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Patient Activation with Knowledge, Self-Management, and Confidence in Chronic Kidney Disease

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Abstract

Background: Chronic kidney disease is a growing health problem on a global scale. The increasing prevalence of chronic kidney disease presents an urgent need to better understand the knowledge, confidence and engagement in self-managing the disease.

Objectives: This study examined group differences in patient activation and health-related quality of life, disease-specific knowledge, self-management, and confidence with managing chronic disease across all 5 stages of chronic kidney disease.

Design: The study employed a descriptive correlational design.

Settings: Participants were recruited from five primary care, three nephrology clinics, and one dialysis center in two Midwestern cities in the United States.

Participants: The convenience sample included 85 adults with hypertension, diabetes mellitus, and chronic kidney disease, including kidney failure, who spoke English.

Measurements: Seven measurements were used to collect data via telephone interviews with participants not receiving hemodialysis, and face-to-face interviews with those receiving hemodialysis at the beginning of their treatment session.

Results: Analyses indicated that half the participants were female (50.58%), the mean age was 63.21years (SD = 13.11), and participants with chronic kidney disease stage 3 were the most activated. Post hoc differences were significant in patient activation and blood pressure self-management and anxiety across chronic kidney disease stages, excluding stage 5 (kidney failure).

Conclusion: The study supports the critical need to activate patients in the self-management of chronic kidney disease. Additionally, it is important for healthcare providers and patients to

develop strategies that will maintain patients' health-related quality of life as kidney disease progresses.

Patient Activation with Knowledge, Self-Management, and Confidence in Chronic Kidney Disease

CKD is a global health concern (Levey et al., 2007) associated with the increased prevalence of diabetes mellitus and hypertension worldwide (World Health Organization, 2012). The increasing incidence in CKD diagnosis is a major public health problem (Kidney Disease Improving Global Outcomes [KDIGO], 2013; United States Renal Data Systems [USRDS], 2014). Amazingly 93% of Americans have a lifetime risk for developing CKD stage 3, followed by 12% and 4% for CKD stages 4 and 5, respectively (Grams, Chow, Segev, & Coresh, 2013). National initiatives like Healthy People 2020 include CKD as a focus area and global initiatives, like the World Kidney Day, heighten CKD awareness worldwide (World Kidney Day, 2015).

In the United States there are 26 million adults afflicted with CKD. Diabetes mellitus (DM) and hypertension (HTN) are the two most common causes of (Bakris et al., 2010; KDIGO, 2013) and many people are diagnosed with all three conditions (National Kidney Foundation [NKF], 2013). Increasing costs, morbidity, and mortality presents a compelling need to better understand how to help this population self-manage the disease to prevent and/or slow progression (NKF, 2013; USRDS, 2014).

Enhancing knowledge, developing self-management skills, and building confidence are considered to be important variables associated with improving outcomes, including health-related quality of life (HRQoL), among patients with chronic disease (Bandura, 2004; Lorig, Ritter, Villa, & Armas, 2009). The Patient Activation Measure is often used to measure patients' knowledge, skills and confidence related to managing their health care (Hibbard, Stockard, Mahoney, & Tusler, 2004; Hibbard, Mahoney, Stockard, & Tusler, 2005). The increasing prevalence of CKD makes investigating patient activation across all 5 CKD stages a priority to

delay disease progression and associated health complications, like cardiovascular disease. Activation has not been described in any CKD stage and we don't know if differences exist across the stages, thus the purpose of this study was to describe patient activation, HRQoL, knowledge, self-management (SM), and confidence in the patients with CKD, including those who have kidney failure. The **specific aim** was to examine if differences exist in patient activation, and HRQoL, knowledge, SM, and confidence across CKD stages.

Background

This study was guided by the theoretical concepts of patient activation and medical self-management. The conceptual underpinnings of patient activation with chronic disease management include self-efficacy, SM, and readiness to change health-related behaviors (Hibbard et al., 2004). Activated patients use knowledge, skills, and confidence to manage their health (Hibbard et al., 2004, 2005). Activated patients, compared to those who are not, tend to participate in more health promotion activities, like engaging in routine exercise or receiving annual eye exams (Rask et al., 2009), experience fewer hospitalizations (Begum, Donald, Ozolins, & Dower, 2011), and show improvement with their hemoglobin A1c scores in the DM population (Remmers et al., 2009). Activation exists on a continuum where patients move between four levels depending on their health, confidence, willingness to engage, and life situations. Attaining activation is an iterative process and higher levels indicate greater activation (Hibbard et al., 2004; Remmers et al., 2009).

CKD decreases HRQoL over time. As CKD progresses to kidney failure, patients may experience a decline in their general health, including physical and social functioning, while experiencing more pain (Kaltsouda et al., 2011; Pagels, Soderkvist, Medlin, Hylander, & Heiwe, 2012). Patients as early as CKD stage 2 begin to experience a decline in their physical function,

vitality and energy, social function, mental health and emotional well-being when compared to a cohort of people of the same age and gender without kidney disease (Pagels et al., 2012).

CKD knowledge includes understanding how the kidneys function and recognizing symptoms associated with disease progression (Wright, Wallston, Elasy, Ikizler, & Cavanaugh, 2011). Teaching patients to manage their CKD is an important part of preserving kidney function (Thomas, 2009). For example, patients need to be taught that maintaining appropriate BP readings (Fraser et al., 2013), tight BG control (Reidy, Kang, Hostetter, & Sustak, 2014), along with medication adherence all work together to protect their kidney health (Thomas, 2009). Patients with CKD who have a poor understanding of their disease process tend to participate less in their health care management, which includes making future decisions about dialysis treatment (Wright-Nunes et al., 2013).

Developing core SM skills, such as problem-solving, decision making, action planning, goal-setting, patient/healthcare provider partnership and resource utilization (Welch et al., 2014) is central to improving adherence to daily SM behaviors. Reading food labels, healthy eating (Lorig et al., 2009), enhancing communication between patients and their healthcare providers, and improving medication taking (Welch et al., 2014) are essential SM behaviors of chronic disease management.

Self-efficacy, or confidence, is having the ability to perform an action to achieve a goal (Bandura, 2004). Developing confidence is core to engaging in SM behaviors for chronic disease management (Barnason et al., 2003; Curtin et al., 2008). Self-efficacy increases over time and is associated with positive health outcomes, like risk factor modifications in coronary artery disease (Barnason et al., 2003), increased physiological and psychosocial functioning in heart and kidney failure patients (Barnason et al., 2003; Curtin et al., 2008), improved SM behaviors and

medication adherence in CKD patients (Curtin et al., 2008), and decreased weight gain in patients receiving dialysis (Tsay, 2003).

In summary, activated individuals are equipped with the knowledge, skills and confidence necessary for daily SM of chronic conditions. However, no studies to date have reported if differences exist across CKD stages in patient activation and findings from this study will begin to fill this gap.

Methods

Setting and Sample

This study used a descriptive correlational design. Eligible participants were at least 19 years old, diagnosed with CKD, DM and HTN, able to speak and read English and provide informed consent, and had access to a telephone and US mail. After receiving Institutional Review Board approval, participants were initially recruited from four primary care clinics, two nephrology clinics, and a dialysis center in a Midwestern city. Healthcare providers assisted with recruitment. Twenty-five out of 41 participants completed the surveys by US mail or Survey Monkey. Additional sites along with research assistants were added to increase participant enrollment. The new sites included a diabetic clinic and a nephrology clinic in another Midwestern city within the same state. Three new surveys were added to better understand patients' medical SM, and confidence in chronic disease management. Research assistants were trained regarding participant recruitment, data collection, and human subjects' protection. Data were collected via telephone interviews for participants not receiving hemodialysis; face-to-face interviews were conducted with patients receiving hemodialysis during their treatment sessions. All interviews lasted 45 to 60 minutes. An addition of 60 participants for a total convenience sample of 85 adults across all 5 CKD stages were used for analysis in this study.

Measures

The 13-item Patient Activation Measure uses a 5-point Likert scale, where higher scores indicate higher levels of activation. Scores range from 0-100. Cronbach's α was reported as .87 and equaled .88 for this study's sample. Two-week test-retest reliability reported 93% of participants within the 95% confidence interval. Three expert judges categorized 10 participants as low or high activation; the Cohen's kappa for the judges' measured activation levels were .80, .90 and .90 (Hibbard et al., 2004, 2005).

HRQoL was assessed using the Patient Reported Outcomes Measurement Information Systems (PROMIS)-29 item profile. A high score corresponds to high levels of the construct being measured. Construct validity was tested against an established measure, the Short Form-36 (SF-36). All domains of the PROMIS-29 were moderately to highly correlated with the SF-36, i.e. physical function (r = .86), anxiety (r = -.50), and depression (r = -.70) (National Institutes of Health, n.d.).

Disease-specific knowledge was assessed using two measures, the Kidney Knowledge Survey (KiKS) and the Blood Pressure Knowledge Scale (revised) (BPKS). The KiKS is a 28-item measure. Scoring is determined by the number of correct answers; a higher score equals greater knowledge. Kuder-Richardson-20 was reported as .72. Cronbach's α = .84 for this study's sample. Face and content validity were reviewed by kidney disease experts; construct validity was documented by comparing KiKS scores with knowledge scores of similar patient characteristics and diagnoses of other chronic diseases, like DM (Wright et al., 2011).

The BPKS (revised)-11-item scale uses a 7-point Likert scale. A sum score is computed; higher scores indicate greater knowledge of BP SM. Scores range from 7 to 77. Cronbach's α was reported as .85 and equaled .77 for this study's sample. Content validity was documented by

African American women as focus group participants. Three experts reported the items as relevant (Peters & Templin, 2008).

Two measures were used to describe SM of comorbid conditions (HTN and CKD), the Blood Pressure Self-Care Scale (revised) (BPSCS) and the CKD Self-Management Scale. The BPSCS (revised)-10-item scale uses a 7-point Likert scale. A sum score is computed; higher scores reflect greater BP self-care. Scores range from 7 to 70. The reported revised scale's Cronbach's α (.57) differs from the original scale's Cronbach's α (.71) due to poor item-total correlation of two items added to the revised scale that focused on drinking alcohol and smoking tobacco (Peters & Templin, 2008). Cronbach's α = .77 for this study's sample.

CKD Self-Management Scale is a newly developed 15-item scale designed to measure CKD SM in patients diagnosed with CKD stage 3. The measure uses a 6-point Likert scale. The last option, not applicable, was counted as missing data. A sum score is computed; higher scores reflect greater SM. Scores range from 15 to 75. One item, "I understand my fluid restriction", was removed for this study given that not all patients with CKD follow a fluid restriction. Cronbach's α = .85 for this study's sample. Content validity was established by an expert panel of four nephrologists, four nurse practitioner, and three experts in measurement development (Welch et al., 2013).

Confidence in managing chronic disease was assessed using the Self-Efficacy for Managing Chronic Disease Scale (SEMCDS)-6-item scale that uses a 10-point Likert scale. A sum score is computed; higher scores indicate greater confidence with managing chronic disease. Scores range from 6 to 60. Cronbach's α was reported as .91 (Lorig , Sobel, Ritter, Laurent, & Hobbs, 2001), and was .88 for this study.

Analysis

Data were analyzed using SPSS version 22.0. Composites for each survey were calculated if they were at least 80% complete and missing values were replaced with the mean of that participant's valid response. Seven KiKS surveys were eliminated from the final analysis due to missing data with 10 items. Descriptive statistics analyzed demographic characteristics across the CKD stages. Group differences in patient activation and HRQoL, knowledge, skills, and confidence across CKD stages were analyzed using Kruskal-Wallis H test, with an alpha level of .05. Post hoc testing used Mann-Whitney U tests for pairwise differences, with a Bonferroni's alpha level of .008 (.05/6 pairwise comparisons). Given the small CKD stage 1 sample size (n = 3), data analyses for CKD stages 1 and 2 were conducted separately and together without statistical differences and thus were combined for data analysis.

Results

All participants had diagnoses of DM, HTN and CKD, of which 43 (50.58%) were female. The mean age was 63.21years (SD = 13.11) with an age range from 28 – 93 years old. Patients with CKD stage 3 were the most activated (M = 64.86, SD = 18.14), followed by CKD stage 4 (M = 63.63, SD = 13.29), and early CKD stages 1 and 2 (M = 62.08, SD = 11.20) compared to patients with kidney failure (CKD stage 5), who were the least activated (M = 58.04, SD = 13.46). See Table 1 for additional demographic data including clinical variables.

Aim: To examine if differences exist in patient activation and HRQol, knowledge, SM, and confidence across CKD stages.

Results from Kruskal-Wallis tests found significant group differences in patient activation and anxiety (Table 2) and BP SM (Table 3). Post hoc testing using the Mann-Whitney U test and a Bonferroni adjusted alpha level of .008 found patients reported less BP SM in early

CKD stages 1 and 2 compared with CKD stage 4 (z = -2.991, p = .003). Moreover, patients reported more anxiety in early CKD stages 1 and 2 than in CKD stage 3 (z = -2.798, p = .005).

Discussion

Results from our study suggest that activating patients in early to mid CKD stages may assist patients with maintaining their physical function and satisfaction with their social role until kidney failure. Depression and anxiety were highest in early CKD stages, with significant group difference between CKD stages 1 and 2, and CKD stage 3. For example, participants with CKD stage 3 reported feeling less fearful and uneasy and not as overwhelmed as their cohorts in CKD stages 1 and 2. This may be due to patients recognizing drastic changes to their daily routine, such as daily CKD SM needed to preserve kidney function and delay disease progression. This daily routine may be overwhelming to patients diagnosed in the early stages, who are asymptomatic. Overall, healthcare providers may assist their patients with developing strategies for maintaining their HRQoL as CKD progresses. For example, the Centers for Medicare and Medicaid Services require dialysis units to routinely assess HRQoL, but regular assessment in earlier CKD stages is not required.

The declining PAM mean from CKD stage 3 to stage 5 may suggest an interesting dynamic that patients in CKD stage 4 may need re-boosting of their knowledge, skills and confidence as the difficulty of CKD SM increases with progression to kidney failure. Or it may suggest that patients lose their interest in or ability to actively self-manage their kidney disease in advance stages.

The kidney knowledge mean score of 62.5 in our study was lower than a reference mean of 66.0 from a prior study of patients diagnosed across all five CKD stages (Wright et al., 2011). Our mean was unexpectedly low given that 81.5% of our participants were in CKD stages 3-5.

The disease-specific knowledge score in our study did not trend upward with disease progression, which suggests the need for patient education remediation across all CKD stages. It is interesting to note that a participant from our study stated, “Maybe a little education about the disease might have made a difference. I didn’t fully understand the function of the kidneys,” when asked what could have been done differently to help patients better self-manage their CKD. Educating patients early in their disease process regarding BP SM, like taking BP readings and medications daily may delay complication from developing, such as heart disease associated with CKD.

Exhibiting confidence assists patients with building SM skills, such as effectively communicating with members of their healthcare team (Curtin et al., 2008) and developing adherent behaviors over time (Barnason et al., 2003; Tsay, 2003). Patients with greater activation reported better SM of their kidney disease and confidence with managing chronic disease. For example, participants in CKD stage 4 scored significantly higher than their cohorts in CKD stages 1 and 2 with their BP SM that included diet, exercise, stress, and medication management. This information supports the need for healthcare providers to assist their patients with building confidence in their ability to daily manage their health care. Without intervention the daily challenges of monitoring HTN to preserve kidney health may impact patients’ activation levels.

In conclusion, the results from this study indicate higher activation is associated with positive patient outcomes. More activated patients with CKD stage 3 reported the greatest number of positive outcomes followed by those with CKD stages 4 and 5. These findings support the need to investigate the effects of patient activation on preserving kidney function and maintaining overall kidney health. Building relationships with patients and engaging them in

their health care may facilitate patients' development of daily SM behaviors that aid in slowed disease progression.

Limitations

This study begins to address the gap in scientific evidence related to differences in patient activation and HRQoL, knowledge, SM, and confidence in CKD. It is important to note that causality cannot be determined with a descriptive study. A small sample size (N = 85) posed a challenge when analyzing data and comparing results across all 5 stages. A very small sample size in CKD stage 1 (n = 3) made it necessary to combine with CKD stage 2 (n = 12) for statistical purposes. However, these two stages are similar from a symptoms and treatment standpoint. Plus, albuminuria conventional units, which could have provided better separation between CKD stages 1 and 2, were not standardized throughout all clinic sites and thus were not used in data analysis. Knowledge of DM was not assessed. Last, data were collected from patients' self-reports and participants may have provided socially desirable responses rather than actual behaviors.

Potential internal threats to validity include limitations with the instruments used, especially the Blood Pressure Self-Care Scale (revised) with a Cronbach's α of .57, along with the addition of new surveys and the research assistants later in the study. There may have been biases with the different approaches to data collection. It is possible that a confounding effect with the face to face interviews only in CKD stage 5 allowed the participants to think longer about a response than participants answering the questions over the telephone, or responding via hard copies and Survey Monkey.

Implications for Nursing

Nurses play a vital role in disease-specific SM education to promote patients' active involvement in their daily health care. Nurses are instrumental in enhancing patients' knowledge about the risk factors associated with CKD progression, such as uncontrolled BP/BG levels. Nurses can assist patients with developing SM skills, such as problem-solving dietary challenges during the holidays, or with daily decision-making when using salt or sugar in cooking. Nurses can assist patients to devise activity action plans that incorporate setting goals with subsequent evaluation; assist patients with building confidence, and reinforce patients' use of SM skills. Additionally, nurses may provide social modeling by connecting their patients with community resources, like support groups for individuals with diabetes that will continue to provide support and education necessary for long-term behavior change.

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Table 1: ***Characteristics of Study Participants***

Characteristic	*n* (%)	M (SD)	Median
Race	84		
Caucasian	71 (85)		
African American	10 (12)		
Hispanic	2 (2)		
Asian	1 (1)		
Marital status	84		
Married	48 (57)		
Not married	36 (43)		
Education	82		
12th grade or less	31 (38)		
Greater than 12th grade	51 (62)		
Employment	83		
Yes	20 (24)		
No	17 (21)		
Retired	46 (55)		
Currently smoking	78		
Yes	17 (22)		
No	61 (78)		
CKD stage	81	Age	Age
Stage 1	3 (4)		
Stage 2	12 (15)	57.07 (10.04)[a]	57.00
Stage 3	30 (37)	64.45 (12.80)	65.00
Stage 4	15 (19)	67.71 (8.39)	68.00
Stage 5, no dialysis	2 (2)		
Stage 5, receiving hemodialysis	19 (23)	64.10 (15.59)[b]	62.00
Patient activation	85		
Level 1	8 (10)		
Level 2	24 (28)		
Level 3	24 (28)		
Level 4	29 (34)		
Length of DM	85	17.92 (12.64)	15.00
Range: 6 months – 55 years			
Length of HTN	85	18.08 (12.96)	15.50
Range: 1 – 50 years			
Length of CKD	85	8.03 (9.66)	5.00
Range: 1 month – 50 years			
Length of receiving hemodialysis (in years)	19 (22)	5.07 (4.51)	3.00
Range: 1.5 – 19 years			

[a] CKD stages 1,2 combined

[b] CKD stage 5, including participants receiving and not receiving hemodialysis

Table 2: ***Means and Standard Deviations with Kruskal-Wallis Test of Differences in Patient Activation and Health-Related Quality of Life across CKD Stages***

	Stages 1,2 (n=15)	Stage 3 (n=29)	Stage 4 (n=15)	Stage 5 (n=21)	χ^2	p
Variable	M (SD)	M (SD)	M (SD)	M (SD)		
Patient Activation	62.08 (11.20)	64.86 (18.14)	63.63 (13.29)	58.04 (13.46)	3.62	.306
Physical Function	40.61 (9.24)	40.20 (9.39)	37.03 (9.45)	37.51 (11.01)	1.50	.682
Fatigue	54.29 (12.06)	51.19 (9.87)	53.90 (12.57)	56.50 (10.78)	2.05	.563
Anxiety	54.69 (10.72)	45.92 (8.61)	44.65 (7.92)	48.75 (9.20)	10.69	.014*
Depression	53.64 (12.59)	47.17 (8.57)	44.43 (5.87)	51.06 (9.54)	7.11	.068
Sleep Disturbance	53.19 (9.38)	50.05 (8.29)	50.86 (8.81)	48.97 (7.65)	1.38	.710
Satisfaction Social Role	45.81 (11.04)	49.45(9.47)	52.69 (10.84)	48.09 (9.52)	3.59	.310
Pain Interference	58.95 (12.73)	52.63 (11.06)	50.48 (10.84)	56.03 (9.00)	4.94	.176

Note. df = 3 for all Kruskal-Wallis tests.
*$p < .05$, two-tailed.

Table 3: ***Means and Standard Deviations with Kruskal-Wallis Test of Differences in Patient Activation and Knowledge, Skills, and Confidence across CKD Stages***

	Stages 1,2 (n=15)	Stage 3 (n=29)	Stage 4 (n=15)	Stage 5 (n=21)	χ^2	p
Variable	M (SD)	M (SD)	M (SD)	M (SD)		
Kidney knowledge	67.56 (12.78)	53.33 (21.90)	61.22 (13.43)	66.33 (16.92)	2.90	.407
BP knowledge	5.56 (.75)	5.76 (.76)	5.72 (.85)	5.69 (1.07)	.82	.845
BP self-care	4.64 (.74)	5.27 (.67)	5.54 (.72)	5.24 (.74)	10.05	.018*
CKD SM skills[a]	3.67 (.70)	3.74 (.67)	3.69 (.37)	----------	.11	.948
Confidence	6.11 (1.64)	6.80 (1.91)	7.49 (1.42)	7.31 (2.19)	2.06	.561

Note. df = 3 for all Kruskal-Wallis tests.
[a]The CKD SM Scale was not designed for patients with kidney failure.
*$p < .05$, two-tailed.