Patient Perception of Risk Factors Associated with Chronic Kidney Disease Morbidity and Mortality

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Background: Educational interventions aimed at empowering patients are successful in chronic disease management. The purpose of this study was to assess patient knowledge of risk factors and complications associated with chronic kidney disease (CKD).

Methods: We determined the perception of risk factors for CKD and its complications in 229 participants with a diagnosis of CKD stage 3 and 4 who completed an anonymous questionnaire. We evaluated predictors of better knowledge as measured by total correct responses using linear regression.

Results: The majority (89.1%) but not all of participants were aware of their diagnosis of CKD. Almost a third (31.5%) of patients that were aware of a diagnosis of CKD did not know their serum creatinine level compared to only 15.4% of participants with diabetes who did not know their last serum glucose level. Most participants identified hypertension (92.1%) and diabetes (86%) as risk factors for CKD, but male sex (59%) and African American race (71.6%) were selected less frequently. While glucose, proteinuria and blood pressure control were commonly associated by participants as known methods to slow progression of CKD, smoking control (79.5%) and use of renin-angiotensin system inhibitors (63.8%) were less known. After adjustment for sociodemographic factors, younger age and presence of a college degree were the only independent predictors of knowledge of CKD risk factors.

Conclusions: Access to CKD education needs to be tailored to the health literacy status of each patient. Educational interventional research studies are needed in early-stage CKD to determine impact on clinical outcomes. (*Ethn Dis*. 2010;20:106–110)

Key Words: Chronic Kidney Disease, Patient Knowledge, Patient Perception, Race Differences, Survey

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Introduction

Chronic kidney disease (CKD) is considered a worldwide epidemic,[1,2] with more than 20 million Americans diagnosed and another 20 million at risk.[3] It is associated with an increased risk of cardiovascular disease (CVD) and death.[2] In an effort to curb the epidemic and raise CKD awareness, several guidelines and education programs have been developed.[4,5]

Educational interventions aimed at empowering patients are successful in chronic disease management including CKD.[6] Educational interventions impact the choice of dialysis modality,[7] prolong time to end-stage renal disease (ESRD), and improve survival on dialysis.[8]

Cancer screening research studies have shown that patients with more knowledge and awareness of their disease are more likely to be screened and more likely to follow methods to slow the progression of their disease.[9] Disease-educated patients are more likely to follow proper treatment and cope more successfully with their diagnosis, and participate in health care decisions that affect their outcomes.[10]

To our knowledge, studies evaluating risk-factor knowledge in patients with early CKD do not exist. The objective of this study was to assess knowledge regarding risk factors that contribute to progression of CKD and mortality in participants with CKD stage 3 and 4. In addition, we were interested in determining if there were any racial differences in CKD knowledge, as CKD is a disease that disproportionately burdens ethnic minorities.

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Participants and Methods

The study population comprised patients aged ≥18 years who visited the renal clinics at Penn-Presbyterian Medical Center or the Hospital of the University of Pennsylvania of the University of Pennsylvania Medical Center and had a diagnosis of stage 3 or 4 CKD in their medical record. These centers serve the racially diverse population of the greater Philadelphia area. The anonymous questionnaires were distributed, from October 2007 to April 2008, by non-healthcare providers who had access to the patients' diagnosis but were not involved in direct patient care. Participants who were not able to read or speak English were excluded from the study. This study was approved by the institutional review board at our institution.

We developed a self-administered questionnaire, based on a literature search of past knowledge assessment studies.[2,4] There were 5 sections in the questionnaire: 1) basic knowledge of personal health; 2) perceptions of factors increasing the risk of CKD; 3) knowledge of therapies to slow CKD progression; 4) perceptions of CKD increasing the risk of other medical conditions; and 5) demographic information. We also collected their self-reported levels of creatinine, glucose and blood pressure.

We created an overall knowledge score based on the sum of the partici-

pants' correct replies to the 7 questions regarding risk factors for CKD and 5 questions regarding methods to slow progression of CKD. Therefore, the maximum total score was 12. If the subject did not answer the question, it was marked as incorrect. We used both linear regression and ordinal regression to evaluate independent predictors of higher overall knowledge score. Results were similar so we present results from the linear regression model.

RESULTS

The questionnaire was completed by 229 participants. The demographic results are summarized in Table 1. The mean age was 53.24 ± 14.05 (SD) years. Of the participants, 56% were male and 54% were Caucasian, 34% African American, and 3% Asian or Asian American. A moderate number of participants (14.9%) reported that a family member had been treated with dialysis. Nearly all participants (96%) reported that they had at least completed high school. Over half of the participants (57.21%) reported that they had private insurance (non-Medicare) and 34.5% reported having Medicare.

Table 2 summarizes patient health knowledge. Only 89.1% of participants knew that they had CKD despite a diagnosis of CKD stage 3 or stage 4 in their medical record. Almost 5% denied having CKD despite being in a nephrologist's office. Only 62.5% of participants reported knowledge of their serum creatinine level. In participants who were aware of their CKD diagnosis, 31.5% did not know their serum creatinine level. Participants with a diagnosis of diabetes (34.9%) were more likely to remember their last glucose level, with only 15.4% of them admitting to not knowing it.

Table 3 shows our study population's perception of risk factors in increasing the risk of CKD, how effective some methods were in slowing the progression of CKD, and CKD increasing the risk of cardiovascular conditions and death. Hypertension (92.1%) and diabetes (86%) were the two risk factors that were perceived as increasing the risk of CKD for the largest proportion of our study population. Other risk factors like obesity (79.9%), family history of CKD (75.1%), smoking (74.7%), African American race (71.6%), and male sex (59%) were less commonly identified as CKD risk factors.

Only 89.1% of participants knew that they had CKD despite a diagnosis of CKD stage 3 or stage 4 in their medical record.

A majority of our subjects thought that all of the methods inquired about (glucose control, proteinuria control, blood pressure control, smoking control, and taking ACE inhibitors or ARBs) were effective in slowing the progression of CKD. Glucose control (89.5%) was the most recognized effective therapy for slowing the progression of CKD. Smoking control (79.5%) and use of renin-angiotensin system inhibitors (63.8%) were the least likely to be identified as effective in slowing the progression of CKD. Most respondents thought that CKD increased the risk for myocardial infarction, stroke, and peripheral vascular disease and death.

Tables 3 also summarizes the perceptions of African Americans versus non-African American participants. Smoking abstinence as method to slow progression of CKD was the only statistically significant difference between the 2 groups.

After adjustment for demographic factors and comorbidities, younger age and a college degree were independent predictors of overall knowledge score (Table 4).

Table 1. Demographic characteristics of the study participants (*N*=229)

Mean age (years) (SD)	53.2 (14)
Sex (%)	
Male	55.9
Female	37.6
Sex not reported	6.5
Race (%)	
White or Caucasian	54.2
Black or African American	33.6
Asian or Asian American	2.6
Native Hawaiian or Pacific Islander	0.9
Mixed race	2.2
Race not reported	6.5
Insurance (%)	
Medicare	34.5
Private (Non-Medicare)	57.2
Insurance not reported	8.3
Income (%)	
<$20,000	17.0
$20,000–$40,000	16.6
$40,000–$80,000	20.1
>$80,000	31.9
Income not reported	14.4
Education (%)	
through high school	25.3
trade school or some college	35.4
College (bachelor's degree)	17.9
any post-college	17.5
Education not reported	3.9

DISCUSSION

We have demonstrated that, in patients with stage 3 and 4 CKD, there is opportunity for improvement of CKD knowledge. Not all participants were aware of a CKD diagnosis, risk factors contributing to CKD, therapies to slow progression of CKD, or comorbid conditions. We believe our study is the first to examine CKD knowledge in early CKD and to evaluate differences in perception of CKD risk factors between African Americans, a high risk population, and non-African Americans. After adjustment for demographic factors and comorbidities, only younger age and a college degree were independent predictors of overall knowledge score.

Table 2. Personal health knowledge in patients with chronic kidney disease

Question	Response (%)		
	Yes	No	Don't know
Do you have kidney disease (or have you ever had kidney disease)?	89.1	4.8	3.5
Are people likely to get kidney disease?	48.5	12.7	34.1
Do any immediate family members have kidney disease?	29.7	65.5	4.4
Do you have diabetes?	34.9	62.0	3.1
Do you consider yourself to be obese?	16.6	79.0	3.5
Do you know your creatinine level?	62.5	32.8	4.7
Do you have high blood pressure or are you taking medication to control your high blood pressure?	63.3	10.0	26.7
Do you know your glucose level?	45.0	53.3	1.7

The barriers to patient education are many. Nephrologists have busy practices with competing financial and time demands. The national supply of CKD educators is limited and funding is not available in every practice. Indeed, gaps in CKD knowledge have been identified in primary care providers (PCPs) and internal medicine trainees. The National Kidney Disease Education Program (NKDEP) assessed the awareness of CKD risk factors among PCPs,[4] and found that those who treated high-risk CKD populations did not have a comprehensive picture of CKD risk factors. PCPs were not as aware of family history being a risk factor and the African American race as an at-risk group for CKD. However, most PCPs were aware of the risks from diabetes and hypertension for CKD. In a recent study, half of US internal medicine trainees were unaware of the definition of CKD and one third was unaware of CKD staging.[11]

African Americans are more likely to have several risk factors for CKD (hypertension, diabetes, and family history of CKD).[5] However, even though half of African Americans had at least one CKD risk factor (in addition to African American race), only a few reported that CKD was a top health concern, and therefore were not seeking screening tests.[7] African Americans listed high blood pressure, diabetes and heart disease as top health concerns. In addition, 22% of PCPs surveyed did not consider African American race to be a CKD risk factor.[3] Similarly, our study found that, despite CKD disproportionately affecting African Americans,[13] almost 30% of CKD patients did not know that African American race increases the risk of CKD. And, while African Amer-

Table 3. Perception of CKD risk factors, methods of control, and increased risk for other conditions

Believe that factor increases risk of CKD	All respondents (%) *N*=229	African Americans (%) *n*=77*	Non-African Americans (%) *n* =137*	*P* Value
African American race	71.6	77.9	71.5	.31
Male sex	59.0	61.0	59.9	.87
Diabetes	86.0	83.1	90.5	.11
Hypertension	92.1	93.5	94.2	.85
Family history of CKD†	75.1	75.7	84.8	.10
Smoking	74.7	70.1	80.3	.09
Obesity	79.9	79.2	85.4	.25
Believe that method slows progression of CKD				
Glucose control	89.5	92.2	91.2	.81
Proteinuria control	85.2	83.1	90.5	.11
Blood pressure control	87.8	87.0	91.2	.33
Smoking control	79.5	74.0	86.1	.03
Taking ACE inhibitors or ARBs	63.8	61.0	68.6	.26
Believe that CKD increases risk for the condition				
Heart attacks	88.7	92.2	89.8	.56
Stroke	87.3	92.2	87.6	.30
Peripheral vascular disease	87.8	87.0	91.2	.33
Death	90.4	89.6	94.9	.15

* Race identification was optional, and therefore the sum of African Americans and non-African Americans is not equal to the total number of respondents for each question.
† Only 206 participants completed this question.

Table 4. Multivariable linear regression of predictors of higher CKD knowledge

Predictor	Coefficient (standard error)	*P* Value
College degree	1.08 (0.34)	.002
Age	−.04 (0.01)	.003
African American race	−.44 (.36)	.22

icans are about six times more likely to report a family history of ESRD,[12] they do not perceive themselves as more at risk for kidney disease. It is possible that CKD patients are overburdened with learning about multiple conditions such as diabetes and hypertension.

As in our study, a high correlation between educational attainment and health outcomes has been reported repeatedly across many health indicators,[14–17] even when controlling for income and family background.[18] However it is debatable whether this relationship is causal.[18] And the effect of education decreases for older subjects.[18,19]

Cancer screening research studies have demonstrated that patients with more knowledge and awareness of their disease are more likely to be screened and more likely to follow methods to slow the progression of their disease.[20] Educated patients are more likely to follow proper treatment and cope more successfully with their diagnosis, and participate in health care decisions that affect their outcomes.[21]

Kidney disease screening programs have been established, like the community CKD screenings though the National Kidney Foundation, which identifies individuals who have kidney disease.[22] But of concern in this report is the fact that, despite a diagnosis of CKD, a small percentage of patients were not aware of their diagnosis. Healthcare providers need to be clear with patients about their condition, inform them of the risk factors that affect their kidney health and also stress the importance of monitoring physiological parameters such as creatinine level, blood pressure, proteinuria and glucose level. It is important that CKD patients know their estimated glomerular filtration rate and/or creatinine level in the same manner that a patient with diabetes should know his hemoglobin A1C and glucose levels in order to help prevent progression of the disease.

Weaknesses in our study include selection bias in patients willing to answer the questionnaire. Those who were willing to take the time to answer the questionnaire may have been more health knowledgeable. The distribution of the questionnaires was limited to the two renal clinics used in this study.

Randomized educational interventional research studies that address both knowledge of the disease and address behavioral change are needed in early CKD to determine impact on clinical outcomes. Although patients often find it difficult to follow treatment and lifestyle advice given by healthcare professionals,[23] information provided in an engaging and easily understandable form, enhances metabolic control, improves risk factors, and general quality of life in patients with diabetes.[24] Kidney disease awareness should be linked to education provided for hypertension and diabetes.

Our study identifies gaps in patient CKD education. The medical community may follow the example of community campaigns, such as breast cancer, to raise awareness among family members of patients with ESRD. Primary care provider's education and predialysis CKD education, along with screening programs, may help curtail the rising epidemic of CKD and its complications.

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AUTHOR CONTRIBUTIONS

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