce hospitalizations,²⁰ and reduce health costs by \$9-60 billion dollars.²¹ Future research is needed to determine why African Americans may not be tested for kidney disease.

As these findings are the first of their kind, comparisons cannot be made to previous research and future work in this area is needed to be able to support these results. Other limitations to this research are that the sample of African Americans surveyed was not representative of African Americans in the US, since the sample is primarily female and the survey methodology required telephone coverage. However, the sample encompasses seven cities in different regions of the United States and uses random digit dialing to allow for as much diversity as possible. Also, since lower socioeconomic status and increased risk for kidney disease are confounded, to learn more about health disparities, future research needs to craft a sample matched on demographic characteristics and include a Caucasian comparison group.

As a focus on treating chronic kidney disease and kidney disease screenings become more prevalent, and research about their effectiveness in improving kidney disease outcomes continues and is disseminated, it is important to look at ways to increase participation in early screening efforts, especially with the African American community that is at highest risk for ESRD. This work suggests that many African Americans do not consider kidney disease a top health concern. Research supporting the Health Belief Model indicates that individuals who perceive an illness as a severe risk may be more motivated to take action regarding that illness. Future research is needed to determine if the people participating in kidney disease screenings are those who have a low awareness of kidney disease- if not, there may be a need to focus on educating the general African American community about kidney disease before attention is

directed towards further screening efforts. Educational interventions that can raise the awareness of the importance and severity of kidney disease in the African American community may be needed to increase health behaviors, such as screenings, that can delay ESRD.

The NKDEP, in partnership with the African American Sororities and Fraternities, the National Black Nurses Association, the National Urban League, the National Medical Association and the International Society of Hypertension in Blacks, has developed educational materials and outreach efforts to increase awareness of kidney disease in the African American community. These products include brochures, videos, website materials, posters and targeted outreach campaigns across the country including at churches, dialysis centers and family reunions. The use of these tools, in addition to other educational efforts by the nephrology community for African Americans, may increase the knowledge of the risk factors and severity of kidney disease in this population. This is a critical step to enhance the success of initiatives such as kidney disease screenings to insure that efforts are taken advantage of by the population that needs them the most.

In summary, although African Americans are aware of and concerned about diabetes and hypertension as health problems, kidney disease isn't yet on the radar for them as a top health concern. African Americans have extremely poor knowledge about what kidney disease is, what causes kidney disease and how to prevent it. Over three-fourths of those who have risk factors for kidney disease do not perceive themselves to be at higher risk, and less than a quarter of African Americans get tested for kidney disease every year. To increase awareness of kidney disease as a health problem and early detection of kidney disease through yearly testing, a multi-pronged effort involving leaders in the African American community, primary care physicians, and public health professionals is likely necessary.

REFERENCES

1. Kiberd BA, Clase CM: Cumulative risk for developing end-stage renal disease in the US population. *J Am Soc Nephrol* 13: 1635-1644, 2002
2. U.S. Renal Data System: Annual Data Report. Bethesda, MD, National Institutes of Health & National Institute of Diabetes and Digestive and Kidney Diseases, 2006
3. U.S. Department of Health and Human Services: Healthy People 2010. Washington, DC: U.S. Government Printing Office, 2000
4. Freedman BI, Spray BJ, Buckalew VM: The familial risk of end-stage renal disease in African Americans. *J Am Soc Nephrol* 21: 387-393, 1993
5. St. Peter WL, Schoolwerth AC, McGowan T, McClellan WM: Chronic kidney disease: Issues and establishing programs and clinics for improved patient outcomes. *Am J Kidney Dis* 41(5): 903-924, 2003
6. Ferdinand KC, Saunders E: Hypertension-related morbidity and mortality in African Americans- Why we need to do better. *J Clin Hypertens* 8(suppl 1): 21-30, 2006
7. Kinchen KS, Sadler J, Fink N, et al: The timing of special evaluation in chronic kidney disease and mortality. *Ann Intern Med* 137: 479-486, 2002
8. Appel LJ, Middleton J, Miller ER, et al: The rationale and design of the AASK cohort study. *J Am Soc Nephrol* 14: S166-S172, 2003
9. National Kidney Foundation: Kidney Early Evaluation Program annual data report. *Am J Kidney Dis* 46(5, supp3): s1-s158, 2005
10. Coresh J, Bryd-Holt D, Briggs JP, et al: Chronic kidney disease awareness, prevalence, and trends among U. S. adults, 1999 to 2000. *J Am Soc Nephrol* 16: 180-188, 2005

11. Nickloas TL, Frisch GD, Opotowsky AR, Arons R, Radhakrishnan J: Awareness of kidney disease in the US population: Findings from the National Health and Nutrition Examination Survey (NHANES) 1999 to 2000. *Am J Kidney Dis* 44(2): 185-197, 2004
12. Ueland AS, Hornung PA, Greenwald B: Colorectal cancer prevention and screening: a health belief model-based research study to increase disease awareness. *Gastroenterol Nurs* 29(5): 367-363, 2006
13. Boling W, Laufman L, Lynch GR, Weinberg AD: Increasing mammography screening through inpatient education. *J Cancer Educ* 20(4): 247-250, 2005
14. National Kidney Foundation: K/DOQI clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. *Am J Kidney Dis* 39(Suppl 1): S1-S266, 2002
15. Jacobs C: Costs and benefits of improving renal failure treatment- where do we go? *Nephrol Dial Transplant* 21: 2049-2052, 2006
16. Centers of Disease Control and Prevention: National diabetes fact sheet: general information and national estimates on diabetes in the United States, 2003. Atlanta, GA, U.S. Department of Health and Human Services, 2004
17. Tarver-Carr ME, Powe NR, Eberhardt MS, et al: Excess risk of chronic kidney disease among African American versus white subjects in the United States: A population-based study of potential explanatory factors. *J Am Soc Nephrol* 13: 2363-2370, 2002
18. Stack AG: Impact of timing of nephrology referral and pre-ESRD care on mortality risk among new ESRD patients in the United States. *Am J Kidney Dis* 41:310-318, 2003

19. Obialo CI, Ofili EO, Quarshie A, Martin PC: Ultralate referral and presentation for renal replacement therapy: Socioeconomic implications. *Am J Kidney Dis* 46(5):881-886, 2005
20. Goransson LG, Bergrem H: Consequences of late referral of patients with end-stage renal disease. *J Intern Med* 250:154-159, 2001
21. Trivedi HS, Pang MMH, Campbell A, Saab P: Slowing the progression of chronic renal failure: economic benefits and patients' perspectives. *Am J Kidney Dis* 39(4): 721-729, 2002

Table 1. Survey Respondent Demographics

		All Respondents (N=2017)	Respondents with Kidney Disease or Kidney Disease Risk Factors (N=903)	Respondents with No Risk Factors (N=1114)
Age**	18-44	42.6%	31.5%	51.8%
	45-64	46.3%	52.0%	41.5%
	≥65	11.1%	16.5%	6.7%
Sex*	% Female	72.4%	75.9%	69.5%
Education**	High School or Less	30.8%	35.4%	27.1%
	Some College	31.3%	27.3%	34.6%
	College Grad	37.9%	37.3%	38.3%
Risk Factors	Hypertension	34.5%	34.5%	0%
	Diabetes	13.4%	13.4%	0%
	Family History of Kidney Disease	11.1%	11.1%	0%
	Kidney Disease	1.1%	1.1%	0%

*Differences between respondents with and without Kidney Disease Risk Factors, $p < .05$;

** $p < .001$

Table 2. Importance of Kidney Disease as an African American Health Problem

	All Respondents Naming Health Problem (N=2017)	Respondents with Kidney Disease or Kidney Disease Risk Factors Naming Health Problem (N=903)	Respondents Naming Health Problem with no Risk Factors (N=1114)
Hypertension**	60.8%	64.2%	58.0%
Diabetes**	54.6%	61.0%	49.4%
Heart Disease**	44.9%	48.0%	42.4%
Cancer**	35.0%	30.7%	38.5%
AIDS/HIV**	25.6%	19.6%	30.5%
Obesity	7.3%	7.6%	7.0%
Kidney Disease	2.8%	3.2%	2.4%
Lack of Insurance	1.5%	1.8%	1.3%
Poverty	1.3%	1.0%	1.6%
Access to Healthcare	1.2%	0.7%	1.4%
Violence*	1.0%	0.6%	1.4%
Accidents	0.6%	0%	1.1%

*p<.05; **p<.001

Table 3. Knowledge about Kidney Disease

	Overall Respondents with Knowledge	Respondents with Kidney Disease or Its Risk Factors with Knowledge (N=903)	Respondents without risk factors with Knowledge (N=1114)
Had heard of kidney disease	89.9%	88.9%	91.3%
Know the correct definition of kidney disease	48.6%	49.7%	47.7%
Know that protein in urine is a symptom of kidney disease**	1.7%	9.1%	5.2%
Know that swelling is a symptom of kidney disease*	13.2%	15.2%	11.6%
Know that people with diabetes are at higher risk**	13.6%	18.0%	10.0%
Know that people with hypertension are at higher risk **	12.1%	17.2%	8.0%
Know that people with a family history of kidney disease are at higher risk	2.4%	2.4%	2.3%
Know that African Americans are at higher risk	18.1%	19.9%	16.6%
Know at least one test that will detect if a person has kidney disease	39.5%	40.2%	38.9%
Know how to prevent or slow progression of disease	65.9%	67.3%	64.8%

*p<.05, **p<.001

Table 4. Perceived Risk for Kidney Disease

		Respondents with Kidney Disease or Its Risk Factors (N=839)	Respondents with No Risk Factors (N=1023)
Perceived Risk for Kidney Disease*	Low	25.6%	8.0%
	Average	52.1%	48.2%
	High	22.3%	43.8%

*X²=153.5, p<.001

Table 5. Actions Taken to Learn about and Prevent Kidney Disease

	Overall Respondents Taking Action	Respondents with Kidney Disease or Its Risk Factors Taking Action (N=903)	Respondents with No Risk Factors Taking Action (N=1114)
Reading Information about Kidney Disease*	28.6%	31.3%	26.4%
Getting Tested for Kidney Disease in the Last Year**	23.5%	33.8%	15.5%
Talking to their Family or Friends about Kidney Disease*	12.9%	14.7%	11.3%
Talking to their Doctor about Kidney Disease**	9.1%	13.3%	5.7%

*p<.05, **p<.001