

Knowledge and Awareness Among Patients with Chronic Kidney Disease Stage 3



Janet L. Welch
Rebecca J. Bartlett Ellis
Susan M. Perkins

Cynthia S. Johnson
Lani M. Zimmerman
Cynthia L. Russell

Christine Richards
David M. Guise
Brian S. Decker

Chronic kidney disease (CKD) is a public health problem affecting 14% of the general United States (U.S.) population. Mortality rates among Medicare patients with CKD are higher than for patients without CKD, and hospitalization rates increase with advancing disease (United States Renal Data System [USRDS], 2015). The acquisition of knowledge is an important prerequisite for self-management that can be used to improve outcomes and reduce mortality rates. For example, Wright-Nunes, Luther, Ikizler, and Cavanaugh (2012) reported that acquiring knowledge about goal blood pressure was an independent predictor of patients achieving blood pressure control; Devins, Mendelsohn, Barré, Taub, and Binik (2005) reported pre-dialysis education improved patient survival.

The purpose of this article is to describe knowledge of CKD and its treatment in a sample of patients with CKD Stage 3 who had coexisting diabetes and hypertension. The following research aims were addressed: 1) to examine the CKD knowledge level of patients with CKD Stage 3, and 2) to assess awareness of a CKD diagnosis.

Background

Self-management in the early stages of CKD targets delaying pro-

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Knowledge is a prerequisite for changing behavior, and is useful for improving outcomes and reducing mortality rates in patients diagnosed with chronic kidney disease (CKD). The purpose of this article is to describe baseline CKD knowledge and awareness obtained as part of a larger study testing the feasibility of a self-management intervention. Thirty patients were recruited who had CKD Stage 3 with coexisting diabetes and hypertension. Fifty-four percent of the sample were unaware of their CKD diagnosis. Participants had a moderate amount of CKD knowledge. This study suggests the need to increase knowledge in patients with CKD Stage 3 to aid in slowing disease progression.

Key Words: Chronic kidney disease, CKD awareness, knowledge, diabetes, hypertension.

gression to more advanced disease and improving outcomes. Slowing the progression of CKD requires performance of key self-management behaviors, including adherence to medications known to slow disease progression (angiotensin-converting enzyme inhibitors [ACEI] or angiotensin receptor blockers [ARB]), avoidance of nonsteroidal anti-inflammatory drugs, blood pressure control, glycemic control, regular exercise, diet, and tobacco avoidance (Agency for Healthcare Research and Quality [AHRQ], 2012; Chadban et al., 2010; Pellicano, Kerr, & Atkins, 2005; Solini & Ferrannini, 2011; Tuot et al., 2013). Self-management is associated with adherence to healthy lifestyles (Walker, Marshal, & Polaschek, 2013), better glomerular filtration rate (GFR) (Chen et al., 2011), blood pressure control (Walker et al., 2013), improved medication adherence (Walker et al., 2013), reduced proteinuria (Walker et al., 2013), and fewer hospitalizations (Chen et al., 2011).

Although existing self-management programs for patients with CKD

and other chronic diseases, such as diabetes, hypertension, and heart failure, often demonstrate improved outcomes (Barnason, Zimmerman, & Young, 2012; Boren, Wakefield, Gunlock, & Wakefield, 2009; Cueto-Manzano, Martinez-Ramirez, Cortes-Sanbria, 2010; Jovicic, Holroyd-Leduc, & Straus, 2006), enhancing CKD knowledge remains a challenge. Such knowledge includes general knowledge about CKD, such as the causes, risks for development, and factors associated with progression (Plantinga, Tuot, & Powe, 2010). In one cross-sectional survey of 210 patients who received care at least three times from a nephrologist over 12 months, 23% identified alcohol as the most common cause of CKD, 44% reported they did not know the common causes of CKD, and 38% were unsure about the treatment for CKD (Gray, Kapojos, Burke, Sammartino, & Clark, 2016). African Americans are at higher risk for CKD than other populations, yet knowledge remains remarkably low in this particular patient population. For example, Kazley,

Johnson, Simpson, Chavin, and Baliga (2015) found that a majority of African Americans participating in focus groups were unaware of risk factors for and causes of CKD, and were unsure of treatments available for CKD.

The ability of patients to acquire knowledge and to self-manage may be limited by disease awareness, including knowledge of CKD and knowledge about CKD self-management (Lopez Vargas et al., 2014). Patients are often unaware of their kidney dysfunction and disease diagnosis (Plantinga et al., 2010; Tout et al., 2011; Wright, Wallston, Elasy, Ikizler, & Cavanaugh, 2011). According to a National Health and Nutrition Examination Survey (Centers for Disease Control and Prevention [CDC], 2012), only about 50% of people with CKD across all age groups were aware they had the disease, and fewer than 15% of people in Stages 3 and 4 CKD were aware of their kidney disease.

Methods

Design

The self-management support component of the Chronic Care

Model provided the overarching theoretical framework for the study because it emphasizes the central role patients have in managing their own care (Wagner, Davis, Schaefer, Von Korff, & Austin, 1999). Knowledge is a prerequisite when providing self-management support and helping patients to manage their own care.

This report presents baseline knowledge and is taken from a larger study testing the feasibility of a self-management intervention. Baseline data were collected at entry into the study. All participants received the usual care provided in a large renal clinic, including outpatient office visits, review of laboratory values, review of all prescribed medical therapeutics, and recommended changes to the regimen. Routine nursing care included measurement of weight and blood pressure.

Recruitment and Sample

Participants were eligible if they a) had CKD Stage 3 with coexisting diabetes and hypertension, b) were 18 years of age or older, c) spoke English, d) were alert and oriented, e) were willing to use technology in the home, f) were able to open a pill bottle, g) self-administered medications, and h) lived in a county served by

Indiana University Home Health Care Indianapolis. Patients were excluded if they a) lived in an assisted-living or extended-care facility, or b) had a score of less than 5 on the 6-item Cognitive Impairment Screener (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002).

Following approval from the Institutional Review Board (IRB), recruitment began in February 2014 and was completed in October 2015. The recruitment plan evolved over time and included the distribution of a flyer during check-in; engaging the services of the Research Network (ResNet) at the Indiana Clinical Translational Sciences Institute (CTSI), which identified patients using the Indiana Network for Patient Care (INPC) electronic medical record database; and altering the process for obtaining baseline data collection to reduce time from consent to group assignment. The study was explained to all potential participants, questions were answered, consent and the authorization for the release of health information were obtained, and eligibility was confirmed.

Procedures

Data collectors were registered nurses, and all received approximately four hours of study-specific, one-on-one training in a private and quiet office by the primary investigator (PI) or project manager using a training manual developed for the project. Training for ResNet staff was provided by the recruitment director of ResNet. Training included a) general information about the study (contact information, study overview, structure, human subjects training, use of technology); and b) role-specific information (position description, recruitment and informed consent, data collection, use of an electronic database for data entry, proper use of back-up paper copies, self-evaluation form). Competency was assessed by practicing and role-playing in a private office. All data collectors were provided with phone numbers to call for any questions.

Janet L. Welch, PhD, RN, FAAN, is a Professor of Nursing, Indiana University, Indianapolis, IN.

Rebecca J. Bartlett Ellis, PhD, RN, ACNS-BC, is an Assistant Professor of Nursing, Indiana University, Indianapolis, IN.

Susan M. Perkins, PhD, is a Professor of Biostatistics, Indiana University, Indianapolis, IN.

Cynthia S. Johnson, MA, is a Biostatistician, Indiana University, Indianapolis, IN.

Lani M. Zimmerman, PhD, RN, FAAN, FAHA, is a Professor of Nursing, University of Nebraska Medical Center, Lincoln, NE.

Cynthia L. Russell, PhD, RN, FAAN, is a Professor of Nursing, University of Missouri-Kansas City, Kansas City, MO.

Christine Richards, RN, is a Project Manager, Indiana University, Indianapolis, IN.

David M. Guise, MSc, MPH, is a Data Manager, Indiana University, Indianapolis, IN.

Brian S. Decker, MD, PharmD, MS, is an Assistant Professor of Clinical Medicine, Indiana University, Indianapolis, IN.

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Data collectors read questionnaire items to participants over the telephone and recorded their responses. All data were directly entered into REDCap (Research Electronic Data Capture), a secure Internet application for building and managing online surveys and databases (Harris et al., 2009). Approximately one interview per participant was audio-recorded for quality assurance and then destroyed. Data from the medical record were collected following baseline data collection.

Measures

Knowledge. Knowledge was assessed using the Kidney Knowledge Survey, a 28-item scale designed to assess knowledge specific to CKD in those who do not require kidney replacement therapy. Knowledge scores are computed by adding the number of correct responses divided by total number of questions and multiplying by 100 to obtain a percentage score. Non-response was scored as incorrect. The items most often skipped were the meaning of GFR ($n = 8$), risk of cardiovascular disease ($n = 4$), serum potassium levels ($n = 4$), unusual itching ($n = 4$), effect of proteinuria ($n = 3$), medications harmful to kidney ($n = 3$), bone health ($n = 3$), and serum phosphorus levels ($n = 3$). Higher scores indicate more knowledge. Internal consistency was reported as 0.72 in past research using the Kuder-Richardson-20 (Wright et al., 2011). Internal consistency reliability of the knowledge scale at baseline was 0.76 in this study.

CKD awareness. Awareness was assessed using one dichotomous item: "Do you have kidney disease?"

Demographic and clinical data. A general information questionnaire was used to collect information about demographic and clinical factors (e.g., age, race, level of education).

Data Analysis

All data analyses were conducted using SAS, Version 9.4 (Cary, NC). Descriptive statistics were used to analyze all study variables and to address the research aims.

Results

Sample

As shown in Table 1, the convenience sample of 30 participants were predominantly female, black, not Hispanic or Latino, educated beyond high school, married, and nonsmokers. There were no significant differences in age, gender, or race between participants and those who were eligible but chose not to enroll.

Knowledge

Participants in this study had a moderate amount of CKD knowledge. The mean score was 64.8% ($SD = 16.2$) out of a possible maximum score of 100%. Knowledge scores ranged from 17.8% to 82.1%.

Table 2 displays the correctly answered CKD knowledge items in rank order. More than 75% of the sample had general knowledge that included CKD stages, mortality risk, and treatment for kidney failure; knew they could take medications to preserve kidney health; were able to identify three functions of the kidney, including cleansing the blood, keeping red blood cell counts normal, and maintenance of blood pressure; knew the kidneys did not function to prevent hair loss; and identified symptoms associated with CKD, including fatigue and nausea/vomiting.

Of the study participants, 72.4% could correctly identify target blood pressure, 69.0% knew they were at risk for cardiovascular disease, and 55.2% knew that some medications could cause additional harm to the kidney. Three additional functions of the kidney were identified, including maintenance of a normal serum potassium, making urine, and keeping serum phosphorus normal. Symptoms commonly associated with CKD were identified, including trouble sleeping, weight loss, metal or bad taste in mouth, shortness of breath, and unusual itching.

In addition, 31.0% knew the meaning of "GFR," and 10.0% knew the effects of proteinuria on the kidney. With regard to the additional

functions of the kidney, 44.8% identified keeping blood sugar normal, and 37.9% identified keeping bones healthy. Confusion was identified as a symptom associated with CKD by 48.3% of participants; however, 55.2% of participants did not know that CKD may be entirely asymptomatic, especially in its early stages.

Awareness

Of the 28 participants who responded to this item, 54.0% were unaware of their CKD diagnosis.

Discussion

Overall, participants had moderate levels of knowledge about their disease. The mean total scale score reported in the present sample (64.8%; $SD = 16.2$) was comparable to the mean score of 66.0% ($SD = 15.0$) reported by Wright et al. (2011) who developed and psychometrically tested the Kidney Knowledge Survey. More than half of participants (54.0%) were unaware of their kidney disease, a finding consistent with the poor awareness of kidney disease reported in the general U.S. population (USRDS, 2015). Unfortunately, this lack of awareness was present despite receiving care by a nephrologist.

Although the Kidney Disease Knowledge Survey is designed as a total scale score, there are some important items on the survey on which participants in this sample scored well. In particular, the sample had relatively greater knowledge (75% or more correct) about mortality risk, stages of CKD, many of the functions of the kidney, medications used to preserve the kidney, and symptoms, including fatigue, nausea, and/or vomiting. Participants scored high on these knowledge items despite patients being unaware of their own diagnosis of CKD. These results may reflect public awareness campaigns and national efforts to increase knowledge in this area. However, the lack of awareness by individual patients of their own disease may reflect a gap in patient-provider communication. This lack of awareness

Table 1
Summary of Demographic and Clinical Variables

Variable	n	%	Mean	Median	SD	Min	Max
Age	30		59.7	60	9	38	74
eGFR (MDRD equation)	28		45.5	46	9.1	31	59
Sex							
Female	19	63					
Male	11	37					
Race							
Black or African American	18	60					
White	12	40					
Ethnicity							
Hispanic or Latino	0	0					
Not Hispanic or Latino	30	100					
Education							
Less than high school	3	10					
High school graduate	11	37					
Some college	12	40					
College degree	1	3					
Post-college	3	10					
Marital status							
Single	4	13					
Married	10	33					
Living with someone	0	0					
Divorced	9	30					
Separated	4	13					
Widowed	3	10					
Aware of CKD diagnosis							
Yes	13	46					
No	15	54					
Current smoker							
Yes	6	20					
No	24	80					

has been reported in other studies. In a sample of 109,285 participants receiving primary care, Whaley-Connell and colleagues (2012) reported that only 9% were aware of their diagnosis and McIntyre, Fluck, McIntyre, and Taal (2012) found that 41% of patients referred to nephrology care were unaware of their diagnosis. Non-disclosure of CKD may be a problem for providers. In particular, communicating the diagnosis and dis-

cussing its implications may be stigmatizing to patients and practitioners have reported difficulty in disclosing a CKD diagnosis (Crimson, Gallagher, Thomas, & de Lusignan, 2010).

Items about which patients in this sample had the least knowledge included knowledge about kidney function as important for keeping blood sugar normal and bones healthy, as well as symptom items including confusion and whether

CKD was associated with symptoms at all. Given the significant relationship between diabetes and CKD, the poor knowledge in this area suggests a need to improve patient understanding about the connection between blood glucose levels and kidney function.

Participants scored the poorest on two additional items: understanding the acronym GFR and the effects of proteinuria. Although these laboratory values are closely monitored in CKD clinics, these medical terms are complex, and we should not be surprised when patients do not fully understand their meaning or the relationship of GFR and proteinuria to CKD management. However, the lack of knowledge about these two clinical terms may reflect low health literacy, that is, the ability to process and understand health-related information (Devraj & Gordon, 2009).

These findings challenge providers to discover how to present information in ways that are comprehensible to all patients.

Limitations

A small convenience sample was obtained from one large, urban, Midwestern city. A larger sample from more diverse areas will be needed to promote generalizability.

Implications for Nursing Practice

Despite these limitations, this study provides important information in which more patient education is needed. It is critical for patients to first understand their own diagnosis of CKD. Because patients in CKD Stage 3 are at risk for repeated healthcare encounters and hospitalizations (Welch, Meek, Bartlett Ellis, Ambuehl, & Decker, in review), it is critical that these patients are aware of their diagnosis and ways that they can self-manage to slow the progression of CKD. Future trials may want to consider including an awareness arm as part of their design before testing an educational intervention.

It is important to assess whether patients comprehend the information

Table 2
Correctly Answered Chronic Kidney Disease Knowledge Items in Rank Order at Baseline

Rank Order	CKD Knowledge Items	Number Answering Item Correctly	Percentage
1	Mortality risk	28	96.55
2	Symptom: increased fatigue	27	93.10
3	Treatment for kidney failure	26	89.66
4	Medications that preserve kidney health	25	86.21
5	Stages of chronic kidney disease	25	86.21
6	Function of kidney to clean blood	24	82.76
7	Function of kidney to keep red blood cell count normal	23	79.31
8	Function of kidney to keep blood pressure normal	23	79.31
9	Function of kidney to keep from losing hair	22	75.86
10	Symptom: nausea and/or vomiting	22	75.86
11	Target blood pressure	21	72.41
12	Function of kidney to keep serum potassium normal	21	72.41
13	Cardiovascular disease risk	20	68.97
14	Symptom: trouble sleeping	20	68.97
15	Symptom: weight loss	20	68.97
16	Symptom: hair loss	19	65.52
17	Function of kidney to make urine	18	62.07
18	Symptom: metal/bad taste in mouth	17	58.62
19	Medications that can hurt the kidney	16	55.17
20	Symptom: shortness of breath	16	55.17
21	Function of kidney to keep serum phosphorus normal	15	51.72
22	Symptom: unusual itching	15	51.72
23	Symptom: confusion	14	48.28
24	Function of kidney to keep blood sugar normal	13	44.83
25	Symptoms: no symptoms at all	13	44.83
26	Function of kidney to keep bones healthy	11	37.93
27	Meaning of acronym "GFR"	9	31.03
28	Effect of proteinuria	3	10.34

Note: *n* = 29. One person did not complete the Kidney Knowledge Survey.

communicated to them by healthcare providers. Participants in our sample were relatively well-educated and had some general knowledge of the disease, which is useful when communicating both with healthcare providers and their significant others. However, presenting information in a way that is understood by patients may be challenging for some, especially when unfamiliar language is used. The teach-back method is one approach

that can assist healthcare providers in assessing how well patients understand. One approach to using the teach-back method is to help prepare patients for how they might communicate the diagnosis to their loved ones, saying, for example: "I know I have shared a lot of information with you today. You might want to share this information with your family. How might you explain to them what we discussed here today?" An open-

ended question like this helps patients to process information and prepares them to explain their diagnosis to their family members. An inability to repeat or paraphrase this information back to the provider may suggest they need further support understanding their diagnosis or that they have further concerns about their diagnosis that can be addressed.

Having patients acquire knowledge is an important first step in CKD

self-management. For example, the nurse can ask patients which medications they take to help preserve kidney function. Or the nurse can ask patients to identify which over-the-counter medication they keep at home that are nephrotoxic and should be avoided to help protect the kidneys from further injury.

Conclusion

Opportunities remain to enhance patients' knowledge about CKD and awareness of CKD diagnoses. Consistent with national trends, in this sample of patients receiving nephrology care for CKD Stage 3, knowledge about CKD was moderate, and awareness of one's own diagnosis remained substantially low. Knowledge and awareness are essential educational components that can enhance self-management efforts. Concerted patient education efforts should be made to increase patients' knowledge about CKD in areas that will best support self-management and include understanding the function of the kidneys, symptoms associated with CKD, and how these are associated with behaviors patients can engage in that can slow disease progression. Even more important is a need to ensure that CKD diagnosis is disclosed to patients in a way they understand. Interventions supporting self-management behaviors are needed, including ways to enhance patient-provider communication diagnoses.

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Learning Outcome

After completing this learning activity, the learner will be able to describe CKD knowledge levels and awareness among patients who have CKD Stage 3 with coexisting diabetes and hypertension.

Evaluation Form (All questions must be answered to complete the learning activity. Longer answers to open-ended questions may be typed on a separate page.)

1. I verify I have completed this education activity. Yes No

	<i>SIGNATURE</i>	Strongly Disagree	(Circle one)	Strongly Agree		
2. The learning outcome could be achieved using the content provided.		1	2	3	4	5
3. I am more confident in my abilities since completing this education activity.		1	2	3	4	5
4. The content was relevant to my practice.		1	2	3	4	5
5. Commitment to change practice (select one):						
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d. I am not yet convinced that any change in practice is warranted.						
e. I perceive there may be barriers to changing my current practice.						
6. What information from this education activity do you plan to implement in practice? What barriers are there to changing your current practice?	_____					
7. This was an effective method to learn this content.					<input type="checkbox"/> Yes <input type="checkbox"/> No	
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9. If no, please explain:	_____					

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Paula Dutka MSN, RN, CNN, disclosed that she is a coordinator of Clinical Trials for the following sponsors: Amgen, Rockwell Medical, Keryx Biopharmaceuticals, Akebia Therapeutics, and Dynavax Technologies.

Norma J. Gomez, MBA, MSN, CNNe, disclosed that she is a member of the ZS Pharma Advisory Council.

Tamara M. Kear, PhD, RN, CNS, CNN, disclosed that she is a Fresenius employee, and freelance editor for Lippincott, Williams & Wilkins and Elsevier publishing companies.

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