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Development and Results of a Kidney Disease Knowledge Survey Given to Patients With CKD

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Abstract

Background—Little is known about disease specific knowledge in patients with chronic kidney disease (CKD). We developed and examined the results of a survey to characterize kidney disease knowledge.

Design—Survey about kidney disease knowledge, with questions developed by experts. Setting and Participants: 401 adult patients with CKD (Stages 1–5) attending a nephrology clinic from April to October 2009.

Outcomes & Measurements—We calculated survey reliability using the Kuder-Richardson-20 coefficient, and established construct validity by testing *a priori* hypotheses of associations between the survey and patient characteristics. We descriptively analyzed survey responses and applied linear regression analyses to evaluate associations with patient characteristics. Health literacy was measured using the Rapid Estimate of Adult Literacy in Medicine.

Results—Participants median age was 58 (25th–75th percentile, 46–68) years, 83% were White, 18% had limited literacy, and 77% had CKD Stages 3–5. The 28 question knowledge survey had good reliability (KR-20=0.72), and mean (SD) knowledge score was 66% (15%). In support of construct validity of our knowledge survey, bivariate analysis shows that scores are associated with age (β , -0.01 per ten years; 95% CI, -0.02–0.005; $p=0.003$), formal education (β , 0.09; 95% CI, 0.03–0.15; $p=0.004$), health literacy (β , 0.06; 95% CI, 0.03–0.10; $p=0.001$), kidney education class participation (β , 0.05; 95% CI, 0.01–0.09; $p=0.009$), knowing someone else with CKD (β , 0.05; 95% CI, 0.02–0.08; $p=0.001$), and awareness of one's own CKD diagnosis (β , 0.07; 95% CI, 0.04–0.10; $p<0.001$). Findings were similar in adjusted analyses.

Limitations—Recruitment from one clinic limits generalizability of findings.

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Conclusions—For patients with CKD, this kidney disease knowledge survey (KiKS) is reliable and valid, and identifies areas of and risk factors for poor kidney knowledge. Further study is needed to determine the impact of CKD knowledge on self-care behaviors and clinical outcomes.

Chronic kidney disease (CKD) affects millions of people within the United States and is estimated to increase in the future.¹ CKD can lead to kidney failure requiring renal replacement therapy, and is associated with morbidity and mortality at all stages.² The health and economic implications of this are enormous.³ Fortunately, therapies exist to reduce complications of disease,^{4–6} and may delay or even halt progression to advanced stages.^{7–8}

However, nearly all therapies aimed at preventing kidney disease progression and reducing associated complications rely heavily on patient self care, including recommendations for adherence to medication regimens,^{9–11} avoidance of further nephrotoxic insults,¹² and in advanced stages, maintenance of strict diet control.¹³ Research indicates more patient knowledge is associated with improved patient self management behaviors in patients receiving hemodialysis,¹⁴ improved glycemic control in patients with diabetes,^{15–16} and increased medication adherence in patients with HIV.¹⁷ Higher kidney disease specific knowledge is associated with lower rates of peritonitis in patients receiving peritoneal dialysis,¹⁸ and less use of catheters for vascular access in those receiving hemodialysis.¹⁹

Among the general population most people are unaware they have kidney disease,²⁰ and perceived kidney disease knowledge is even low in patients with CKD under the care of a nephrologist.²¹ In a study of 676 patients with CKD Stages 3–5, 35% of patients reported knowing little or nothing about their own chronic kidney disease diagnosis, and nearly half reported they had no knowledge about treatment options if their kidneys failed.²¹ This is striking considering patients on average had been seeing a nephrologist for more than four years in this cohort.

In addition, descriptive research repeatedly reveals that patients want and need more disease specific knowledge to support self care behaviors,^{22–26} and that lack of effective provider communication is seen as a barrier to receiving and understanding this information.²⁷ Although educational interventions have been shown to delay initiation of dialysis and reduce risk of death,²⁸ it is notable that a recent review of randomized trials of educational interventions in kidney disease revealed no studies were performed in patients with early CKD.²⁹ Conceptual models have been developed to describe the relationship between individual capacity, system/provider factors, and health outcomes, and patient knowledge is often noted as an important and necessary component of these relationships.^{30–31} Yet, little is known about actual knowledge in patients with all stages of CKD on topics relevant to optimizing and preserving kidney function. Assessment of patient disease-specific knowledge is clinically relevant in that it may reveal topics difficult for patients to understand, and aid in the development of educational interventions that specifically target areas of low knowledge. Questionnaires have been developed to measure some aspects of knowledge in patients with or at risk for CKD.^{14, 19, 32–36} However, not all have been validated in populations that include patients with CKD Stages I–V, nor do they focus on areas specific to optimizing self-care in early CKD to prevent disease progression.

The aim of this study was to develop a valid and reliable survey to measure kidney disease specific knowledge in patients with CKD not yet requiring renal replacement therapy, and use it to describe areas of and patient characteristics associated with low knowledge. We hypothesized disease specific knowledge in patients with established chronic kidney disease would be limited.

METHODS

Survey Validation Process

Survey development—We developed a survey to assess kidney disease knowledge in a step-wise fashion. *A priori* we developed survey questions to represent knowledge about topics important to kidney disease management. Approximately 100 questions were first generated to maximize content relevant to kidney knowledge. These content areas included the functions of the kidney, treatment options for kidney failure, signs and symptoms of disease progression, medications of potential benefit or harm to the kidney, blood pressure targets, and other topics important to preserving kidney function. We conducted a content review of kidney knowledge questionnaires,^{18–19, 21, 32–37} patient perspectives on disease specific information needs,^{14, 22–25, 38–42} and convened experts in various areas of kidney disease care, including nephrologists (3), nurses (3), dieticians (2), research personnel (6), and a kidney disease educator (1). In addition, we solicited methodological input from experts (3) in health literacy, scale validation, and psychometric analysis. Through an iterative process the items were reviewed for face and content validity, and redundancy, and ultimately reduced to 34 kidney knowledge questions. These were field tested in a small group of clinical and nonclinical personnel for clarity. Approximately the first 20 study participants were asked to comment on clarity and content, and there were no additional suggestions. The survey score was defined as the sum of the correct responses to each survey question divided by the total number of questions.

Survey psychometric analyses—We performed factor analysis to determine if there were underlying subscales within our survey and to assist in reducing the number of questions. Then the Kuder-Richardson-20 coefficient (KR-20) was used to determine internal consistency, a measure of internal reliability for surveys with dichotomous responses.⁴³ All survey items except one had only one correct response. In the survey item with two correct responses (asking the participant to identify two potential treatments for kidney failure), the item was considered correct only if both treatments were checked. We eliminated any item that received $\geq 95\%$ correct responses. These items with low difficulty would not contribute to discrimination between different levels of patient knowledge.⁴³ Items with negative item-rest correlations, implying they were not associated in the same direction with other survey questions, nor the underlying construct of patient knowledge, were also removed.

There is no universal ‘gold standard’ for measuring patient kidney knowledge to compare correlations with our new survey. Therefore, we established evidence of construct validity by defining an *a priori* model of patient characteristics we hypothesized to be associated with kidney disease knowledge (Figure 1). Where able, we were informed by associations observed in knowledge scales in other chronic diseases, for example HIV¹⁷ and diabetes.^{15, 44} If our knowledge scores were associated similarly with patient characteristics, this would support construct validity of our new instrument.^{43,45}

Study Design

Study participants—In calculating an adequate sample size for survey validation, 5–10 participants are generally recommended for each question.⁴³ We estimated 10 participants for 34 knowledge questions, giving us a sample size enrollment goal of 340 participants. The final sample size was inflated for a dropout rate of 10–15%, to account for potential study withdrawals.

Adult patients with CKD (Stages 1–5) were enrolled from April 2009 to October 2009. Eligible patients were at least 18 years of age, English-speaking, and had chronic kidney

disease as defined by National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (KDOQI) guidelines.⁴⁶ All had seen a nephrologist in the Vanderbilt Nephrology Clinic at least once prior to enrollment. Excluded were patients who had a kidney transplant or were currently receiving dialysis, as it was felt their disease specific knowledge may include topics outside the scope of general CKD knowledge. Patients with a pre-existing cognitive or vision impairment (prohibiting ability to see the materials) were also excluded. Subjects were offered monetary compensation for participation. The institutional review board from Vanderbilt University Medical Center approved the study and written consent was obtained from all participants.

The study population was composed of eligible patients enrolled during a visit to the nephrology clinic. Literacy was assessed using the Rapid Estimate of Adult Literacy in Medicine (REALM), a validated measure of pronunciation ability that correlates well with reading comprehension.⁴⁷ The survey was written at a 6th grade reading level. If participants scored less than a sixth-grade reading level by the REALM, the knowledge survey was administered orally so that low reading comprehension would not be a barrier to its completion.

We abstracted from the medical record patient age, visit information (e.g. disease diagnosis, number of visits in the past year), and laboratory values. Additional variables collected included self-reported race, income, highest level of educational attainment, and attendance in a kidney education session. Two additional questions targeted awareness of chronic kidney disease diagnosis; we asked patients if they had a "kidney problem" and also asked, "Do you have chronic kidney disease?"

Statistical Analysis

Descriptive statistics were calculated as median (25th–75th percentile) for continuous variables or frequency and percentage for categorical variables. Stage of chronic kidney disease was determined using laboratory serum creatinine and urinary protein measurements abstracted from the medical record. The 4-variable MDRD Study equation was applied to calculate estimated glomerular filtration rate (eGFR),⁴⁸ and patients were assigned CKD stage according to KDOQI guidelines.⁴⁶ To examine differences in participant baseline characteristics, we used the Kruskal-Wallis test and Pearson's chi-square or Fisher's exact tests in continuous or categorical variables by CKD stage, as appropriate. Bivariate associations with overall knowledge scores were calculated using simple linear regression for the patient characteristics as defined in our *a priori* model and additional exploratory analyses were performed for age, sex, and race. We report beta coefficients for both unadjusted and adjusted analyses. The adjusted model used ordinary least squares regression and retained variables with significant associations in bivariate analyses, and diagnostic testing was performed to evaluate model assumptions.

For all statistical analyses, findings with a p value ≤ 0.05 are considered statistically significant. We performed all statistical analyses using STATA version 10.0 (Stata Corporation, www.stata.com).

RESULTS

Participant characteristics

Four hundred and six consecutive consenting patients were recruited from a nephrology speciality clinic (67% response rate). The most common reason for not participating was insufficient time. We do not have information on non-participants. The survey took an average of 25 minutes to complete. Five of the participants withdrew due to illness (2), did not want to finish (1), and time (2), leaving 401 participants.

Overall, participants were a median of 58 (25th-75th percentile, 46–68) years old, 53% were male, and 83% were White (Table 1). Most had an education level of high school graduate or more (94%), yet 18% had limited health literacy (< 9th grade reading level). Forty-eight percent reported a household income greater than \$55,000 per year. Seventy-seven percent had CKD Stages 3–5 and 58% had seen a nephrologist at least three times in the past year. Seventeen percent of participants reported attending a kidney education session. Although 94% of participants were aware they had a “kidney problem,” when asked “Do you have chronic kidney disease?” only 69% responded “yes.”

Participant characteristics, stratified into three categories by CKD Stage, are presented in Table 1. More advanced kidney disease was significantly associated with older age, diabetes, hypertension, more frequent visits with a nephrologist, participation in kidney education class, and awareness of kidney disease.

Knowledge Survey Results

Factor analysis revealed no clear subscales in the knowledge survey. Table 2 presents the initial 34 knowledge item topics, the proportion of correct responses, the item-rest correlations and factor loading onto the first factor. Although there seemed to be similar loadings for items onto one factor related to kidney functions and symptoms (factor loadings ≥ 0.4), these loadings were modest, and overall the factor analysis revealed no clear knowledge subscales. There were 5 items that $\geq 95\%$ of participants answered correctly and these were removed. One remaining item had negative correlations with the rest and was also removed. The 28 question kidney knowledge survey (KiKS; Item S1, available as online supplementary material) was analyzed for internal consistency, and the Kuder-Richardson-20 reliability coefficient was 0.72. KiKS had a mean (SD) score of 0.66 (0.15), and a range of 0.11 – 0.96.

Descriptively, we looked at each survey question to determine topic areas where patient knowledge may be low (Table 2). Topics where less than 50% of the cohort answered correctly included the relationship of proteinuria to poor kidney function (19%), role of the kidney in glucose control (40%), and knowledge about some of the symptoms of progressing kidney disease, specifically, a lack of understanding that there may not be any symptoms at all (22%).

Topics in which greater than 90% of the cohort answered correctly included knowledge of blood pressure goal (91%), understanding there are stages of CKD (93%), and recognizing fatigue as a sign of kidney disease (93%). In bivariate analyses, KiKS score was associated with age (β , -0.01 per ten years; 95% CI, -0.02 to -0.005 ; $p=0.003$), education (β , 0.09 ; 95% CI, 0.03 – 0.15 ; $p=0.004$), health literacy (β , 0.06 ; 95% CI, 0.03 – 0.10 ; $p=0.001$), kidney education class participation (β , 0.05 ; 95% CI, 0.01 – 0.09 ; $p=0.009$), knowing someone else with CKD (β , 0.05 ; 95% CI, 0.02 – 0.08 ; $p=0.001$), and awareness of their own CKD diagnosis (β , 0.07 ; 95% CI, 0.04 – 0.10 ; $p<0.001$) (Table 3). Knowledge scores were not associated with race or sex in this cohort. A subgroup analysis for participants with an eGFR of < 60 ml/min/1.73m² ($n=309$), showed similar results.

The multivariable analysis included age, stage of CKD, education, health literacy level, participation in a kidney education class, knowing someone with CKD, and awareness of CKD diagnosis. Similar to the bivariate analyses, younger age (β , -0.01 per ten years; 95% CI, -0.02 to -0.002 ; $p=0.02$), higher health literacy (β , 0.05 ; 95% CI, 0.01 – 0.09 ; $p=0.04$), previous attendance in a kidney education class (β , 0.04 ; 95% CI, 0.002 – 0.09 ; $p=0.04$), knowing someone with CKD (β , 0.04 ; 95% CI, 0.009 – 0.07 ; $p=0.01$), and awareness of chronic kidney disease diagnosis (β , 0.05 ; 95% CI, 0.02 – 0.09 ; $p=0.001$) remained independently associated with higher KiKS score.

DISCUSSION

Through a systematic method of survey design, development, administration, and analysis, we have created an instrument that is valid and reliable in measuring disease-specific knowledge in patients with chronic kidney disease. The reliability calculated for our knowledge survey is similar to other knowledge scales in similar populations (hemodialysis)^{14, 19} and in patients with other chronic diseases.⁴⁴ KiKS performed as expected with our *a priori* model, and showed similar bivariate associations as those found in knowledge scales in other diseases providing evidence supporting its validity.^{14–15, 44}

We identified many topic areas important to patient self care that are not well understood by patients with kidney disease. We often counsel patients to avoid non-steroidal anti-inflammatory medications as use may promote kidney dysfunction,^{49–51} however 28% of patients did not identify this as the medication to avoid. Further, although reducing proteinuria is one of our mainstays of therapy, 81% of our patients did not fully understand that urinary protein is not only a marker of damage, but left uncontrolled may contribute to further disease progression.⁵² Studies suggest that patients want to know more about what can be done to protect existing kidney function, including information on appropriate use of medications, and guidance in understanding the meaning and interpretation of tests used to monitor potential disease progression.^{22, 39}

In addition, we found there appears to be limited knowledge regarding basic information about the kidney. For example, patients did not seem to understand some of the kidney's actions, as over a third of our participants did not know that the kidney makes urine. A lack of understanding regarding fundamentals of major organs, including anatomy, has been previously noted in patients with chronic disease.⁵³ In addition, over 30% of our study population did not understand the term "GFR." An estimate of GFR is one of the recommended methods for CKD testing and considered one of the best overall measures of kidney function.⁵⁴ It is used by many healthcare centers,^{55–57} and is recommended for use by providers when explaining kidney test results with patients.⁵⁸ Although patients⁵⁹ and providers⁶⁰ express the desire for additional resources to support patient education in kidney disease, lack of understanding common vocabulary may contribute to patient confusion and frustration.

Patient knowledge of symptoms was also limited, and only 22% of participants correctly responded that as CKD progresses there may not be any symptoms. It is possible that if participants selected any of the symptoms in our survey, they may have felt the response "no symptoms" was incorrect. However, this also highlights a potential gap in patient understanding: even without symptoms, CKD may be progressing to advanced stages of disease. People at risk for CKD believe knowledge about symptoms is one of the most important concepts for patients to understand.²⁷ Further emphasis that symptoms may not manifest until disease is well advanced may provide additional information our patients need to motivate regular follow up and testing, rather than reliance on "how one feels" when seeking out kidney care.

KiKS scores were lower than we expected given that patients were established within the nephrology clinic, and most had moderate to severe CKD. Low knowledge and low health literacy were significantly associated, as with other chronic diseases,^{61–63} and addressing low literacy using clear communication principles may be beneficial.⁶⁴

Awareness of chronic kidney disease diagnosis is low in the general population,²⁰ and we found that even in a nephrology specialty clinic, patients understanding they have "chronic kidney disease" cannot be assumed. When asked "Do you have chronic kidney disease?", over one third of participants answered "no", suggesting a lack of understanding of how to

interpret their own kidney testing evaluation, or the information discussed by their provider. It is also possible that providers may choose not to disclose some information to patients, or that patients are in denial regarding their diagnosis. This may be related to low perceived susceptibility to kidney disease,⁶⁵ uncertainty or fear of treatments, or mistrust in information from their provider. In one qualitative study exploring self-management experiences of people with CKD (Stages 1–3), participants admitted they knew they had a “kidney problem” but did not know “how big (of) a problem,” and in some cases did not “really even want to know.”²⁵ Patients discussed a struggle with uncertainty about the permanence of kidney disease, and recommended avoidance of the term “chronic,” using instead terms like “life-long” and “forever.”²⁵ Other patients, however, felt uninformed about the fact that their condition was “chronic,” and considered this inappropriate “withholding” of information on the part of the provider.²⁵ These perspectives highlight complexity providers face in assessing and determining a patient’s readiness to accept and process information about their diagnosis. Although many mechanisms underlying poor awareness of CKD remain unknown, improving awareness of kidney disease is a newly identified priority of Healthy People 2020.⁶⁶

There are several limitations to this study. First, this is a cross sectional study, and thus causality cannot be inferred. Second, this population was a convenience sample enrolled from a single nephrology clinic, and resources limited our ability to approach all potentially eligible patients. Thus, our results are not generalizable to the entire CKD population. Thirdly, KiKS score was not consistently associated with stage of CKD, nor the number of visits to the provider in the past year. We suspect that duration of seeing a kidney specialist may be an important factor in these potential associations, but were not able to capture a measure of duration in this sample. Patients more comfortable with their level of knowledge and educational background in general, may have been more willing to take our knowledge survey, however we do not have measures in our nonparticipants for comparison.

We have yet to fully determine the clinical significance of observed differences in KiKS scores and the potential impact on outcomes in kidney disease. However, when educational interventions are provided to patients near renal replacement, we see benefit of increases in time to dialysis initiation, partly attributed to increased patient knowledge,⁶⁷ and even modest differences observed with a dialysis knowledge survey (3% difference) were associated with an important clinical outcome.¹⁹

Still there are important implications of our research. Our survey measured knowledge in participants with a CKD diagnosis that was recognized, established, and treated under the care of a nephrologist. Yet, studies indicate that the majority of patients with early stages of CKD are seen by primary care providers,⁶⁸ where adherence to optimal CKD treatment guidelines,⁶⁹ as well as recognition of CKD diagnosis,^{70–71} are lower than those seen by kidney specialists. Thus, patient disease specific knowledge, and potential subsequent cues to optimal self-care behaviors, may also be lower in these settings.

In addition, although not all patient characteristics associated with low knowledge are modifiable, they still may serve as a guide to providers to identify those patients who may have low knowledge. Providing targeted and tailored education is modifiable, and we did find higher scores in those who reported seeing a CKD educator. Recent changes in reimbursement policy by the Centers for Medicare and Medicaid Services (CMS), supports kidney education in advanced CKD,⁷² and also calls for tools to ensure comprehension of education provided. Tools such as our knowledge survey may have use as an initial starting point for such assessments, or be used to monitor response to an existing educational program.

In summary, we have developed a survey to measure patient knowledge about many topics integral to self-care practices and prevention of CKD progression. Reliability and validity have been supported and are similar to other knowledge scales. With better understanding of the particular areas of low patient knowledge, we see that even within an optimal setting of kidney disease specific care, communicating disease related concepts with patients is complex. Further research is needed to validate the survey in other populations with CKD and assess how knowledge and outcomes are modified through targeted interventions.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. U.S. Renal Data System. USRDS 2009 Annual Data Report: Atlas of Chronic Kidney Disease and End Stage Renal Disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; Bethesda MD: 2009.
2. Go AS, Chertow GM, Fan D, McCulloch CE, Hsu CY. Chronic kidney disease and the risks of death, cardiovascular events, and hospitalization. *N Engl J Med* Sep 23;2004 351(13):1296–1305. [PubMed: 15385656]
3. Levey AS, Schoolwerth AC, Burrows NR, Williams DE, Stith KR, McClellan W. Comprehensive public health strategies for preventing the development, progression, and complications of CKD: Report of an expert panel convened by the Centers for Disease Control and Prevention. *Am J Kid Dis* 2009;53(3):522–535. [PubMed: 19231739]
4. Bucher HC, Griffith LE, Guyatt GH. Systematic review on the risk and benefit of different cholesterol-lowering interventions. *Arterioscler Thromb Vasc Biol* Feb;1999 19(2):187–195. [PubMed: 9974397]
5. SHEP Cooperative Research Group. Prevention of stroke by antihypertensive drug treatment in older persons with isolated systolic hypertension. Final results of the Systolic Hypertension in the Elderly Program (SHEP). *JAMA* Jun 26;1991 265(24):3255–3264. [PubMed: 2046107]
6. Sever PS, Dahlöf B, Poulter NR, et al. Prevention of coronary and stroke events with atorvastatin in hypertensive patients who have average or lower-than-average cholesterol concentrations, in the Anglo-Scandinavian Cardiac Outcomes Trial--Lipid Lowering Arm (ASCOT-LLA): a multicentre randomised controlled trial. *Lancet* Apr 5;2003 361(9364):1149–1158. [PubMed: 12686036]
7. Lewis EJ, Hunsicker LG, Bain RP, Rohde RD. The effect of angiotensin-converting-enzyme inhibition on diabetic nephropathy. The Collaborative Study Group. *N Engl J Med* Nov 11;1993 329(20):1456–1462. [PubMed: 8413456]
8. Lewis EJ, Hunsicker LG, Clarke WR, et al. Renoprotective effect of the angiotensin-receptor antagonist irbesartan in patients with nephropathy due to type 2 diabetes. *N Engl J Med* Sep 20;2001 345(12):851–860. [PubMed: 11565517]
9. National Kidney Foundation. K/DOQI clinical practice guidelines for management of dyslipidemias in patients with kidney disease. *Am J Kidney Dis* Apr;2003 41(4 Suppl 3):I–IV. S1–91. [PubMed: 12671933]
10. National Kidney Foundation. K/DOQI clinical practice guidelines on hypertension and antihypertensive agents in chronic kidney disease. *Am J Kidney Dis* May;2004 43(5 Suppl 1):S1–290. [PubMed: 15114537]

11. National Kidney Foundation. K/DOQI clinical practice guidelines for cardiovascular disease in dialysis patients. *Am J Kidney Dis* Apr;2005 45(4 Suppl 3):S1–153.
12. Harkonen S, Kjellstrand C. Contrast nephropathy. *Am J Nephrol* 1981;1(2):69–77. [PubMed: 6758574]
13. National Kidney Foundation. K/DOQI Clinical practice guidelines for nutrition in chronic renal failure. *Am J Kidney Dis* Jun;2000 35(6 Suppl 2):S1–140. [PubMed: 10895784]
14. Curtin RB, Sitter DC, Schatell D, Chewning BA. Self-management, knowledge, and functioning and well-being of patients on hemodialysis. *Nephrol Nurs J* Jul-Aug;2004 31(4):378–386. 396. quiz 387. [PubMed: 15453230]
15. Huizinga MM, Elasy TA, Wallston KA, et al. Development and validation of the Diabetes Numeracy Test (DNT). *BMC Health Serv Res* 2008;8:96. [PubMed: 18452617]
16. Fitzgerald JT, Funnell MM, Hess GE, et al. The reliability and validity of a brief diabetes knowledge test. *Diabetes Care* May;1998 21(5):706–710. [PubMed: 9589228]
17. Osborn CY, Davis TC, Bailey SC, Wolf MS. Health literacy in the context of HIV treatment: introducing the Brief Estimate of Health Knowledge and Action (BEHKA)-HIV version. *AIDS Behav* Feb;2010 14(1):181–188. [PubMed: 19023653]
18. Kazancioglu R, Ozturk S, Ekiz S, Yucel L, Dogan S. Can using a questionnaire for assessment of home visits to peritoneal dialysis patients make a difference to the treatment outcome? *J Ren Care* Jun;2008 34(2):59–63. [PubMed: 18498569]
19. Cavanaugh KL, Wingard RL, Hakim RM, Elasy TA, Ikizler TA. Patient dialysis knowledge is associated with permanent arteriovenous access use in chronic hemodialysis. *Clin J Am Soc Nephrol* May;2009 4(5):950–956. [PubMed: 19389825]
20. Coresh J, Byrd-Holt D, Astor BC, et al. Chronic kidney disease awareness, prevalence, and trends among U.S. adults, 1999 to 2000. *J Am Soc Nephrol* Jan;2005 16(1):180–188. [PubMed: 15563563]
21. Finkelstein FO, Story K, Firanek C, et al. Perceived knowledge among patients cared for by nephrologists about chronic kidney disease and end-stage renal disease therapies. *Kidney Int* Nov; 2008 74(9):1178–1184. [PubMed: 18668024]
22. Schatell D, Ellstrom-Calder A, Alt PS, Garland JS. Survey of CKD patients reveals significant gaps in knowledge about kidney disease. Part 2. *Nephrol News Issues* May;2003 17(6):17–19. [PubMed: 12778612]
23. Schatell D, Ellstrom-Calder A, Alt PS, Garland JS. Survey of CKD patients reveals significant GAPS in knowledge about kidney disease. Part 1. *Nephrol News Issues* Apr;2003 17(5):23–26. [PubMed: 12715623]
24. Rantanen M, Kallio T, Johansson K, Salanterä S, Virtanen H, Leino-Kilpi H. Knowledge Expectations of Patients on Dialysis Treatment. *Continuing Nursing Education* May-June;2008 35(3):249–255.
25. Costantini L, Beanlands H, McCay E, Cattran D, Hladunewich M, Francis D. The self-management experience of people with mild to moderate chronic kidney disease. *Continuing Nursing Education* March-April;2008 35(2):147–155.
26. Lewis AL, Stabler KA, Welch JL. Perceived informational needs, problems, or concerns among patients with Stage 4 Chronic Kidney Disease. *Nephrology Nursing Journal* March-April;2010 37(2):143–148. [PubMed: 20462074]
27. Jennette CE, Vupputuri S, Hogan SL, Shoham DA, Falk RJ, Harward DH. Community perspectives on kidney disease and health promotion from at-risk populations in rural North Carolina, USA. *Rural Remote Health* Apr-Jun;2010 10(2):1388. [PubMed: 20504048]
28. Devins GM, Mendelssohn DC, Barre PE, Taub K, Binik YM. Predialysis psychoeducational intervention extends survival in CKD: a 20-year follow-up. *Am J Kidney Dis* Dec;2005 46(6): 1088–1098. [PubMed: 16310575]
29. Mason J, Khunti K, Stone M, Farooqi A, Carr S. Educational interventions in kidney disease care: a systematic review of randomized trials. *Am J Kidney Dis* Jun;2008 51(6):933–951. [PubMed: 18440681]
30. Baker DW. The meaning and the measure of health literacy. *J Gen Intern Med* Aug;2006 21(8): 878–883. [PubMed: 16881951]

31. Devraj R, Gordon EJ. Health literacy and kidney disease: toward a new line of research. *Am J Kidney Dis* May;2009 53(5):884–889. [PubMed: 19324481]
32. Devins GM, Binik YM, Mandin H, et al. The Kidney Disease Questionnaire: a test for measuring patient knowledge about end-stage renal disease. *J Clin Epidemiol* 1990;43(3):297–307. [PubMed: 2313319]
33. Waterman AD, Browne T, Waterman BM, Gladstone EH, Hostetter T. Attitudes and behaviors of African Americans regarding early detection of kidney disease. *Am J Kidney Dis* Apr;2008 51(4):554–562. [PubMed: 18371531]
34. Schatell D, Wise M, Klicko K, Becker BN. In-center hemodialysis patients' use of the internet in the United States: a national survey. *Am J Kidney Dis* Aug;2006 48(2):285–291. [PubMed: 16860195]
35. Gordon EJ, Wolf MS. Health literacy skills of kidney transplant recipients. *Prog Transplant* Mar;2009 19(1):25–34. [PubMed: 19341060]
36. Chambers JK, Boggs DL. Development of an instrument to measure knowledge about kidney function, kidney failure, and treatment options. *ANNA J* Dec;1993 20(6):637–642. 650. discussion 643. [PubMed: 8267407]
37. Hejaili FF, Tamim H, Ghamdi GA, et al. Level of health awareness of Saudi patients on renal replacement therapy. *Saudi Med J* May;2007 28(5):747–751. [PubMed: 17457444]
38. Ormandy P. Information topics important to chronic kidney disease patients: A systematic review. *Journal of Renal Care* 2008;34(1):19–27. [PubMed: 18336519]
39. Coupe D. Making decisions about dialysis options: an audit of patients' views. *EDTNA ERCA J* Jan-Mar;1998 24(1):25–26. 31. [PubMed: 9873281]
40. Curtin RB, Walters BA, Schatell D, Pennell P, Wise M, Klicko K. Self-efficacy and self-management behaviors in patients with chronic kidney disease. *Adv Chronic Kidney Dis* Apr;2008 15(2):191–205. [PubMed: 18334246]
41. Macnicol AM, Wright AF, Watson ML. Education and attitudes in families with adult polycystic kidney disease. *Nephrol Dial Transplant* 1991;6(1):27–30. [PubMed: 2057113]
42. Murray MA, Brunier G, Chung JO, et al. A systematic review of factors influencing decision-making in adults living with chronic kidney disease. *Patient Educ Couns* Aug;2009 76(2):149–158. [PubMed: 19324509]
43. DeVellis, RF. *Scale Development: Theory and Applications*. 2. Thousand Oaks, CA: Sage Publications, Inc; 2003.
44. Rothman RL, Malone R, Bryant B, et al. The Spoken Knowledge in Low Literacy in Diabetes scale: a diabetes knowledge scale for vulnerable patients. *Diabetes Educ* Mar-Apr;2005 31(2):215–224. [PubMed: 15797850]
45. Glanz, K.; Rimer, BK.; Viswanath, K. *Health Behavior and Health Education*. 4. San Francisco, CA: John Wiley & Sons, Inc; 2008. Types of Validity; p. 492
46. National Kidney Foundation. KDOQI Clinical Practice Guidelines and Clinical Practice Recommendations for Diabetes and Chronic Kidney Disease. *Am J Kidney Dis* Feb;2007 49(2 Suppl 2):S12–154. [PubMed: 17276798]
47. Davis TC, Long SW, Jackson RH, et al. Rapid estimate of adult literacy in medicine: a shortened screening instrument. *Fam Med* Jun;1993 25(6):391–395. [PubMed: 8349060]
48. Levey AS, Coresh J, Balk E, Kausz AT, Levin A, Steffes MW, Hogg RJ, Perrone RD, Lau J, Eknoyan G. National Kidney Foundation practice guidelines for chronic kidney disease: Evaluation, classification, and stratification. *Ann Intern Med* 2003;139:137–147. [PubMed: 12859163]
49. Nanra RS, Stuart-Taylor J, de Leon AH, White KH. Analgesic nephropathy: etiology, clinical syndrome, and clinicopathologic correlations in Australia. *Kidney Int* Jan;1978 13(1):79–92. [PubMed: 362034]
50. Forel CM, Ejerblad E, Lindblad P, et al. Acetaminophen, aspirin, and chronic renal failure. *N Engl J Med* Dec 20;2001 345(25):1801–1808. [PubMed: 11752356]
51. Gooch K, Culleton BF, Manns BJ, et al. NSAID use and progression of chronic kidney disease. *Am J Med* Mar;2007 120(3):280, e281–287. [PubMed: 17349452]

52. Burton C, Harris KP. The role of proteinuria in the progression of chronic renal failure. *Am J Kidney Dis* Jun;1996 27(6):765–775. [PubMed: 8651239]
53. Weinman J, Yusuf G, Berks R, Rayner S, Petrie KJ. How accurate is patients' anatomical knowledge: a cross-sectional, questionnaire study of six patient groups and a general public sample. *BMC Fam Pract* 2009;10:43. [PubMed: 19523189]
54. Vassalotti JA, Stevens LA, Levey AS. Testing for chronic kidney disease: a position statement from the National Kidney Foundation. *Am J Kidney Dis* Aug;2007 50(2):169–180. [PubMed: 17660017]
55. Accetta NA, Gladstone EH, DiSogra C, Wright EC, Briggs M, Narva AS. Prevalence of estimated GFR reporting among US clinical laboratories. *Am J Kidney Dis* Oct;2008 52(4):778–787. [PubMed: 18676076]
56. den Hartog JR, Reese PP, Cizman B, Feldman HI. The costs and benefits of automatic estimated glomerular filtration rate reporting. *Clin J Am Soc Nephrol* Feb;2009 4(2):419–427. [PubMed: 19176794]
57. Wyatt C, Konduri V, Eng J, Rohatgi R. Reporting of estimated GFR in the primary care clinic. *Am J Kidney Dis* May;2007 49(5):634–641. [PubMed: 17472845]
58. National Kidney Disease Education Program. Resources Explaining Your Kidney Test Results, A Tear-Off Pad for Clinical Use. Jun. 2010
59. Rubin HR, Jenckes M, Fink NE, et al. Patient's view of dialysis care: development of a taxonomy and rating of importance of different aspects of care. CHOICE study. Choices for Healthy Outcomes in Caring for ESRD. *Am J Kidney Dis* Dec;1997 30(6):793–801. [PubMed: 9398123]
60. Powe NR, Thamer M, Hwang W, et al. Cost-quality trade-offs in dialysis care: a national survey of dialysis facility administrators. *Am J Kidney Dis* Jan;2002 39(1):116–126. [PubMed: 11774110]
61. Cavanaugh K, Wallston KA, Gebretsadik T, et al. Addressing literacy and numeracy to improve diabetes care: two randomized controlled trials. *Diabetes Care* Dec;2009 32(12):2149–2155. [PubMed: 19741187]
62. DeWalt DA, Malone RM, Bryant ME, et al. A heart failure self-management program for patients of all literacy levels: a randomized, controlled trial [ISRCTN11535170]. *BMC Health Serv Res* 2006;6:30. [PubMed: 16533388]
63. Jacobson TA, Thomas DM, Morton FJ, Offutt G, Shevlin J, Ray S. Use of a low-literacy patient education tool to enhance pneumococcal vaccination rates. A randomized controlled trial. *JAMA* Aug 18;1999 282(7):646–650. [PubMed: 10517717]
64. Kripalani S, Weiss BD. Teaching about health literacy and clear communication. *J Gen Intern Med* Aug;2006 21(8):888–890. [PubMed: 16881953]
65. Boulware LE, Carson KA, Troll MU, Powe NR, Cooper LA. Perceived susceptibility to chronic kidney disease among high-risk patients seen in primary care practices. *J Gen Intern Med* Oct; 2009 24(10):1123–1129. [PubMed: 19711135]
66. Department of Health and Human Services. Healthy People 2020 Public Meetings. 2009 Draft Objectives. [Accessed 5/8/2010]. CKD HP2020--14. <http://www.healthypeople.gov/HP2020/>
67. Devins GM, Mendelssohn DC, Barre PE, Binik YM. Predialysis psychoeducational intervention and coping styles influence time to dialysis in chronic kidney disease. *Am J Kidney Dis* Oct;2003 42(4):693–703. [PubMed: 14520619]
68. Nissenson AR, Collins AJ, Hurley J, Petersen H, Pereira BJ, Steinberg EP. Opportunities for improving the care of patients with chronic renal insufficiency: current practice patterns. *J Am Soc Nephrol* Aug;2001 12(8):1713–1720. [PubMed: 11461944]
69. Patwardhan MB, Samsa GP, Matchar DB, Haley WE. Advanced chronic kidney disease practice patterns among nephrologists and non-nephrologists: a database analysis. *Clin J Am Soc Nephrol* Mar;2007 2(2):277–283. [PubMed: 17699425]
70. Boulware LE, Troll MU, Jaar BG, Myers DI, Powe NR. Identification and referral of patients with progressive CKD: a national study. *Am J Kidney Dis* Aug;2006 48(2):192–204. [PubMed: 16860184]
71. Israni RK, Shea JA, Joffe MM, Feldman HI. Physician characteristics and knowledge of CKD management. *Am J Kidney Dis* Aug;2009 54(2):238–247. [PubMed: 19359079]

72. Department of Health & Human Services (DHHS), Centers for Medicare & Medicaid (CMS). CMS Manual System, Pub 100-04 Medicare Claims Processing, Transmittal 1876. Dec 182009 [January 25, 2010]. Accessed online at: <http://www.cms.gov/transmittals/downloads/R1876CP.pdf>

Figure 1.
Model of hypothesized associations with knowledge about chronic kidney disease

Table 1

Participant Characteristics, Stratified by CKD Stage

Participant Characteristic	All Participants n=401	CKD Stage			p-value
		1-2 (n=92)	3 (n=195)	4-5 (n=114)	
Age (years)	58 (46, 68)	40 (30,55)	62 (52, 69)	62 (54, 71)	<0.001
Male	213 (53)	46 (50)	105 (54)	62 (54)	0.8
Race					0.009
White	333 (83)	69 (75)	173 (89)	91 (80)	
Nonwhite	68 (17)	23 (25)	22 (11)	23 (20)	
Formal Educational Attainment ≥ High School Graduate	375 (94)	89 (97)	182 (93)	104 (91)	0.3
Health Literacy Level ≥ 9 th grade reading level	330 (82)	82 (89)	157 (81)	91 (80)	0.1
Annual Household Income					0.2
≤\$25,000	71 (19)	16 (18)	27 (15)	28 (26)	
\$25,001-\$55,000	128 (34)	28 (31)	68 (37)	32 (30)	
> \$55,000	181 (48)	46 (51)	88 (48)	47 (44)	
Self-reported kidney education class	67 (17)	0 (0)	19 (10)	48 (42)	<0.001
≥ 3 kidney provider visits in past year	232 (58)	41 (45)	103 (53)	88 (77)	<0.001
Know someone with CKD	198 (50)	41 (45)	94 (49)	63 (56)	0.3
Aware of 'Kidney Problem'	375 (94)	83 (90)	181 (93)	111 (97)	0.08
Aware of CKD Diagnosis	278 (69)	50 (54)	130 (67)	98 (86)	<0.001
Self Reported Diabetes (n=380)	145 (38)	18 (21)	76 (42)	51 (46)	0.001
Self Reported High BP (n=394)	338 (86)	71 (78)	162 (85)	105 (93)	0.01

Values are given as median (25th, 75th percentile) or n (%)

Abbreviations: BP, blood pressure; CKD, chronic kidney disease

Table 2

KiKS Individual Question Topics and Psychometric Testing Results,

Topic	Item Difficulty (% Correct)	Item-rest Correlation	Factor Loading
General Knowledge			
Reasons why protein in urine is a problem	19	0.079	0.052
Understanding increased risk of heart disease	66	0.35	0.43
Definition of 'GFR'	68	0.23	0.089
Medications a person with CKD should avoid	72	0.20	0.17
Treatment options for kidney failure	74	0.25	0.17
Understanding increased risk of mortality	78	0.25	0.35
Medications important to kidney health	84	0.17	0.15
Blood pressure goal	91	0.051	0.06
Knowing there are stages of CKD	93	0.22	0.19
Understanding CKD is a condition that does not go away	95	0.13	0.082
How kidney function is checked	96	-0.026	-0.10
Understanding high BP can hurt the kidneys	97	0.13	0.12
Understanding diabetes can hurt the kidneys	98	0.11	0.11
Number of kidneys a person normally has	99	0.091	0.13
Knowledge of kidney functions:			
Role in glucose control	40	0.0067	-0.17
Role in bone health	49	0.26	0.43
Role in BP control	68	0.25	0.41
Urine production	68	0.13	0.22
Role in anemia	71	0.30	0.44
Role in hair loss	78	0.040	-0.18
Role in phosphorus control	78	0.33	0.44
Role in potassium control	83	0.38	0.49
Role in waste clearance ('cleaning blood')	88	0.37	0.38
Knowledge of symptoms of progression or failure:			
No symptoms at all	22	0.071	0.11
Unusual itching	41	0.37	0.49
Confusion	48	0.37	0.50
Metallic/Bad taste	53	0.34	0.42
Shortness of breath	57	0.29	0.46
Difficulty sleeping	59	0.37	0.50
Blindness	59	-0.0061	-0.21
Nausea/vomiting	62	0.42	0.46
Weight loss	63	0.34	0.43
Hair loss	69	0.018	-0.19
Increased fatigue	93	0.32	0.34

Abbreviations: CKD, chronic kidney disease; BP, blood pressure; KiKS, kidney knowledge survey; GFR, glomerular filtration rate

Table 3

Associations between Kidney Knowledge Score and Patient Characteristics

Patient Characteristic	Unadjusted Model β Coefficient (95% CI)	p value	Adjusted Model [±] β Coefficient (95% CI)	p value
Age, per 10 years	−0.01 (−0.02 to −0.005)	0.003	−0.01 (−0.02 to −0.002)	0.02
Sex, male vs. female	−0.01 (−0.04 to 0.02)	0.4		
Race, Nonwhite vs white	0.02 (−0.02 to 0.06)	0.4		
Annual household income				
\$25,001–\$55,000 vs ≤ \$25,000	−0.01 (−0.06 to 0.03)	0.5		
> \$55,000 vs ≤ \$25,000	0.03 (−0.01 to 0.07)	0.2		
Stage of CKD				
Stage 3 vs Stages 1–2	−0.04 (−0.08 to −0.004)	0.03	−0.03 (−0.07 to 0.02)	0.2
Stages 4–5 vs Stages 1–2	0.003 (−0.04 to 0.04)	0.9	−0.004 (−0.05 to 0.04)	0.9
Formal Education, HS Graduate vs Non HS Graduate	0.09 (0.03 to 0.15)	0.004	0.05 (−0.009 to 0.11)	0.1
Health Literacy Level, ≥ 9th grade vs < 9th grade	0.06 (0.03 to 0.10)	0.001	0.05 (0.01 to 0.09)	0.04
Kidney education class, attended vs not attended	0.05 (0.01 to 0.09)	0.009	0.04 (0.002 to 0.09)	0.04
Number of visits in past year, ≥ 3 visits vs ≤ 2 visits	0.02 (−0.01 to 0.05)	0.2		
Know someone with CKD, Yes vs No	0.05 (0.02 to 0.08)	0.001	0.04 (0.009 to 0.07)	0.01
Aware of ‘Chronic Kidney Disease’ Diagnosis vs Not aware	0.07 (0.04 to 0.10)	<0.001	0.05 (0.02 to 0.09)	0.001

[±]The adjusted linear regression analysis includes age, stage of ckd, formal education, health literacy level, kidney education class, knowing someone with CKD, and awareness of CKD diagnosis. The R² for the adjusted model is 0.13

Abbreviations: HS, high school; CKD, chronic kidney disease