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Correlates of Chronic Kidney Disease Knowledge in an Urban Nephrology

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ABSTRACT

To determine CKD knowledge and its association with health literacy, we conducted a cross-sectional study on patients in an urban nephrology clinic from February-August 2016. Patients completed a survey assessing their CKD knowledge, health literacy, physician-patient communication, and patient activation. Data were analyzed using logistic regression. Of 161 participants, 27.3% had adequate CKD knowledge and 19% had adequate health literacy. CKD knowledge was not associated with health literacy or demographic characteristics. Only patient activation and physician communication were associated with CKD knowledge (OR 0.11, 95% CI 0.01-0.97, high v low patient activation; OR 5.69, 95% CI 1.43, 22.63, excellent communication v not). Health literacy and CKD knowledge were low, though not associated. Our study highlights intervention targets to increase patients' CKD knowledge.

INTRODUCTION

Chronic kidney disease (CKD) affects 14% of the US population and is associated with increased morbidity and mortality (United States Renal Data System (USRDS), 2023). End-stage kidney disease (ESKD), the most severe form of CKD, further exacerbates these outcomes. Therefore, it is vital to determine factors that help people manage their CKD, slow its progression, and improve their health outcomes.

CKD-specific knowledge is linked to improved self-management and slower decline in kidney function (Lin et al., 2013; Nguyen et al., 2019). However, many people with CKD, even those under nephrologists' care, lack basic understanding of the disease. Health literacy, the ability to access, comprehend, and process medical information to make health decisions, has been positively associated with CKD knowledge, self-management, and improved patient outcomes in other studies (Shah et al., 2021; Taylor et al., 2018). We conducted a cross-sectional study on patients from an urban nephrology clinic to determine baseline patient CKD knowledge and whether CKD knowledge is associated with health literacy. We hypothesized that patients with higher health literacy would have greater CKD knowledge.

METHOD

Study Design

In this retrospective cross-sectional study in an urban, academic Midwestern nephrology clinic, participants were recruited from the clinic waiting area, consented, and surveyed.

Participants

Returning patients from the adult nephrology clinic were recruited over a 12-week period in 2016. We excluded patients who reported that this was their first nephrology visit and those without proficiency in written and spoken English.

Measures

Our outcome variable, CKD knowledge, was assessed using a modified Kidney Disease Knowledge Survey (KiKS) to assess patients' understanding of CKD, its management, and its prevention (Wright et al., 2011). There were 9 question stems, some with multiple appropriate answers for a total of 26 possible correct answers (**Supplemental Table 1**). CKD knowledge scores, the proportion of questions that were answered correctly, were considered adequate if scored > 66% and inadequate if < 66% (Wright et al., 2011). Predictor variables included health literacy, patient activation (PAM), satisfaction with physician communication (CAT), demographics, and clinical characteristics. Health literacy was measured using the BHLS (Basic Health Literacy Screen), a 3-item survey. (Chew et al., 2004) Responses were given on a 5-point scale from 1 (never/not at all) to 5 (always/extremely). Questions 1 and 3 were reverse scored, and responses were summed. BHLS scores > 9 were considered adequate HL (health literacy), while those ≤ 9 were inadequate.

The Communication Assessment Tool (CAT) is a 15-item questionnaire that assesses a patient's perception of their physician's communication abilities (Makoul et al., 2007). Participants rated 14 statements, excluding an item about general staff from the original tool, on a 5-point scale from 1 (poor) to 5 (excellent). Scores were calculated by obtaining the proportion of "excellent" responses for each participant.

The Patient Activation Measure (PAM) is a 10-item questionnaire to measure patient activation (Hibbard et al., 2005). Responses were given on a 4-point Likert scale from 1 (disagree strongly) to 4 (agree strongly). Scores were summed and converted to patient activation levels from 1, indicating patient disengagement, to 4, which indicates active maintenance of healthy behaviors.

Participants' estimated glomerular filtration (eGFR) rate at the time of the clinic visit was abstracted from the electronic medical record (EMR) and categorized by CKD stage. Patient-reported values were marked correct (awareness) if they were the same as the lab-confirmed CKD stage. Race and gender were by patient self-report. Age was based on date of birth in the EMR. Neighborhood social deprivation index (SDI) was determined for each participant by linking patient zip code from the EMR to the social deprivation index 2014–2018 ZCTA (ZIP Code Tabulation Areas) file (Social Deprivation Index (SDI), 2024). The SDI is used to quantify the socio-economic variation in health outcomes using a composite measure of area-level deprivation, based on seven demographic characteristics collected in the American Community Survey: percent living in poverty, percent with less than 12 years of education, percent single-parent households, the percent living in rented housing units, the percent living in an overcrowded housing unit, percent households without a car, and percent non-employed adults under 65 years of age (Butler et al., 2013). The final SDI measure ranges from 1–100 (higher score = greater deprivation), based on weighted factor loading scores for each measure. We divided SDI into tertiles (high, medium, low).

Analysis

Analyses were conducted using RStudio software (RStudio: Intergrated Development Environment for R, 2024). To compare adequate and inadequate CKD knowledge groups, t-tests and $\chi 2$ analyses were conducted for continuous and categorical variables, respectively. We used bivariable and multivariable logistic models to examine health literacy, demographics (age, gender, race, SDI, CKD stage), CAT ratings, and PAM scores as predictors of CKD knowledge.

Ethics

The study was approved by the institutions' Internal Review Board (IRB15-1419).

RESULTS

Our sample included 161 participants, 59% were women and 80% were African American with an average age of 63 (SD 15), and more than 72% lived in high SDI neighborhoods (**Table 1**). Participants were younger and had a similar proportions of women and African American/Black patients compared to the corresponding clinic population (age 74, 54.5% women, and 75% African American/Black). Only 19% of participants had adequate health literacy, and 27.3% (44/161) were found to have adequate CKD knowledge.

When examining CKD topics by CKD knowledge adequacy (**Supplemental Table 1**), those with adequate CKD knowledge were more likely to have a correct answer for most questions. The two groups had a similar lack of knowledge about what GFR means (68/53%), the number of CKD stages (41/24%), and how proteinuria can indicate kidney damage (75/58%), and similarly high knowledge about kidney transplants as a treatment for CKD (95/82%).

Neither health literacy nor demographic variables were associated CKD knowledge in the bivariable or multivariable models (**Table 2**). The CAT (OR = 5.69, $p < 0.05$) and PAM scores (OR = 0.11, Level 1, lowest activation, and Level 2, OR = 0.15, both compared to reference, Level 4 with $p < 0.05$) were associated with CKD knowledge in bivariable models. In multivariable models CAT remained significant (CAT: OR = 4.95, $p < 0.05$) and PAM had an attenuated association with CKD knowledge (PAM: Level 1 OR = 0.1 2, NS, and Level 2 OR 0.14 $p < 0.05$, compared to reference).

DISCUSSION

We found that a low proportion of patients in this urban nephrology clinic (27%) had adequate CKD knowledge. The average knowledge score was 54% which was lower than prior studies where knowledge scores averaged 66–70 (Molnar et al., 2020; Shah et al., 2021). These differences may be due to how clinicians provided education or patients retained the information provided.

We also found that health literacy was low, only 19% of participants had adequate health literacy; however, health literacy did not predict CKD knowledge. Some prior studies have found health literacy to be positively associated with

CKD knowledge; however, our work is consistent with other studies that found no relationship between CKD knowledge and health literacy (Shah et al., 2021; Taylor et al., 2018). Health literacy was lower in our study participants than in other studies. A review found the prevalence of low health literacy in individuals with CKD to be about 25%, which is markedly lower than our finding of 81% (Taylor et al., 2017). Differences may be explained by different measures of health literacy or different patient populations.

Patient activation (PAM) and perception of physician communication (CAT) were the only factors associated with CKD knowledge. Race, gender, age, SDI and CKD stage, did not predict CKD knowledge. In our study, higher PAM scores, which indicate greater confidence and skills to manage one's health, are associated with a greater likelihood of having adequate CKD knowledge. Prior work has also shown that greater self-management is associated with higher CKD knowledge (Nguyen et al., 2019). In our study higher CAT scores also predicted a greater likelihood of having adequate CKD knowledge. This finding is mixed in the literature (Nunes et al., 2011; Tzeggai et al., 2020). Strong physician communication skills may help impart disease-specific knowledge to patients. Alternatively, patients with better baseline knowledge may perceive better physician communication.

Our study has some limitations. First, we were unable to account for other variables such as income or education that may influence both CKD knowledge and health literacy (Taylor et al., 2017; Vart et al., 2020). SDI (social depravation index) served as a proxy socioeconomic status (SES) but may not have fully captured individual SES. However, prior work has shown a higher prevalence of CKD in low SES neighborhoods, even after adjusting for individual SES (Bowe et al., 2017; Ghazi et al., 2021). Future studies should research different populations and control for confounding variables. Finally, this study is cross-sectional, and therefore any causality between patient activation, physician communication, and CKD knowledge cannot be established. Despite these limitations, this study provides additional evidence about patient and physician factors related to patients' CKD knowledge.

For patients in this urban academic nephrology clinic, CKD knowledge was low and was not associated with health literacy. Our study underscores the need for literacy-sensitive interventions to increase CKD knowledge and enhance patients' overall CKD management. Nephrology nurses and social workers can play an active role and assess and improve patient knowledge. It also indicates the need for interventions to improve physicians' communication skills and to motivate patients to take an active role in their health.

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TABLE

TABLE 1. PARTICIPANT CHARACTERISTICS, OVERALL AND BY CKD KNOWLEDGE

	CKD Knowledge			
Characteristic	**Overall** **(*N* = 161)**	**Adequate** **(*n*=337)**	**Inadequate** **(*n* = 117)**	***p*-value**
Age				0.841
Mean (SD)	63 (SD = 15)	63 (13)	63 (15)	
Median (Min, Max)	66 (18, 94)	66 (27, 85)	66 (18, 94)	
Gender				> 0.999
Female	95 (59%)	26 (59%)	69 (59%)	
Male	66 (41%)	18 (41%)	48 (41%)	
Race				0.833
African American	128 (80%)	34 (77%)	94 (80%)	
Non-AA	33 (20%)	10 (23%)	23 (20%)	
SDI				0.228
High	102 (72%)	26 (63%)	76 (75%)	
Medium	23 (16%)	10 (25%)	13 (13%)	
Low	17 (12%)	5 (12%)	12 (12%)	
Health Literacy				0.891
Adequate	30 (19%)	9 (20%)	21 (18%)	
Inadequate	131 (81%)	35 (80%)	96 (82%)	
CAT				< 0.001
Mean (SD)	0.75 (0.37)	0.90 (0.26)	0.70 (0.39)	
PAM Level				0.005
1 (disengaged)	13 (8.2%)	1 (2.3%)	12 (10%)	
2	22 (14%)	2 (4.5%)	20 (17%)	
3	82 (52%)	22 (50%)	60 (52%)	
4 (active)	42 (26%)	19 (43%)	23 (20%)	
CKD Stage				0.888
1–2	19 (12%)	6 (14%)	13 (12%)	
3	66 (42%)	20 (45%)	46 (41%)	
4	51 (32%)	13 (30%)	38 (34%)	
5	21 (13%)	5 (11%)	16 (14%)	
CKD Stage Awareness				0.33
Yes	34 (32%)	12 (29%)	22 (21%)	
CKD Knowledge Score				0.888
Mean (***SD***)	0.54 (0.19)	0.77 (0.09)	0.45 (0.14)	
Median (Min, Max)	0.56 (0.00, 1.00)	0.74 (0.67, 1.00)	0.48 (0.00, 0.63)	

Welch Two Sample t-test used for age, CAT, and CKD knowledge scores. All other variables used Pearson's Chi-squared test. 4 participants were missing CAT data, 2 were missing PAM data, 4 were missing CKD stage data.

Abbreviations: CAT = communication assessment tool; CKD = chronic kidney disease; PAM = patient activation measure; SDI = social depravation index; SD = standard deviation

TABLE 2: PREDICTORS ASSOCIATED WITH CKD KNOWLEDGE ADEQUACY

	Bivariable Analysis	**Multivariable Analysis**
Predictor	Odds Ratio (95% CI)	Odds Ratio (95% CI)
Age	1.00 (0.98–1.03)	1.00 (0.98–1.03)
CKD Stage 1-2 (Reference: CKD Stage 5)	2.18 (0.49–9.58)	2.45 (0.46–13.02)
CKD Stage 3	1.90 (0.56–6.46)	2.14 (0.56–8.25)
CKD Stage 4	1.37 (0.38–4.91)	1.56 (0.38–6.41)
Gender, Male	1.01 (0.48–2.11)	1.13 (0.48–2.64)
Health Literacy, Adequate	1.31 (0.53–3.22)	1.54 (0.55–4.29)
PAM Level 1 (Reference: PAM Level 4)	0.11 (0.01–0.97) *	0.12 (0.01–1.15)
PAM Level 2	0.15 (0.03–0.73) *	0.14 (0.03–0.72) *
PAM Level 3	0.51 (0.22–1.16)	0.49 (0.20–1.17)
CAT	5.69 (1.43–22.63) *	4.95 (1.17–20.97) *
Race, Non-African American/ Black	1.41 (0.59–3.36)	0.79 (0.25–2.52)
Stage Match, Incorrect	0.66 (0.29–1.51)	0.54 (0.21–1.44)
SDI Score, Medium/Low	1.75 (0.80–3.83)	1.72 (0.62–4.83)

* $p < 0.05$. Four participants were missing CAT data, 2 were missing PAM data, 4 were missing CKD stage data. These participants were excluded from the respective regression analyses.

Abbreviations: CAT = communication assessment tool; CKD = chronic kidney disease; PAM = patient activation measure; SDI = social depravation index; SD = standard deviation

APPENDIX TABLE 1. CKD KNOWLEDGE RESULTS BY PROPORTION ANSWERING CORRECTLY

	Overall *(N = 161)*	Adequate *(n = 44)*	Inadequate *(n = 117)*	*p*-value [a]
Important jobs of the kidney include…				
Making urine	113 (70%)	42 (95%)	71 (61%)	< 0.001
Filtering and cleaning blood	136 (84%)	43 (98%)	93 (79%)	0.02
Keeping bones healthy	42 (26%)	30 (68%)	12 (10%)	< 0.001
Keeping red blood cell counts normal	56 (35%)	28 (64%)	28 (24%)	< 0.001
Keeping potassium levels in the blood normal	84 (52%)	37 (84%)	47 (40%)	< 0.001
Keeping phosphorous levels in the blood normal	53 (33%)	30 (68%)	23 (20%)	< 0.001
Causes of chronic kidney disease include…				
High blood pressure	145 (90%)	44 (100%)	101 (86%)	0.03
Diabetes	127 (79%)	44 (100%)	83 (71%)	< 0.001
Inherited condition	104 (65%)	39 (89%)	65 (56%)	< 0.001
"GFR" stands for…				
Glomerular Filtration Rate – tells us the level of kidney function.	92 (57%)	30 (68%)	62 (53%)	0.12
The number of CKD stages is				
5	46 (29%)	18 (41%)	28 (24%)	0.05
Too much protein is bad for the kidney(s) because…				
It can scar the kidney.	31 (19%)	18 (41%)	13 (11%)	< 0.001
It is a sign of kidney damage.	101 (63%)	33 (75%)	68 (58%)	0.07
One medication CKD patients should avoid taking is…				
Ibuprofen (Motrin ® or Advil ®)	105 (65%)	35 (80%)	70 (60%)	0.03
Actions that can slow the progression of CKD include…				
Diabetes (glucose) control	91 (57%)	37 (84%)	54 (46%)	< 0.001
Proteinuria control	38 (24%)	22 (50%)	16 (14%)	< 0.001
Blood pressure control	124 (77%)	42 (95%)	82 (70%)	< 0.01
Reducing or stopping smoking	72 (45%)	36 (82%)	36 (31%)	< 0.001
Taking certain medication(s)	82 (51%)	36 (82%)	46 (39%)	< 0.001
CKD increases the risk for…				
Heart attacks	76 (47%)	37 (84%)	39 (33%)	< 0.001
Stroke	75 (47%)	36 (82%)	39 (33%)	< 0.001
Peripheral vascular disease	53 (33%)	26 (59%)	27 (23%)	< 0.001
Death	91 (57%)	38 (87%)	53 (45%)	< 0.001
Possible treatments for CKD include…				
A kidney transplant	138 (86%)	42 (95%)	96 (82%)	0.06
Dialysis in a dialysis center	141 (88%)	43 (98%)	98 (84%)	0.04
Dialysis at home	93 (58%)	34 (77%)	59 (50%)	< 0.01

[a] Calculated using $\chi 2$ test.