Utilizing Community Programs to Build Kidney Disease Self-Management Skills CE

Allyce Haney Smith, MSW, Caitlin Loughery, MPH, Ann M. Andrews, MPH, NKF of Michigan, Ann Arbor, MI; Susan Walker, MSW, Beaumont Health System, Royal Oak, MI

Kidney disease self-management relies on patient knowledge and self-efficacy to develop skills for day-to-day care of their chronic condition(s). The Chronic Disease Self-Management Program (CDSMP) is effective in promoting chronic disease self-management among people with a variety of health conditions, but has not been studied among people with kidney disease. In 2016, the National Kidney Foundation of Michigan (NKFM) collaborated with Metro Detroit transplant programs to offer the CDSMP for people living with kidney disease and their caregivers. The study examined the effectiveness of the CDSMP with kidney disease patients by adding two kidney disease-specific sessions. A total of 45 people participated in the pilot program. Results included improvements in patient activation and self-efficacy to manage kidney disease.

INTRODUCTION

Kidney disease is a demanding chronic condition that presents challenges with patient self-management. In the absence of self-management skills, people with kidney disease are at risk for a host of complications and decreased quality of life. Positive health outcomes for kidney patients depend heavily on the individual's ability to manage the day-to-day tasks required to live well with the disease. Those affected by kidney disease must take an active role in their care, gain information, and build self-management skills to achieve optimal health outcomes. Self-management skills for those with kidney disease include communicating effectively, developing an active partnership with the care team, taking part in self-care activities (including making dietary changes and increasing physical activity), and adherence to medication and treatment regimens (Curtin et al., 2008). According to the Chronic Care Model, the health system must partner with the community to foster active, informed patients to reach optimal health outcomes for those living with a chronic condition (Barr et al., 2003). However, few studies have focused on the development of kidney disease-focused, community-based programs to support self-management skills. Self-management is associated with improved health, including lower self-reported pain and fatigue, improved healthcare utilization and physician communication, decreased emergency room visits, and lower hospitalization rates (Ory et al., 2013). It is essential for providers to refer individuals to community-based self-management programs to encourage self-management and improve health outcomes.

In this study, we examined the effectiveness of the Chronic Disease Self-Management Program (CDSMP) with the addition of two modules pertaining to kidney disease self-management. Implemented worldwide, the CDSMP, a six-week, community-based self-management program, helps individuals manage chronic conditions through improving self-efficacy and skill development. The CDSMP workshops meet for one session per week; each session is 2.5 hours. CDSMP participants learn self-management tasks, such as action planning, problem solving, communicating with support system and providers, healthy eating, physical activity, relaxation techniques, and medication management. CDSMP workshops are open to anyone with any chronic condition and led by two trained leaders, at least one of whom has a chronic condition. Leaders are trained to uphold program fidelity by following the CDSMP curriculum closely and leading group discussion and brainstorming in a manner which enhances participant development. For this study, leader training was provided by the National Kidney Foundation of Michigan (NKFM).

A 2013 meta-analysis of 23 studies regarding the effectiveness of CDSMP in English-speaking countries found the CDSMP provided health benefits for participants through improving communication with physicians, cognitive symptom management, and energy/fatigue management, as well as increasing aerobic activity (Brady, Murphy, O'Colmain, & Beauchesne, 2013). This program is a beneficial component to comprehensive chronic disease management, and is accessible to many communities, as the program is widely implemented. Information about the program's availability can be found on the Evidence-Based Leadership Council website (**www.eblcprograms.org**).

Corresponding author: Allyce Haney Smith, National Kidney Foundation of Michigan, 1169 Oak Valley Drive, Ann Arbor, MI, 48108; **asmith@nkfm.org**

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The CDSMP has been recommended for those living with kidney disease (Washington, Hilliard, & McGill, 2013). Based on Lorig's findings that a program specifically designed for individuals with arthritis was more effective than the generic CDSMP, we hypothesized that the addition of kidney-specific content to the CDSMP curriculum may result in improved symptom management and improved self-efficacy for participants living with kidney disease (Lorig, Ritter, & Plant, 2005). Our initial experience of offering the six-week CDSMP to a cohort comprised exclusively of individuals with kidney disease showed the participants bonded more quickly than those in a cohort of individuals with varied conditions. The NKFM created two sessions focusing on kidney disease self-management offered with the original six-week CDSMP. A pilot program began in 2012 in partnership with the University of Michigan Transplant Center (UMTC). The eight-week workshops were led by two trained leaders, at least one of whom had kidney disease.

METHOD

The research focused on determining the effectiveness of a kidney-disease self-management program for individuals with kidney disease in southeast Michigan. The study examined levels of patient activation and self-efficacy. All study procedures and protocols were approved by the Argis Institutional Review Board.

Study Setting and Sample

The study was conducted in 2016 in four Michigan counties, Washtenaw, Wayne, Oakland, and Genesee. NKFM partnered with local transplant centers to reach people with kidney disease and their caregivers; these centers included Beaumont Hospital Transplant Program, the University of Michigan Transplant Center, and St. John Hospital Transplant Program. Participants were recruited through transplant center mailings; flyers distributed at dialysis centers; promotion through both the Michigan Council of Nephrology Social Work and Council on Renal Nutrition listservs and their quarterly meetings; and utilized testimonials from previous workshop participants to talk with their nephrologists and fellow patients.

Data and Measures

We reached 45 people living with kidney disease and their caregivers for the Kidney CDSMP pilot project. Four scales were used to assess kidney disease self-management and patient activation at baseline and follow-up: Patient Activation Measure (PAM) (Hibbard, Mahoney, Stockard, & Tusler, 2005); the Chronic Kidney Disease Self-Efficacy (CKD-SE) instrument (Lin et al., 2012); the Self-Efficacy for Managing Chronic Disease (SEMCD) scale (Lorig et al., 2000); and the Communication with Physicians Scale (CPS) (Lorig, 1996). Participants completed demographic questions and a baseline survey at the first workshop session. At the last session, participants completed a follow-up survey identical to the baseline survey.

Demographics

Self-reported demographic variables (age, gender, and race) were captured on a separate form completed at the start of the workshop. An additional demographic question was used at baseline and follow-up to determine each participant's kidney disease status. They were asked if they were currently on dialysis, had a functioning transplant, had CKD and were not yet on dialysis, or were they a caregiver. Participants were also asked the self-rated health question, "In general, would you say your health is…" (Idler & Angel, 1990).

Patient Activation Measure

The 13-item version of the Patient Activation Measure (PAM) was used to assess workshop participants' self-reported knowledge, skills, and confidence for self-management of their chronic disease(s) (Hibbard et al., 2005). Patient activation level is considered a broader underlying construct than prior related concepts, such as self-efficacy, locus of control, and readiness for change (transtheoretical model) (Greene & Hibbard, 2012). Sample items include "When all is said and done, I am the person responsible for taking care of my health"; "I know what each of my medications do"; and "I am confident that I can tell when I need to go to the doctor and when I can take care of a health problem myself."

There are 4 levels of patient activation, with higher scores indicating higher levels of activation. Patients scoring in Level 1 (score 0–47) are disengaged from care, low in confidence and rely on the healthcare team to manage their disease. In Level 2 (47.1–55.1), patients are starting to become aware of the importance of self-management and are beginning to set health-related goals. In Level 3 (score 55.2–67.0), patients are starting to take action towards disease self-management and understand the importance of their own roles in managing their disease(s). To manage a chronic disease well, patients will ideally reach Level 4 (score 67.1–100), at which patients are routinely self-managing their condition and can continue to do so during times of adversity or stress.

CKD Self-efficacy Instrument

An adaptation of the 25-item CKD-SE (CKD Self-efficacy) instrument was used to measure patients' perceived self-efficacy related to kidney disease management (Lin et al., 2012). We included the 6-item "problem solving" subscale and the 4-item "seeking social support" subscale. Sample items included, "I can understand the meaning of relevant laboratory data," and "I can discuss my questions and worries about CKD with my friends and family."

Self-Efficacy for Managing Chronic Disease

The 6-item scale developed for the Chronic Disease Self-Management Program was used to measure symptom control, role function, and emotional functioning (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2000). Sample items on this scale include, "How confident are you that you can keep the fatigue caused by your disease from interfering with the

Table 1. Participant demographics (*n* = 45)

	N(%)
Age Group	
Below 50	4 (8.89)
50-59	14 (31.11)
60-69	15 (33.33)
70-79	8 (17.78)
Above 80	2 (4.44)
Missing	2 (4.44)
Gender (Female)	28 (62)
Race	
American Indian/Alaska Native	2 (4.44)
Asian	0 (0)
Black/African American	22 (48.89)
Native Hawaiian/Pacific Islander	0 (0)
White	19 (42.22)
Multi-racial	1 (2.22)
Missing	2 (4.44)
Kidney disease status	
On dialysis	9 (20.00)
Has a functioning transplant	6 (13.33)
CKD (no dialysis)	16 (35.56)
Caregiver	11 (24.44)
No response	3 (6.67)

things you want to do?" and "How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?"

Medical Care Scale

The 3-item Communication Scale was incorporated to measure patient participation in shared decision-making during healthcare visits (Lorig, 1996). Participants were asked how often they performed each item during visits with their doctors. Sample items included "prepare a list of questions for your doctor" and "discuss any personal problems that may be related to your illness."

RESULTS

A total of 50 patients and caregivers enrolled in five Kidney CDSMP workshops, held between March and December 2016. Of these, 45 completed the baseline survey, and 26 (58%) completed the follow-up survey; their surveys were analyzed and are presented here. There is missing post-test data from the first workshop, as the workshop leaders did not administer the post-test survey related to kidney disease with the group. The workshop completion rate was 68%; completion was defined as attending at least 4 of 6 CDSMP sessions and 1 of 2 kidney disease sessions. The average attendance was 5 out of 8 sessions among the 50 participants enrolled.

Sample Characteristics

Table 1 provides data on workshop participant demographics. More than half (62%) of participants identified as female. The average age of participants was 62 years; 31.1% were between ages 50–59 and 33% were ages 60–69, while 18% were ages 70–79. About half (49%) of participants identified as Black/African American. Regarding modality; 36% of participants were early stage kidney disease not needing dialysis; 13% had a functioning kidney transplant, 20% were on dialysis; and 24% of participants were caregivers of individuals living with kidney disease.

Patient Activation Measure (PAM) Findings

The mean PAM score for the sample was 70.15 (SD = 18.51) at baseline and rose to 71.15 (SD = 22.79) at follow up. **Table 2** shows the descriptive statistics of the PAM scores, stratified by kidney disease status. People with CKD not yet on dialysis at baseline experienced decreased PAM scores and decreased patient activation level. After completing the workshop, 46% of participants remained at the same patient activation level; 27% increased one patient activation level; and 23% decreased by one patient activation level.

CKD Self-efficacy (CKD-SE) Findings

The mean score for the "problem-solving" subscale of the CKD-SE instrument was 7 (SD = 3.35) at baseline and 8 (SD = 2.48) at follow-up. The mean score for the "seeking social support" subscale of the CKD-SE instrument also increased from 7 (SD = 3.40) at baseline to 8 (SD = 2.18) post-workshop. **Table 3** shows the descriptive statistics of the CKD-SE measure with pre-/post-mean scores for each survey question.

Self-efficacy for Managing Chronic Disease (SEMCD)

The mean score was 7 out of 10 at baseline and follow-up **(Table 3)**. Mean scores improved by 1 point for 5 of the 6 items on the Self-Efficacy for Managing Chronic Disease scale.

Medical Care Scale

The mean score on the Communication with Physicians scale was 3 at both baseline and follow-up **(Table 3)**. There were no changes in mean score on individual items. For the self-rated health question, there was a slight decrease in mean scores from baseline (3.00 SD = 1.41) to follow-up (3.00 SD = 1.43). Results were not statistically significant.

DISCUSSION

The results indicate that the Kidney CDSMP is beneficial to people living with kidney disease and their caregivers. However, more research is needed to determine the extent

Table 2. Patient Activation Measure (PAM) findings

Kidney disease status (at baseline)	Pre-test	Post-test	Difference
	Mean Score (SD)	Mean Score (SD)	(***P*** value; 95% CI)
On dialysis [a]	74.49 (23.05)	72.28 (18.81)	-2.21 (p = 0.87; -26.85 – 31.27)
Functioning transplant [b]	74.40 (20.78)	85.83 (13.55)	11.43 (p = 0.36; -38.83 – 15.97)
CKD (no dialysis) [c]	64.19 (15.98)	56.00 (27.29)	-8.19 (p = 0.36; -10.02 – 26.40)
Caregiver [d]	73.05 (19.28)	73.33 (19.02)	0.28 (p = 0.97; -19.94 – 19.38)
Missing [e]	71.13 (11.90)	85.40 (17.85)	14.27 (p = 0.31; -48.66 – 20.12)
TOTAL [f]	70.15 (18.51)	71.15 (22.79)	1.00 (p = 0.84; -10.91 – 8.91)
Patient Activation Level (pre- vs. post-)	*N*(%)		
Remained at same level	12 (46.15)		
Increases one level	7 (26.92)		
Decreased one level	6 (23.08)		
No response	1 (3.85)		
TOTAL	26		

a Pre: n = 9, Post: n = 4; **b** Pre: n = 6, Post: n = 4; **c** Pre: n = 16, Post: n = 8; **d** Pre: n = 11, Post: n = 7; **e** Pre: n = 3, Post: n = 3; **f** Pre: n = 45, Post: n = 26

which the program affects kidney disease self-management skills. Although not statistically significant, due to the small sample size, the participants did see an increase in average PAM score after completing the workshop. Increased patient activation is associated with improved patient self-management (Hibbard, Mahoney, Stock, & Tusler, 2007), and is associated with a broad range of health-related outcomes (Greene & Hibbard, 2012). Improving patient activation levels among this population may also result in healthcare cost savings (Greene, Hibbard, Sacks, Overton, & Parrotta, 2015). Participants also experienced an increase in mean scores related to "problem solving" and "seeking social support," as assessed by the CKD-SE measure. This suggests the Kidney CDSMP is effective in improving aspects of patient self-management essential to living well with kidney disease.

Baseline patient activation scores collected for this pilot project were higher compared to those reported in a study published in 2016 by Michelle Johnson and colleagues (Johnson et al., 2016). Johnson's team examined group differences in patient activation levels among each stage of kidney disease. Patients with stage 3 kidney disease were found to be the most activated, and those in stage 5 CKD least activated. The authors theorized that decreased activation for people with stage 5 CKD may suggest that those starting dialysis may feel less confident in self-management as the disease becomes more complex to manage and prevention of complications more challenging (Johnson et al., 2016). However, we did not find participants with early stage CKD to have higher patient activation scores; these participants had slightly lower PAM scores. The mean PAM scores in Johnson's study was 58.04 (SD = 13.46) for those with end-stage renal disease (ESRD), while the mean PAM scores collected for our pilot were approximately 74.4 for both participants on dialysis (SD = 23.05) and living with a kidney transplant (SD = 20.78). This suggests that patients with higher patient activation are more likely to attend a workshop compared to the overall community living with kidney disease.

The Kidney CDSMP was successful in engaging participants living with kidney disease as participants bonded over sharing similar disease experiences. Further research is needed to determine the extent of benefits Kidney CDSMP provides to those with kidney disease compared to how the generic program may benefit the same population. Both programs have a positive impact, and in some disease populations, the disease-specific programs should be considered first when resources allow (Lorig et al., 2005).

The study has several limitations. The small sample size did not yield conclusive results on the impact of the program. We were not able to collect clinical outcomes to assess the impact of the measures. Our team will continue to offer the Kidney CDSMP and evaluate its effectiveness. One of the most significant limitations of this pilot project was missing post-test data, as the leaders of an early 2016 workshop did

Table 3. Chronic Kidney Disease Self-Efficacy and Medical Care Scales

	Pre- (*N* = 45) Mean Score (SD)	Post- (*N* = 26) Mean Score (SD)
CKD-SE Instrument: Problem Solving		
1. Understand meaning of relevant lab data	7 (3.18)	8 (2.53)
2. Seek out information that explains CKD-related signs and symptoms	8 (2.86)	8 (2.41)
3. Find information about kidney disease from a variety of sources	8 (3.07)	9 (1.77)
4. Actively understand the risk factors associated with CKD	7 (3.32)	8 (2.30)
5. Find resources needed to better control my CKD	6 (3.91)	8 (2.90)
6. Actively seek out precautions to prevent CKD from worsening	7 (3.78)	8 (2.97)
TOTAL	**7 (3.35)**	**8 (2.48)**
CKD-SE Instrument: Seeking Social Support		
7. Find help when I am feeling stressed	8 (2.97)	9 (1.37)
8. Discuss questions/worries about CKD with my family and/or friends	7 (3.63)	8 (2.90)
9. Ask family or friends for help when I am feeling helpless or frustrated	8 (3.22)	8 (1.78)
10. Actively discuss treatment plan with family/friends to gain support	7 (3.77)	8 (2.67)
TOTAL	**7 (3.40)**	**8 (2.18)**
Self-Efficacy for Managing Chronic Disease		
11. Keep fatigue caused by disease from interfering with activities	6 (3.46)	7 (3.28)
12. Keep physical discomfort or pain of disease from interfering with activities	6 (3.46)	7 (3.31)
13. Keep emotional distress caused by disease from interfering with activities	6 (3.40)	7 (3.44)
14. Keep other symptoms or health problems from interfering with activities	7 (2.73)	8 (2.29)
15. Can do different tasks/activities needed to manage health to reduce doctor visits.	7 (3.08)	8 (2.26)
16. Can do things other than taking medication to reduce how illness affects everyday life	7 (3.11)	7 (2.80)
TOTAL	**7 (3.21)**	**7 (2.90)**
Medical Care Scale		
17. Prepare list of questions for doctor	3 (1.52)	3 (1.68)
18. Ask questions about things I want to know or don't understand about my treatment	4 (1.25)	4 (1.08)
19. Discuss personal problems related to illness	3 (1.44)	3 (1.54)
TOTAL	**3 (1.41)**	**3 (1.43)**

not administer all follow-up surveys. In order to address this issue, the project team improved the Kidney CDSMP leader training to better explain the evaluation components. We also changed how we organized the program file box, which sorts all program materials for leaders, making it clearer when to administer each evaluation component. These changes helped to avoid missing further evaluation data. We also did not capture the treatment modality for patients who reported being on dialysis. Through leader feedback, we know that the patients were on various forms of dialysis, including in-center hemodialysis, home hemodialysis, and peritoneal dialysis. We will capture this data in the future by changing the survey tool. In this study, caregivers completed the same survey tool as the kidney patients. In the future, we will include a separate tool to assess caregiver burden. We also found that our program tends to attract people with high patient activation scores at baseline. We will continue to experiment with different forms of participant recruitment to reach people with lower patient activation scores, including utilizing more face-to-face recruitment instead of passive recruitment strategies (mailings and posting flyers).

Community-based programs serve as a resource for people living with kidney disease. Providers should refer patients to evidence-based programs, which can help them build kidney-disease self-management skills. The Kidney CDSMP shows promise in increasing patient activation and self-efficacy among people living with kidney disease and their caregivers. Further research is needed on the Kidney CDSMP to determine the extent of its impact on those managing kidney disease.

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