Awareness and Discussions About Chronic Kidney Disease Among African-Americans with Chronic Kidney Disease and Hypertension: a Mixed Methods Study

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BACKGROUND: Routine primary care visits provide an educational opportunity for African-Americans with chronic kidney disease (CKD) and CKD risk factors such as hypertension. The nature of patient-physician discussions about CKD and their impact on CKD awareness in this population have not been well explored.

OBJECTIVE: To characterize patient CKD awareness and discussions about CKD between patients and primary care physicians (PCPs).

DESIGN: Mixed methods study.

PATIENTS: African-American patients with uncontrolled hypertension ($\geq 140/90$ mmHg) and CKD (albuminuria or eGFR < 60 ml/min/1.73 m²) recruited from an urban primary care clinic.

MAIN MEASURES: We assessed patient CKD awareness with questionnaires and audio-recorded patients-PCP discussions during a routine visit. We characterized discussions and used multivariate regression analysis to identify independent patient and visit predictors of CKD awareness or CKD discussions.

RESULTS: Among 48 African-American patients with uncontrolled hypertension and CKD, 29% were aware of their CKD. After adjustment, CKD awareness was associated with moderate-severe CKD (stages 3–4) (vs. mild CKD [stages 1–2]) (prevalence ratio [PR] 2.82; 95% CI 1.18–6.78) and inversely associated with diabetes (vs. without diabetes) (PR 0.28; 95% CI 0.10–0.75). CKD discussions occurred in 30 (63%) visits; most focused on laboratory assessment ($n = 23$, 77%) or risk factor management to delay CKD progression ($n = 19$, 63%). CKD discussions were associated with moderate-severe CKD (vs. mild CKD) (PR 1.57; 95% CI 1.04–2.36) and diabetes (vs. without diabetes) (PR 1.42; 95% CI 1.09–1.85), and inversely associated with uncontrolled hypertension (vs. controlled)

(PR 0.58; 95% CI 0.92–0.89). In subgroup analysis, follow-up CKD awareness did not change by presence or absence of CKD discussion (10.5% vs. 7.7%, $p = 0.8$).

CONCLUSIONS: In patients at risk of CKD progression, few were aware of CKD, and CKD discussions were not associated with CKD awareness. More resources may be needed to enhance the clarity of clinical messages regarding CKD and its significance for patients' health.

TRIAL REGISTRATION: [ClinicalTrials.gov](https://clinicaltrials.gov) Identifier: NCT01902719

KEY WORDS: chronic kidney disease; primary care; chronic disease; awareness; hypertension.

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INTRODUCTION

Chronic kidney disease (CKD) is associated with significant morbidity and mortality, especially among those who develop end-stage kidney disease (ESKD).^{1–5} African-Americans, who have poorer control of CKD risk factors, including hypertension and diabetes, as well as greater prevalence of advanced kidney disease, are disproportionately affected by CKD and its associated cardiovascular morbidity and mortality.^{1, 6–10} Patients' awareness and understanding of their CKD diagnosis, and its implications for future health status, may motivate their greater adherence to self-management of CKD helping to prevent or delay CKD progression.^{8, 11} However, patients' awareness and understanding of CKD are persistently low, ranging from 23 to 40%.^{12–15}

Patients often receive information about their CKD diagnosis and risk factors from their primary care physicians (PCPs).^{8, 16–19} However, PCPs may sub-optimally recognize the presence of CKD and infrequently discuss CKD with patients.^{16, 17} Despite this, primary care-based discussions about CKD have not been well characterized, and the extent

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to which patients' awareness of CKD is associated with their discussions with PCPs is unclear.

In a study of African-Americans with uncontrolled hypertension and CKD who received primary care at an urban clinic, we sought to quantify patients' awareness of CKD and predictors of awareness. We also sought to describe patient and clinic visit predictors of patient-physician discussions about CKD, and to explore the content of these discussions. We hypothesized that patients' awareness of CKD would be low, but that patient-centered encounters would use clear language to discuss CKD and would improve awareness.

METHODS

Study Design and Population

We conducted a cross-sectional study among African-Americans with CKD and uncontrolled hypertension using data from the Achieving Blood Pressure Control Together (ACT) study, a single-center, pragmatic randomized comparative effectiveness trial that studied the effectiveness of self-management interventions in improving blood pressure control for socially disadvantaged African-Americans receiving primary care.²⁰ Between September 2013 and September 2014, the ACT study enrolled 159 African-American participants who received primary care in an urban clinic in Baltimore, MD. Eligible participants were identified through the electronic health record if they were English-speaking, aged ≥ 18 years, self-identified as African-American, and had uncontrolled hypertension, as defined by two measures of systolic blood pressure ≥ 140 mmHg or diastolic blood pressure ≥ 90 mmHg in the 6-month time period prior to recruitment.²⁰ After enrollment, participants were randomly assigned to an intervention arm with community health worker (CHW), CHW with communication skills training, or CHW plus problem-solving skills training.²⁰ Participants were asked if the next regularly scheduled visit with their PCP could be audio-recorded. These routine clinic visits occurred after enrollment and were not linked to study interventions. Participants' PCPs were consented. All eight physicians were English-speaking. No additional provider characteristics were collected.²⁰

We studied a subset of ACT participants ($n = 62$) with uncontrolled hypertension and CKD based on study enrollment laboratory results (either presence of albuminuria [urine albumin-to-creatinine ratio > 30 mg/g] or estimated glomerular filtration rate (eGFR) < 60 ml/min/1.73 m²).¹¹ To be included in our analyses, participants had to have available data on age, and sex, completed questionnaires about CKD awareness, and consented to having their routine clinic visit audio-recorded. We excluded ACT study participants with an eGFR < 15 ml/min/1.73 m², since awareness and clinical care may differ in patients with kidney failure. Participants provided verbal consent to have all questionnaire, physical examination, and audio-recorded data collected. Companions provided

written consent to be audio-recorded if present at participants' clinic visits. The parent ACT study followed participants for 12 months. We used study enrollment data for cross-sectional analyses, and we used 4-month data to assess changes in participants' CKD awareness. This study was approved by the Johns Hopkins and Duke University institutional review boards and registered with [ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT01902719) (NCT01902719).

Data Collection

At enrollment, participants completed structured telephone interviews and in-person questionnaires to obtain data on sociodemographic characteristics and medical history. All demographic, questionnaire, and audio-recorded data used in this study were collected as part of the parent ACT study. The parent ACT study also collected anthropometric measures (height, weight), blood pressure readings, and blood and urine samples at study enrollment. Participants received reports on study laboratory results in the mail after enrollment.

Patient Characteristics

We used the Charlson Comorbidity Index²¹ to characterize participants' self-reported comorbidities (myocardial infarction, cerebrovascular accident, hypertension, heart failure, peripheral arterial disease, chronic obstructive pulmonary disease, diabetes, cancer, dementia, cirrhosis, HIV/AIDS), dichotomized at cumulative score ≥ 3 based on literature and median distribution of data.¹⁶ We assessed literacy with the Wide Range Achievement Test.²² Participants completed the short form Patient Activation Measure (PAM), a validated 13-question uni-dimensional assessment of self-reported knowledge, skill, and confidence to manage chronic disease.²³ Scores were translated to standardized levels (level 1, ≤ 47 ; level 2, 47.1–55.1; level 3, 55.2–72.4; level 4, score ≥ 72.5), with higher levels representing greater patient activation and engagement.²³ We calculated eGFR with the CKD-EPI formula.²⁴ We defined CKD stages using the Kidney Disease: Improving Global Outcomes (KDIGO) criteria: stage 1 with eGFR > 90 ml/min/1.73 m² and presence of albuminuria; stage 2 with eGFR 60–90 ml/min/1.73 m² and presence of albuminuria; stage 3 with eGFR 30–59 ml/min/1.73 m²; and stage 4 with eGFR 15–29 ml/min/1.73 m².²⁵ Poor glycemic control was defined as hemoglobin A1c $> 7\%$.²⁶

Assessment of CKD Awareness and Patient-Physician Discussions About CKD

At enrollment and 4-month follow-up, we assessed participants' awareness of CKD by asking, "Do you have a kidney problem or chronic kidney disease?" (Yes or No). We characterized whether participants reporting no awareness at enrollment reported the presence of awareness at 4 months.

Participant-physician discussions that related only to CKD were transcribed verbatim for content analysis by trained

research assistants.²⁷ Only participant and PCP voices were heard on audio-recordings. Using a deductive and inductive approach, two members (KAM, RCG) independently reviewed all transcripts and then coded text segments representing relevant concepts that emerged during participant-physician discussions about CKD. A priori codes were derived from the literature¹⁶ and additional codes were inductively derived from the transcriptions until no new concepts emerged. The coders then compared, discussed, and reconciled differences in codes and organized the codes by similarity in concept to create a final list of hierarchical themes and subthemes. Negative case analysis was used to revise hypothetical themes,²⁸ and the final coding scheme was applied to transcripts. Final themes and sub-themes were reviewed by all study authors.

We characterized patient-physician communications using the Roter Interaction Analysis System (RIAS).²⁹ The RIAS assigns a mutually exclusive code to each complete thought by participant or physician. These codes are combined to create a patient-centeredness score, operationalized as a ratio of statements encompassing the patient's socioemotional and psychosocial agenda versus the physician's biomedical and procedural agenda.^{29, 30} Higher scores indicate a more patient-centered visit. Physician verbal dominance was determined using the total number of physician statements divided by the total patient statements. Scores greater than 1 indicate greater physician verbal dominance.²⁹ We also measured visit total duration and classified it into tertiles (short, medium, long).

Statistical Analysis

We described participants' CKD awareness and the prevalence of visits that included a discussion about at least one of the following chronic diseases: CKD, hypertension, or diabetes. We performed bivariate (chi-square) analyses to identify characteristics associated with our outcomes of interest (1) awareness of CKD and (2) discussion about CKD. We dichotomized severity of CKD as mild (stages 1 and 2 for participants with $\text{eGFR} \geq 60 \text{ ml/min/1.73 m}^2$ with proteinuria) versus moderate-severe (stages 3 and 4 for participants with $\text{eGFR} < 60 \text{ ml/min/1.73 m}^2$ with or without proteinuria). We dichotomized age (< 65 years vs. ≥ 65 years) and PAM score at the median distribution of data (levels 1–3 vs. level 4). We used a two-sample *t* test with unequal variance to compare the length of visits which contained (versus did not contain) discussions about CKD. Because the prevalence of CKD awareness and discussions were $> 10\%$, we used multivariate log-binomial regression³¹ to estimate the prevalence ratio of CKD awareness or discussions among participants with given patient and visit characteristics. We used Poisson regression analyses with robust variance when binomial regression models failed to converge.³¹ Multivariate regression models included only participant or visit covariates of statistical significance ($p < 0.05$) from bivariate analysis or clinical significance based on prior literature.^{16, 32} Multivariate analysis for presence of discussion

accounted for clustering of participants by physician and their parent study intervention status. In a subgroup of participants unaware of CKD diagnosis at study enrollment and with CKD awareness data at 4 months, we used bivariate analysis to assess whether presence of discussion was associated with CKD awareness at 4-month follow-up. Stata SE 15 (StataCorp LLC, College Station, TX) was used for statistical analysis.

RESULTS

Characteristics of Participants

Among 62 participants in our initial study sample, we excluded 5 participants with ESKD and 9 participants with no audiotape available, for a final study sample of 48 participants. The median age was 58.8 years and two-thirds were women (Table 1). Forty-two percent had not completed high school and 56% read at greater than a 6th grade level. At study enrollment, 63% of participants were obese and 65% had diabetes. Of those with diabetes, two-thirds had poor glycemic control. While all participants had uncontrolled blood in the six months prior to study recruitment, 73% had uncontrolled blood pressure at study enrollment. Fifty-four percent had albuminuria ($> 30 \text{ mg/g}$) and 35% had severely elevated albuminuria ($> 300 \text{ mg/g}$). Using KDIGO criteria, 25% had stage 1, 35% had stage 2, 33% had stage 3, and 6% had stage 4 CKD. Participants included in the study did not differ significantly from excluded participants by enrollment characteristics.

Prevalence and Predictors of Patient Awareness of CKD

At enrollment, less than one-third ($n = 14$, 29%) of participants were aware of their CKD. Participants with more advanced CKD were more aware of CKD diagnosis at enrollment (Fig. 1). In multivariate analysis, CKD awareness was lower among those with diabetes (PR 0.28; 95% CI 0.10–0.75) and higher among those with moderate-severe CKD (i.e., stages 3 and 4) (PR 2.82; 95% CI 1.18–6.78) (Table 2). CKD awareness was not associated with patient or other clinical characteristics (e.g., blood pressure control at study enrollment) (Table 2).]

Prevalence, Characteristics, and Predictors of Patient-Physician Discussions About CKD

Routine clinic visits occurred a median of 51.5 days (IQR 20–93.5) after study enrollment. Almost two-thirds of the participants ($n = 30$, 63%) had a discussion about CKD with their PCP. In contrast, 98% of participants discussed hypertension and among participants with diabetes, 94% discussed diabetes. Visits with discussions about CKD were longer than visits without discussions about CKD (mean length (SD) 26.2 min (12.3) versus 22.1 min (10.1)); however, this difference did not reach statistical significance ($p = 0.21$). When CKD was discussed, it was discussed for 1 min or less in half of the visits

Table 1 Demographic Characteristics of Patients at Study Enrollment

Characteristic	Total (%) (n = 48)
Age, median years (min, max)	58.8 (32.5, 82.4)
Age $\geq$ 65 years, n (%)	15 (31)
Male, n (%)	16 (33)
Less than high school diploma, n (%)	20 (42)
Reading level $\leq$ 6th grade, n (%)	27 (56)
Annual household income $<$ \$10,000, n (%)	13 (27)
Obese (BMI $\geq$ 30), n (%)	30 (63)
Blood pressure $\geq$ 140/90 mmHg, n (%)	35 (73)
Diabetes, presence of	31 (65)
Diabetes with A1c $>$ 7%, n (%)*	21 (68)
Albuminuria	
$<$ 30 mg/g	5 (10)
30–300 mg/g	26 (54)
$>$ 300 mg/g	17 (35)
KDIGO stage of CKD, n (%)	
Stage 1 (eGFR $>$ 90 ml/min/1.73 m ² and albuminuria)	12 (25)
Stage 2 (eGFR 60–90 ml/min/1.73 m ² and albuminuria)	17 (35)
Stage 3 (eGFR 30–59 ml/min/1.73 m ²)	16 (33)
Stage 4 (eGFR 15–29 ml/min/1.73 m ²)	3 (6)
Charlson Comorbidity Index $\geq$ 3, n (%)	26 (54)
Patient Activation Measure score	
Level 1 ($<$ 55.2)	0 (0)
Level 2 ($<$ 55.2)	9 (19)
Level 3 (55.2–72.5)	21 (44)
Level 4 ($>$ 72.5)	18 (38)

*n = 31 for patients with diabetes

BMI body mass index, BP blood pressure, CKD chronic kidney disease, eGFR estimated glomerular filtration rate

and more than 5 min in three visits. Most visits were not patient-centered (median patient-centeredness score = 0.69, IQR 0.48–0.89) and physicians spoke 24% more than participants (median verbal dominance score = 1.24, IQR 0.96–1.55).

In multivariate models, discussions about CKD were associated with participants with advanced CKD (e.g., stages 3 and 4) (PR 1.57; 95% CI 1.04–2.36) or diabetes (PR 1.42; 95% CI 1.09–1.85), but was less common in participants who had uncontrolled blood pressure (PR 0.58; 95% CI 0.38–0.90) (Table 3). The presence of discussions about CKD was not associated with other participant or visit characteristics.

Content of Discussions About CKD

Participant-physician discussions about CKD focused on five main themes: diagnosis, assessment and review of laboratory data, management to delay CKD progression, complications of CKD, and coordination of care with nephrologist (Table 4). Among 30 visits with a CKD discussion, PCPs used different terminology to describe CKD. The most common terms conveyed kidney dysfunction or damage (i.e., “kidneys are abnormal” or “early sign of kidney damage”) (n = 6, 20%). The term “chronic kidney disease” was used once (3%).

Blood or urine test results related to CKD were reviewed or recommended during 23 (77%) visits. Most discussions about

Figure 1 Awareness of chronic kidney disease (CKD) at study enrollment stratified by CKD stage (stage 1 with eGFR $>$ 90 ml/min/1.73 m² and albuminuria, stage 2 with eGFR 60–90 ml/min/1.73 m² and albuminuria, stage 3 with eGFR 30–59 ml/min/1.73 m², and stage 4 with eGFR 15–29 ml/min/1.73 m²).

Table 2 Association of Awareness of Chronic Kidney Disease at Study Enrollment and Patient Demographic and Clinical Covariates

	Univariable analysis		Multivariate analysis*	
	Prevalence ratio (95% CI)	p value	Prevalence ratio (95% CI)	p value
Age				
< 65 years	Ref	0.67	Ref	0.49
≥ 65 years	1.22 (0.49–3.03)		1.33 (0.59–2.95)	
Sex				
Female	Ref	0.66	Ref	0.26
Male	0.80 (0.30–2.72)		1.57 (0.72–3.41)	
eGFR				
≥ 60 ml/min/1.73 m ²	Ref	0.03	Ref	0.02
< 60 ml/min/1.73 m ²	2.75 (1.09–6.95)		2.82 (1.18–6.78)	
Highest education attained				
≥ High school diploma	Ref	0.38		
< High school diploma	1.52 (0.60–3.81)			
Reading level				
> 6th grade	Ref	0.24		
≤ 6th grade	0.58 (0.24–1.42)			
Annual household income				
> \$10,000	Ref	0.99		
≤ \$10,000	0.99 (0.37–2.64)			
Obesity (BMI ≥ 30)				
No	Ref	0.87		
Yes	1.08 (0.43–2.72)			
Blood pressure				
< 140/90 mmHg	Ref	0.58	Ref	0.72
≥ 140/90 mmHg	1.36 (0.45–4.12)		1.26 (0.35–4.53)	
Diabetes				
No	Ref	0.01	Ref	0.01
Yes	0.30 (0.12–0.76)		0.28 (0.10–0.75)	
Diabetes control (among persons with diabetes)				
A1c ≤ 7%	Ref	0.54		
A1c > 7%	1.90 (0.24–14.91)			
Charlson Comorbidity Index				
< 3	Ref	0.32		
≥ 3	0.63 (0.26–1.55)			
Patient Activation Measure				
Levels 1–3	Ref	0.62		
Level 4	1.25 (0.52–3.02)			

eGFR estimated glomerular filtration rate, BMI body mass index, CKD chronic kidney disease

*Multivariate analyses adjusted for age, sex, eGFR, blood pressure control, and diabetes

lab tests were brief and few participants ($n = 9$, 30%) were provided with a clear explanation of the test purpose or implications for clinical care. Some participants ($n = 5$, 17%) and physicians ($n = 2$, 25%) referenced lab results from the ACT study.

Risk factor management to delay CKD progression was discussed in 19 (63%) visits. Management strategies discussed included control of diabetes ($n = 6$ visits, 20%), control of blood pressure ($n = 7$ visits, 23%), reduction of albuminuria with ACE inhibitors or angiotensin receptor blockers (ARBs) ($n = 5$ visits, 17%), medication safety ($n = 11$ visits, 37%) including avoidance of NSAIDs or adjustment of medication, and lifestyle modifications ($n = 4$ visits, 13%) including diet and exercise. The consequences of CKD, such as symptoms (e.g., fluid overload) or progression to dialysis, were discussed at 5 (17%) visits. In a few discussions, ($n = 3$, 10%) dialysis appeared to be used as a scare tactic to motivate patients to improve their self-management of their CKD risks. Some discussions also focused on care coordination with nephrologists ($n = 8$, 27%), including need for appointments or update after nephrology visits.

Change in Awareness of CKD

Among the subgroup of 32 participants who were unaware of CKD diagnosis at study enrollment and had awareness data at 4-month follow-up, most ($n = 19$, 59%) participants had a discussion about CKD. Among those with a CKD discussion, 2 (10.5%) improved their awareness, compared with 1 (8%) who did not have a discussion about CKD ($p = 0.79$).

DISCUSSION

We found awareness of CKD was low among urban primary care patients at high risk for CKD progression, particularly among those with earlier stage CKD or diabetes. Two-thirds of routine primary care visits included discussions about CKD. However, the majority of discussions about CKD were brief (less than 1 min), and most focused on laboratory data or management of risk factors to delay CKD progression. CKD discussions occurred less frequently than discussions about diabetes or hypertension. CKD discussions were most common among people with more advanced stage CKD, controlled blood pressure, and diabetes. Among participants not

Table 3 Association Between Presence of Chronic Kidney Disease Discussion and Patient Demographic and Clinical Covariates

	Univariable analysis		Multivariate analysis*	
	Prevalence ratio (95% CI)	p value	Prevalence ratio (95% CI)	p value
Age				
< 65 years	Ref	0.41	Ref	0.10
≥ 65 years	0.80 (0.47–1.36)		0.60 (0.33–1.09)	
Sex				
Female	Ref	1.00	Ref	0.31
Male	1.00 (0.63–1.60)		0.88 (0.69–1.13)	
eGFR				
≥ 60 ml/min/1.73 m ²	Ref	0.049	Ref	0.03
< 60 ml/min/1.73 m ²	1.53 (1.00–2.33)		1.57 (1.04–2.36)	
Length of visit				
Short/medium (< 26.8 min)	Ref	0.51		
Long (> 26.8 min)	1.16 (0.75–1.79)			
Patient-centered				
Low/med tercile (< 0.8)	Ref	0.51		
High tercile (> 0.8)	1.16 (0.75–1.79)			
Verbal dominance by physician				
No	Ref	0.22		
Yes	1.49 (0.79–2.79)			
Blood pressure				
< 140/90 mmHg	Ref	0.002	Ref	0.02
≥ 140/90 mmHg	0.56 (0.39–0.80)		0.58 (0.38–0.90)	
Diabetes				
No	Ref	0.34	Ref	0.01
Yes	1.28 (0.77–2.13)		1.42 (1.09–1.85)	
Diabetes control (among persons with diabetes)				
A1c ≤ 7%	Ref	0.08		
A1c > 7%	2.02 (0.92–4.45)			
Charlson Comorbidity Index				
< 3	Ref	0.88		
≥ 3	0.97 (0.62–1.50)			
Awareness of CKD at study enrollment				
No	Ref	0.22		
Yes	1.21 (0.79–1.88)			
Patient Activation Measure				
Levels 1–3	Ref	0.88		
Level 4	0.96 (0.61–1.53)			

eGFR estimated glomerular filtration rate, BMI body mass index, CKD chronic kidney disease

*Multivariate analyses adjusted for age, sex, eGFR, blood pressure, and diabetes, intervention status, and physician. Intervention status was not associated with presence of discussion surrounding CKD ($p = 0.73$)

aware of their CKD diagnosis at study enrollment, CKD discussions were not associated with greater CKD awareness.

To our knowledge, our study is the first to explore the association of CKD discussions with patient awareness of CKD. We observed more frequent discussions about CKD, compared with the only other primary care study (67% vs. 33% respectively).¹⁶ However, this prior study similarly identified that CKD discussions as short and focusing on laboratory assessment, treatment of risk factors, and cause of CKD.¹⁶ While finding of more frequent discussions could reflect improved PCP focus on CKD discussion since the prior study, it could also reflect differences in study design. For instance, ACT participants were mailed their study laboratory results, which may have prompted subsequent CKD discussions by both participants and PCPs. Our finding that 29% were aware of CKD is consistent with prior work demonstrating 6–40% awareness of CKD in national surveys^{12, 32–35} and outpatient settings.^{36, 37} In contrast to other studies noting an association between CKD awareness and diagnosis of diabetes,^{12, 32} we did not find this association. This may reflect not only

differences in study populations (e.g., potentially worse diabetes severity among participants in other studies)^{12, 32} but also the use of different questions (with varying sensitivity) across studies to ascertain CKD awareness.^{12, 13, 32}

The quality of CKD discussions may have contributed to the lack of association between discussions and patient awareness. Specifically, physicians described CKD inconsistently, rarely referring to it as “chronic kidney disease” and more commonly discussing “kidney damage”. Physicians also often discussed CKD as a consequence of hypertension or diabetes or in the context of laboratory testing or logistical coordination of subspecialty care, potentially hindering participants’ recognition of CKD as a distinct medical concern. While encouraging discussions about CKD in the context of other comorbidities may address visit time constraints,³⁸ efforts to identify CKD as a unique clinical problem requiring independent monitoring and treatment could help raise patients’ awareness. Measures of patient-centeredness, which have been shown to influence health behaviors and outcomes,^{39, 40} were not associated with the presence of CKD discussions. It is possible

Table 4 Major Themes and Sub-themes from Patient-Physician Discussions About Chronic Kidney Disease with Representative Quotations

	Representative quotations
Diagnosis of CKD	"...like I said, your kidneys are not exactly working perfectly" (physician 8) "This goes along with your chronic kidney disease." (physician 5)
Assessment and review of laboratory data	"So the first test we're looking at is the kidney function test, the creatinine. Your number is exactly stable with what we've been seeing, your number has been between 1.3 and 1.4... which is actually an improvement from a year ago." (physician 4) "Now you're due for some blood work. Gotta check on your kidneys and we'll see where everything else is." (physician 1) "We definitely do need to see what's happening with your kidney's function, so if you could come tomorrow. I won't make any changes to any medicines until we have that number back." (physician 8)
Management to delay CKD progression	
Control of risk factors	"Well, if you control your blood pressure better, maybe your kidney test will improve." (physician 6) "Um but really the most critical thing is to get the diabetes under control. Because those [blood pressure] medications can really only do so much. The critical thing really is to get those sugars down." (physician 4)
ACE inhibitors and ARBs	"It's the Irbesartan...It's for blood pressure and it also protects the kidneys, especially when they're not filtering protein properly. (physician 6) "...so there are a group of blood pressure medicines that have been shown to slow down that type of damage in the kidneys. ...since we've seen two urine tests that show a little bit of that protein and the fact that the blood pressure is not quite as good as we need it to be yet, what I would like to recommend to you is that we add a low dose of one of these medicines to what you're already taking." (physician 4)
Medication safety	"Unfortunately, when they drew your blood in June, your kidney test was worse, so you can't take Metformin now." (physician 6) "I know we talked about not taking the aleve or advil, Right? because of your kidneys". (physician 2)
Complications of CKD	"And the reason for the bloodwork tomorrow, like I said, your kidneys are not exactly working perfectly which may also be part of the reason that you're swelling so we want to make sure nothing has changed with that." (physician 8) "And another one who had kidney failure, she's on dialysis. And she had a lot of complications with fluids. Fluid, fluid, fluid. Back and forth to the hospital." (physician 7)
Coordination of care with a nephrologist	"So, we have to refer you to a nephrologist to sit down and talk to you about your kidneys." (physician 5) "Yeah. So here I'm kind of reviewing the kidney, you saw the nephrologist almost 4 months ago." (physician 3)

improved communication could facilitate greater patient engagement around the health implications and management of CKD.

Targeted interventions are needed that address the challenges PCPs experience with CKD management. PCPs report significant barriers to CKD patient education, including time, knowledge, and skills to discuss CKD, and insufficient ancillary support (e.g., staff resources).^{38, 41–45} Just as diabetes education has expanded to include nurses, pharmacists, and other health professionals,⁴⁶ the CKD education team could expand utilizing similar resources. Educational tools and training in CKD could also improve primary care teams' capacity to care for patients with CKD. For example, the NIH/NIDDK Kidney Results Tear-Off Pad equips PCPs with a two-page guide to facilitate patient engagement around CKD diagnosis and self-management, including figures and clear explanations of kidney function, diagnosis of CKD (defining terminology of albuminuria and eGFR), and risk factor modification (blood pressure, glycemic control, diet).^{47, 48} Use of effective strategies of asking for "teach back" may also help clarify and reinforce clinical messages about CKD.⁴⁹ Finally, electronic decision support could help alleviate clinical uncertainty by identifying patients with CKD and facilitating access to patient education tools about CKD during busy primary care encounters.^{50–53}

Our study has limitations. First, this was a small study of African-American patients at a single urban primary care clinic, which may limit generalizability to other practice settings or populations. We did not collect provider-level data to

assess whether provider characteristics were associated with CKD awareness or discussion. However, our findings were consistent with work demonstrating low awareness of CKD in outpatient settings.^{12, 32} Second, the estimated prevalence of CKD awareness could vary based on how awareness is ascertained.^{13, 15} While we tried to maximize the sensitivity of our measure by incorporating two phrases to describe CKD,^{13, 15} it is possible that our observed prevalence of CKD awareness may underestimate the true prevalence of CKD awareness. Third, we analyzed discussions occurring during single clinical visits, which may not reflect prior discussions about CKD. However, our findings are consistent with an earlier study of low frequency of CKD discussions in primary care.¹⁶ Finally, our analysis of discussions focused exclusively on discussions related to CKD and did not include discussions of other topics or comorbidities. It is possible that understanding additional context to the visit discussions could shed light on why limited CKD discussions occurred.

In conclusion, awareness of CKD was low among African-American patients at high risk for CKD progression in primary care. Patient-physician discussions about CKD during routine visits were sub-optimal and were not associated with patients' awareness of CKD. Future efforts to improve the frequency and quality of patient-physician discussions about CKD could improve patients' awareness and self-management of their CKD progression risks.

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Compliance with Ethical Standards:

Participants provided verbal consent to have all questionnaire, physical examination, and audio-recorded data collected. Participants' PCPs also provided consent. Companions provided written consent to be audio-recorded if present at participants' clinic visits. This study was approved by the Johns Hopkins and Duke University institutional review boards and registered with [ClinicalTrials.gov](https://www.clinicaltrials.gov) (NCT01902719).

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REFERENCES

- Sarnak MJ, Levey AS, Schoolwerth AC, Coresh J, Culleton B, Hamm LL, McCullough PA, Kasiske BL, Kelepouris E, Klag MJ, Parfrey P, Pfeffer M, Raij L, Spinosa DJ, Wilson PW. American Heart Association Councils on Kidney in Cardiovascular Disease HBP/CC, Epidemiology, Prevention. Kidney disease as a risk factor for development of cardiovascular disease: a statement from the American Heart Association Councils on Kidney in Cardiovascular Disease, High Blood Pressure Research, Clinical Cardiology, and Epidemiology and Prevention. Hypertension (Dallas, Tex : 1979). 2003;42(5):1050-1065.
- Lloyd-Jones D, Adams R, Carnethon M, De Simone G, Ferguson TB, Flegal K, Ford E, Furie K, Go A, Greenlund K, Haase N, Hailpern S, Ho M, Howard V, Kissela B, Kittner S, Lackland D, Lisabeth L, Marelli A, McDermott M, Meigs J, Mozaffarian D, Nichol G, O'Donnell C, Roger V, Rosamond W, Sacco R, Sorlie P, Stafford R, Steinberger J, Thom T, Wasserthiel-Smoller S, Wong N, Wylie-Rosett J, Hong Y. Heart disease and stroke statistics-2009 update: a report from the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. Circulation. 2009;119(3):480-486.
- Center for Disease Control. National Chronic Kidney Disease Fact Sheet 2017. 2017. https://www.cdc.gov/diabetes/pubs/pdf/kidney_factsheet.pdf. Accessed September 24, 2019.
- Coresh J, Selvin E, Stevens LA, Manzi J, Kusek JW, Eggers P, Van Lente F, Levey AS. Prevalence of chronic kidney disease in the United States. Jama. 2007;298(17):2038-2047.
- Levey AS, Astor BC, Stevens LA, Coresh J. Chronic kidney disease, diabetes, and hypertension: what's in a name? Kidney Int. 2010;78(1):19-22.
- Norton JM, Moxey-Mims MM, Eggers PW, Narva AS, Star RA, Kimmel PL, Rodgers GP. Social Determinants of Racial Disparities in CKD. J Am Soc Nephrol. 2016;27(9):2576-2595.
- Crews DC, Pfaff T, Powe NR. Socioeconomic factors and racial disparities in kidney disease outcomes. Semin Nephrol. 2013;33(5):468-475.
- Narva AS, Norton JM, Boulware LE. Educating Patients about CKD: The Path to Self-Management and Patient-Centered Care. Clin J Am Soc Nephrol. 2016;11(4):694-703.
- Tarver-Carr ME, Powe NR, Eberhardt MS, LaVeist TA, Kington RS, Coresh J, Brancati FL. 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. 2002;13(9):2363-2370.
- Hsu CY, Lin F, Vittinghoff E, Shlipak MG. Racial differences in the progression from chronic renal insufficiency to end-stage renal disease in the United States. J Am Soc Nephrol. 2003;14(11):2902-2907.
- Stevens PE, Levin A. Kidney Disease: Improving Global Outcomes Chronic Kidney Disease Guideline Development Work Group M. Evaluation and management of chronic kidney disease: synopsis of the kidney disease: improving global outcomes 2012 clinical practice guideline. Ann Intern Med. 2013;158(11):825-830.
- Nickolas TL, Frisch GD, Opatowsky 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. 2004;44(2):185-197.
- Tuot DS, Zhu Y, Velasquez A, Espinoza J, Mendez CD, Banerjee T, Hsu CY, Powe NR. Variation in Patients' Awareness of CKD according to How They Are Asked. Clin J Am Soc Nephrol. 2016;11(9):1566-1573.
- Wright JA, Wallston KA, Elasy TA, Ikizler TA, Cavanaugh KL. Development and results of a kidney disease knowledge survey given to patients with CKD. Am J Kidney Dis. 2011;57(3):387-395.
- Tuot DS, Wong KK, Velasquez A, Crews DC, Zonderman AB, Evans MK, Powe NR. CKD Awareness in the General Population: Performance of CKD-Specific Questions. Kidney Med. 2019;1(2):43-50.
- Greer RC, Cooper LA, Crews DC, Powe NR, Boulware LE. Quality of Patient-Physician Discussions About CKD in Primary Care: A Cross-sectional Study. Am J Kidney Dis. 2011;57(4):583-591.
- Allen AS, Forman JP, Orav EJ, Bates DW, Denker BM, Sequist TD. Primary Care Management of Chronic Kidney Disease. J Gen Intern Med. 2011;26(4):386-392.
- Vassalotti JA, Centor R, Turner BJ, Greer RC, Choi M, Sequist TD. National Kidney Foundation Kidney Disease Outcomes Quality I. Practical Approach to Detection and Management of Chronic Kidney Disease for the Primary Care Clinician. Am J Med. 2016;129(2):153-162 e157.
- Lo C, Illic D, Teede H, Fulcher G, Gallagher M, Kerr PG, Murphy K, Polkinghorne K, Russell G, Usherwood T, Walker R, Zoungas S. Primary and tertiary health professionals' views on the health-care of patients with co-morbid diabetes and chronic kidney disease - a qualitative study. BMC Nephrol. 2016;17(1):50.
- Ephraim PL, Hill-Briggs F, Roter DL, Bone LR, Wolff JL, Lewis-Boyer L, Levine DM, Aboumatar HJ, Cooper LA, Fitzpatrick SJ, Gudzone KA, Albert MC, Monroe D, Simmons M, Hickman D, Purnell L, Fisher A, Matens R, Noronha GJ, Fagan PJ, Ramamurthi HC, Ameling JM, Charlston J, Sam TS, Carson KA, Wang NY, Crews DC, Greer RC, Sneed V, Flynn SJ, DePasquale N, Boulware LE. Improving urban African Americans' blood pressure control through multi-level interventions in the Achieving Blood Pressure Control Together (ACT) study: a randomized clinical trial. Contemp Clin Trials. 2014;38(2):370-382.
- Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. J Chronic Dis. 1987;40(5):373-383.
- Wilkinson G, Robertson GJ. Wide range achievement test four professional manual. Lutz, FL: Psychological Assessment Resources, 2006.
- Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. Health Serv Res. 2005;40(6 Pt 1):1918-1930.
- Levey AS, Stevens LA, Schmid CH, Zhang YL, Castro AF, 3rd, Feldman HI, Kusek JW, Eggers P, Van Lente F, Greene T, Coresh J, Ckd EPI. A new equation to estimate glomerular filtration rate. Ann Intern Med. 2009;150(9):604-612.
- Levey AS, Becker C, Inker LA. Glomerular filtration rate and albuminuria for detection and staging of acute and chronic kidney disease in adults: a systematic review. Jama. 2015;313(8):837-846.
- American Diabetes Association. 6. Glycemic Targets: Standards of Medical Care in Diabetes-2018. Diabetes Care. 2018;41(Suppl 1):S55-S64.
- Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. Nurs Health Sci. 2013;15(3):398-405.
- Morse JM. Critical Analysis of Strategies for Determining Rigor in Qualitative Inquiry. Qual Health Res. 2015;25(9):1212-1222.
- Roter D, Larson S. The Roter interaction analysis system (RIAS): utility and flexibility for analysis of medical interactions. Patient Educ Couns. 2002;46(4):243-251.
- Roter DL, Larson S. The relationship between residents' and attending physicians' communication during primary care visits: an illustrative use of the Roter Interaction Analysis System. Health Commun. 2001;13(1):33-48.
- McNutt L-A, Wu C, Xue X, Hafner JP. Estimating the Relative Risk in Cohort Studies and Clinical Trials of Common Outcomes. Am J Epidemiol. 2003;157(10):940-943.
- Plantinga LC, Boulware LE, Coresh J, Stevens LA, Miller ER, 3rd, Saran R, Messer KL, Levey AS, Powe NR. Patient awareness of chronic kidney disease: trends and predictors. Arch Intern Med. 2008;168(20):2268-2275.
- Tuot DS, Plantinga LC, Hsu CY, Jordan R, Burrows NR, Hedgeman E, Yee J, Saran R, Powe NR. Chronic kidney disease awareness among individuals with clinical markers of kidney dysfunction. Clin J Am Soc Nephrol. 2011;6(8):1838-1844.

34. **Dharmarajan SH, Bragg-Gresham JL, Morgenstern H, Gillespie BW, Li Y, Powe NR, Tuot DS, Banerjee T, Burrows NR, Rolka DB, Saydah SH, Saran R.** State-Level Awareness of Chronic Kidney Disease in the U.S. *Am J Prev Med.* 2017;53(3):300-307.
35. **Kurella Tamura M, Anand S, Li S, Chen SC, Whaley-Connell AT, Stevens LA, Norris KC.** Comparison of CKD awareness in a screening population using the Modification of Diet in Renal Disease (MDRD) study and CKD Epidemiology Collaboration (CKD-EPI) equations. *Am J Kidney Dis.* 2011;57(3 Suppl 2):S17-23.
36. **McIntyre NJ, Fluck R, McIntyre C, Taal M.** Treatment needs and diagnosis awareness in primary care patients with chronic kidney disease. *Br J Gen Pract.* 2012;62(597):e227-232.
37. **Devraj R, Borrego ME, Vilay AM, Pailden J, Horowitz B.** Awareness, self-management behaviors, health literacy and kidney function relationships in specialty practice. *World J Nephrol.* 2018;7(1):41-50.
38. **Greer RC, Crews DC, Boulware LE.** Challenges Perceived by Primary Care Providers to Educating Patients About Chronic Kidney Disease. *J Renal Care.* 2012;38(4):174-181.
39. **Zolnierok KB, Dimatteo MR.** Physician communication and patient adherence to treatment: a meta-analysis. *Med Care.* 2009;47(8):826-834.
40. **Weiner SJ, Schwartz A, Sharma G, Binns-Calvey A, Ashley N, Kelly B, Dayal A, Patel S, Weaver FM, Harris I.** Patient-centered decision making and health care outcomes: an observational study. *Ann Intern Med.* 2013;158(8):573-579.
41. **Vest BM, York TR, Sand J, Fox CH, Kahn LS.** Chronic Kidney Disease Guideline Implementation in Primary Care: A Qualitative Report from the TRANSLATE CKD Study. *J Am Board Family Med.* 2015;28(5):624-631.
42. **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.* 2006;48(2):192-204.
43. **Fox CH, Brooks A, Zayas LE, McClellan W, Murray B.** Primary care physicians' knowledge and practice patterns in the treatment of chronic kidney disease: an Upstate New York Practice-based Research Network (UNYNET) study. *J Am Board Family Med.* 2006;19(1):54-61.
44. **Nash DM, Garg AX, Brimble KS, Markle-Reid M.** Primary care provider perceptions of enablers and barriers to following guideline-recommended laboratory tests to confirm chronic kidney disease: a qualitative descriptive study. *BMC Fam Pract.* 2018;19(1):192.
45. **Crinson I, Gallagher H, Thomas N, de Lusignan S.** How ready is general practice to improve quality in chronic kidney disease? A diagnostic analysis. *Br J Gen Pract.* 2010;60(575):403-409.
46. **Golden SH, Maruthur N, Mathioudakis N, Spanakis E, Rubin D, Zilbermint M, Hill-Briggs F.** The Case for Diabetes Population Health Improvement: Evidence-Based Programming for Population Outcomes in Diabetes. *Curr Diabetes Reps.* 2017;17(7):51.
47. **Donald M, Kahlon BK, Beanlands H, Straus S, Ronksley P, Herrington G, Tong A, Grill A, Waldvogel B, Large CA, Large CL, Harwood L, Novak M, James MT, Elliott M, Fernandez N, Brimble S, Samuel S, Hemmelgarn BR.** Self-management interventions for adults with chronic kidney disease: a scoping review. *BMJ Open.* 2018;8(3):e019814.
48. **Lopez-Vargas PA, Tong A, Howell M, Craig JC.** Educational Interventions for Patients With CKD: A Systematic Review. *Am J Kidney Dis.* 2016;68(3):353-370.
49. **Schillinger D, Piette J, Grumbach K, Wang F, Wilson C, Daher C, Leong-Groth K, Castro C, Bindman AB.** Closing the loop: physician communication with diabetic patients who have low health literacy. *Arch Intern Med.* 2003;163(1):83-90.
50. **Sim JJ, Rutkowski MP, Selevan DC, Batech M, Timmins R, Slezak JM, Jacobsen SJ, Kanter MH.** Kaiser Permanente Creatinine Safety Program: A Mechanism to Ensure Widespread Detection and Care for Chronic Kidney Disease. *Am J Med.* 2015;128(11):1204-1211.e1201.
51. **Patwardhan MB, Kawamoto K, Lobach D, Patel UD, Matchar DB.** Recommendations for a clinical decision support for the management of individuals with chronic kidney disease. *Clin J Am Soc Nephrol.* 2009;4(2):273-283.
52. **Gulla J, Neri PM, Bates DW, Samal L.** User Requirements for a Chronic Kidney Disease Clinical Decision Support Tool to Promote Timely Referral. *Int J Med Inform.* 2017;101:50-57.
53. **Drawz PE, Archdeacon P, McDonald CJ, Powe NR, Smith KA, Norton J, Williams DE, Patel UD, Narva A.** CKD as a Model for Improving Chronic Disease Care through Electronic Health Records. *Clin J Am Soc Nephrol.* 2015;10(8):1488-1499.

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