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# Self-Management Interventions in Stages 1-4 Chronic Kidney Disease: An Integrative Review

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# Abstract

The prevalence, effect on health outcomes, and economic impact of chronic kidney disease (CKD) have created interest in self-management interventions to help slow disease progression to kidney failure. Seven studies were reviewed to identify knowledge gaps and future directions for research. All studies were published between 2010 and 2013; no investigations were conducted in the United States. Knowledge gaps included the focus on medical self-management tasks with no attention to role or emotional tasks, lack of family involvement during intervention delivery, and an inability to form conclusions about the efficacy of interventions because methodological rigor was insufficient. Educational content varied across studies. Strategies to improve self-management skills and enhance self-efficacy varied and were limited in scope. Further development and testing of theory-based interventions are warranted. There is a critical need for future research using well-designed trials with appropriately powered sample sizes, well-tested instruments, and clear and consistent reporting of results.

#### Keywords

self-management; knowledge; self-efficacy; chronic kidney disease; renal insufficiency

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Chronic kidney disease (CKD) is a national public health problem affecting 26 million Americans (Coresh et al., 2007) and 6 in 10 Americans are at risk for developing the disease in their lifetime (Grams, Chow, Segev, & Coresh, 2013). The prevalence, effect on health outcomes (CKD Prognosis Consortium, 2010; Plantinga et al., 2011), and economic impact (Honeycutt et al., 2013; United States [U.S.] Renal Data System, 2013) have created a national focus to slow progression of CKD, including recognition as a priority objective within Healthy People 2020 (Healthy People 2020, 2013). The need for patients to selfmanage their care is important for optimal patient outcomes in chronic disease (Lorig, Ritter, Villa, & Armas, 2009; Lorig et al., 2008) and is vital for people with CKD who need effective self-management to slow disease progression to end stage renal disease (ESRD).

Self-management is conceptually defined as a process in which people perform day-to-day activities in the management of chronic disease (Lorig & Holman, 2003). This definition includes the three attributes of self-management described by Schilling, Knafl, and Grey (2002) - process, activities, and goals – and is consistent with the assertion that chronic disease management occurs in the context of daily living (Grey, Knafl, & McCorkle, 2006; Schilling et al., 2002). Slowing disease progression in CKD requires daily performance of key self-management behaviors that include adherence to angiotensin-converting enzyme inhibitor (ACE-I) or angiotensin receptor blocker (ARB) medications, avoidance of nonsteroidal anti-inflammatory drugs (NSAIDS), diet modifications, glycemic control, regular exercise, systolic blood pressure control, and tobacco avoidance (Tuot et al., 2013).

Supporting self-management enables patients to self-identify problems and provides techniques to help them make decisions, take action, and alter behaviors (U.S. Department of Defense, 2012). Lorig and Holman (2003) recommend the inclusion of six core self-management skills in self-management support programs: action planning, decision-making, patient-provider partnerships, problem solving, resource utilization, and self-tailoring. Development of these skills will enable people to accomplish key self-management tasks associated with medical, role, and emotional management (Battersby et al., 2010; Lorig & Holman, 2003),

Self-management of Stages 1-4 CKD is an emerging area in nephrology. Initial studies examining the efficacy of self-management interventions have only been reported in the last few years. The purpose of this integrative review of CKD self-management interventions is to identify knowledge gaps and future directions for research. Three questions guided this review: (1) What components of self-management were included? (2) What methods were used when testing the interventions? (3) Were the interventions efficacious in improving CKD patient outcomes?

#### Methods

This integrative review followed the processes identified by Cooper (1989). A comprehensive computerized search of EBSCOhost Cumulative Index to Nursing and Allied Health (CINAHL), OVID MEDLINE, Web of Science, and EMBASE was conducted at the university library by an experienced nursing librarian using four exploded search terms. "Kidney diseases" was combined using "AND" with "self-care," "OR" "medication

adherence," "OR" "patient education as topic" to find 494 citations. Reference lists were hand searched to locate additional literature. Studies were retained for review if they were written in English, included adults 18 years of age or older who had Stage 1-4 CKD, included an experimental or quasi-experimental design, and tested a self-management intervention. Studies were excluded if any of the participants had Stage 5 CKD or ESRD; were at risk for, but did not have, CKD; or if the intervention was solely educational in nature. Seven studies met the inclusion criteria. All were published between 2010 and 2013. Each study was read in detail by two authors, with data extracted into tables by one author and independently verified by a second author. Discrepancies were discussed until differences were resolved and consensus was reached.

#### Results

#### **Components of the Interventions**

Systematic efforts to improve knowledge, self-management, or self-efficacy were included in all studies. Table 1 summarizes these findings.

**Knowledge**—Knowledge development was the most frequent component of the tested interventions. Each study included some education; however, no investigation included all content associated with key CKD self-management behaviors. As shown in Table 1, the most frequently delivered educational content focused on nutrition, diet modifications, eating out, or reading food labels (Choi & Lee, 2012; Flesher et al., 2011; Kazawa & Monyama, 2013; Walker, Marshall, & Polaschek, 2013). Educational content associated with the other key components of CKD self-management in decreasing order of frequency included exercise (Flesher et al., 2011; Kazawa & Monyama, 2013; Walker et al., 2011; Kazawa & Monyama, 2013; Walker et al., 2011; Kazawa & Monyama, 2013; Walker, & Gorelik, 2012), adherence to ACE-I or ARB therapy (Kazawa & Monyama, 2013). None of the studies included content on avoidance of NSAIDS or smoking cessation/ tobacco avoidance.

Additional educational content was diverse. The most frequently delivered content was associated with hypertension (Byrne et al., 2011; Walker et al., 2013; Williams et al., 2012) or self-management (Choi & Lee, 2012; Flesher et al., 2011; Lin, Tsai, Lin, Hwang, & Chen, 2013). Other educational content in decreasing order of frequency included CKD and kidney health (Choi & Lee, 2012; Walker et al., 2013), diabetes and nephropathy (Kazawa & Monyama, 2013; Walker et al., 2013), a review of medications (Walker et al., 2013; Williams et al., 2012), kidney replacement therapies (Choi & Lee, 2012), foot care (Kazawa & Monyama, 2013), and stress or emotional management (Kazawa & Monyama, 2013).

**Self-management skills**—Three self-management skills, action planning, problemsolving, and enhancing patient-provider partnerships, were evident in the tested interventions. There was no evidence of decision making, resource utilization, or selftailoring.

Action planning was used most frequently and included in five studies. Goal settings, strategies to achieve goals, and self-evaluation of strategies to achieve goals were used in one study (Lin et al., 2013). In another (Byrne et al., 2011), participants developed an action plan to set, achieve, and maintain goals for blood pressure control, but no additional follow-up was conducted. Goal setting was included in four other studies (Flesher et al., 2011; Kazawa & Monyama, 2013; Lin et al., 2013; Walker et al., 2013); it was not clear if an action plan was established or whether there was any follow-up on these goals.

Problem-solving was included in two studies. Participants in one were instructed to identify target problems and self-monitor activities to determine causes of problems (Lin et al., 2013). In a second study, concerns and barriers to taking medications were identified (Williams et al., 2012). Neither study described if nor how they taught problem-solving skills.

Enhancing patient-provider partnerships was included in three studies. Self-monitoring of blood pressure (Kazawa & Monyama, 2013; Walker et al., 2013; Williams et al., 2012), blood glucose (Kazawa & Monyama, 2013; Walker et al., 2013), or exercise (Walker et al., 2013) was used in all three studies, presumably to enhance patient-provider partnerships by communicating accurate information to the provider. In one, the interventionists acted as advisors to patients and primary physicians to foster good communication between the two (Kazawa & Monyama, 2013).

**Self-efficacy**—Efforts to enhance self-efficacy were included in five studies (see Table 1). In one (Lin et al., 2013), modeling of self-management behaviors, vicarious experience by observing others, and recognition of outcome performance were used to improve self-efficacy. In another (Williams et al., 2012), self-efficacy was enhanced vicariously when people described daily medication management on video clips. A final study (Kazawa & Monyama, 2013) used positive feedback when changes in target behaviors were achieved. Strategies to improve self-efficacy were not described in two other studies (Byrne et al., 2011; Flesher et al., 2011).

#### Methods Used When Testing Interventions

**Design**—As shown in Table 2, the studies included three randomized controlled trials (RCTs; Byrne et al., 2011; Flesher et al., 2011; Williams et al., 2012) and four quasiexperimental designs (Choi & Lee, 2012; Kazawa & Monyama, 2013; Lin et al., 2013; Walker et al., 2013). Three of the latter used a one-group pretest/posttest design (Kazawa & Monyama, 2013; Lin et al., 2013; Walker et al., 2013) and one used a nonequivalent control group non-synchronized design (Choi & Lee, 2012). Two RCTs (Byrne et al., 2011; Williams et al., 2012) and one quasi-experimental study (Lin et al., 2013) were described as pilot or feasibility studies.

**Sample/Setting**—Subjects were recruited from out-patient nephrology or primary care clinics and hospitals. Studies were conducted in Australia (Williams et al., 2012), Canada (Flesher et al., 2011), Japan (Kazawa & Monyama, 2013), New Zealand (Walker et al., 2013), South Korea (Choi & Lee, 2012), Taiwan (Lin et al., 2013), and the United Kingdom (Byrne et al., 2011). No studies were conducted in the U.S.

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The sample sizes ranged from 30 to 81 participants. Power calculations were used to determine sample sizes in three studies (Choi & Lee, 2012; Flesher et al., 2011; Williams et al., 2012); however, one study was unable to recruit the required number of participants (Flesher et al., 2011). Rates of subject accrual varied. Recruitment was hampered because potential participants did not meet inclusion criteria (Williams et al., 2012), lacked time and interest or were unaware they had problems with their kidneys (Byrne et al., 2011), were lost to follow-up after initial screening (Williams et al., 2012), or withdrew before intervention delivery (Williams et al., 2012). One investigator reported an inability to recruit (Flesher et al., 2011), but did not report problems encountered.

Mean age of the participants ranged from 57.5 (Walker et al., 2013) to 67 years (Kazawa & Monyama, 2013; Lin et al., 2013; Williams et al., 2012), and 52% to 69% were men (Byrne et al., 2011; Choi & Lee, 2012; Flesher et al., 2011; Lin et al., 2013; Williams et al., 2012). Smoking history was reported in two studies and 26% to 35% were current smokers (Walker et al., 2013; Williams et al., 2012).

Stage of CKD varied across the studies. Four (Choi & Lee, 2012; Flesher et al., 2011; Kazawa & Monyama, 2013; Williams et al., 2012) included participants in CKD Stages 3-4. Other investigations included participants with CKD stages 1-4 (Byrne et al., 2011), Stages 1-3a (Lin et al., 2013) and Stage 2 (Walker et al., 2013).

Attrition rates varied in the studies reviewed. One (Lin et al., 2013) had a total attrition rate of 39%. Of the 44 subjects recruited, 37 completed the baseline measures and the intervention; of these, 27 completed all three posttests. The remaining 10 subjects dropped out due to unwillingness to complete follow-up or due to physical condition. In another study (Byrne et al., 2011), 37.5% of participants randomized to the intervention group did not attend the education session. Those who did attend were more likely to be older and have lower levels of self-efficacy. Attrition rates were 11% or less in the other studies (Flesher et al., 2011; Kazawa & Monyama, 2013; Williams et al., 2012), and reasons for the attrition included death, withdrawal, or refusal to take part in study protocol. One study reported no attrition (Choi & Lee, 2012) and another did not report attrition rates (Walker et al., 2013).

**CKD Self-Management Interventions**—The length of intervention sessions ranged from 30 to 180 minutes each (Byrne et al., 2011; Choi & Lee, 2012; Flesher et al., 2011; Kazawa & Monyama, 2013; Lin et al., 2013; Williams et al., 2012) with the number of contacts ranging from 1 to 36 (Byrne et al., 2011; Choi & Lee, 2012; Flesher et al., 2011; Kazawa & Monyama, 2013; Lin et al., 2013; Walker et al., 2013; Williams et al., 2012). In six studies, it was not clear whether participants attended all intervention sessions, if the group sessions lasted for the same lengths of time, or if participants stayed for the entire length of time. The length and content of telephone sessions (Williams et al., 2012) or the amount and content of e-mail messages (Kazawa & Monyama, 2013) were not described. The total duration of the contacts over time ranged from a single session (Byrne et al., 2011) to 6 months (Kazawa & Monyama, 2013). The mode for intervention duration was 12 weeks (Flesher et al., 2011; Walker et al., 2013; Williams et al., 2012). The dose of the control condition was not described in any reviewed study.

The self-management intervention were provided on an individual level in three studies (Kazawa & Monyama, 2013; Walker et al., 2013; Williams et al., 2012) and on a group level in four others with group sizes ranging from 2-8 (Byrne et al., 2011; Choi & Lee, 2012; Flesher et al., 2011; Lin et al., 2013); one did not report group size (Flesher et al., 2011). All interventions were delivered face-to-face, although telephone (Kazawa & Monyama, 2013; Williams et al., 2012), e-mail (Kazawa & Monyama, 2013), videotapes (Lin et al., 2013), and a Digital Versatile Disc (DVD; Williams et al., 2012) were used. Motivational interviewing was used in one (Williams et al., 2012). Most were delivered at the institution (Byrne et al., 2011; Choi & Lee, 2012; Kazawa & Monyama, 2013; Walker et al., 2013), followed in frequency by home visits (Kazawa & Monyama, 2013; Walker et al., 2013; Williams et al., 2012), and at a gym (Flesher et al., 2011). Setting was not reported in one (Lin et al., 2013) and the location of a cooking class (Flesher et al., 2011) was not described.

In all studies, the interventionist was a nurse for at least one portion of the intervention. Other interventionists included a certified exercise physiologist (Flesher et al., 2011), cook educator (Flesher et al., 2011), and dietician (Choi & Lee, 2012; Flesher et al., 2011). In one study (Lin et al., 2013), the interventionist was identified only as a member of the research team. No peers, pharmacists, social workers, or health coaches were used as interventionists.

Use of a theory to guide study design or intervention development was reported in four studies. Two investigations (Byrne et al., 2011; Kazawa & Monyama, 2013) used social cognitive theory to examine the effect of self-management on CKD outcomes. In one (Lin et al., 2013), self-regulation theory was used to evaluate the effect of self-management on CKD progression. In the fourth study (Williams et al., 2012), the Health Belief Model was used to guide examination of the impact of an intervention to improve blood pressure control and adherence to medication. It was not clear, however, how central constructs of the theories were integrated into the intervention or study design. Moreover, intervention mechanisms were not tested in these studies. Use of a theory to guide the studies or intervention development was not reported in three studies (Choi & Lee, 2012; Flesher et al., 2011; Walker et al., 2013).

Two investigators provided information about training providers. Skills were assessed in one study by observing a pilot session (Byrne et al., 2011), but no information was provided about how training occurred or how skills were maintained. In a second study (Kazawa & Monyama, 2013), the provider received lectures from CKD experts, participated in role playing the intervention, and team conferences ensured quality of the interventions over time.

Use of standardized instruction books was reported in three studies (Byrne et al., 2011; Choi & Lee, 2012; Kazawa & Monyama, 2013). One used a written script and checklist (Williams et al., 2012); content and results were not reported.

Receipt and enactment of the intervention by participants often went unreported. In one study (Kazawa & Monyama, 2013) self-monitoring data was reviewed to assess ability to perform skills, but other skills needed to initiate an action plan were not assessed. In another (Lin et al., 2013), it was not clear whether group discussions allowed comprehension of self-

regulation strategies to be assessed, but participants self-evaluated actual performance of skills needed to meet short-term goals. Although a cooking and exercise class was implemented in another study (Flesher et al., 2011), no findings pertaining to receipt or enactment were reported.

#### Outcomes following intervention delivery

The effects of the self-management interventions were measured at different times, though all were at one year or less. The timelines included baseline to 8 weeks (Choi & Lee, 2012), baseline to 6 months (Kazawa & Monyama, 2013), and baseline to 12 months (Flesher et al., 2011; Lin et al., 2013; Walker et al., 2013; Williams et al., 2012). In one study the measurement timeline was not stated (Byrne et al., 2011).

Annual decline in eGFR was the outcome measure in one study. In this study of 40 participants (Flesher et al., 2011), eGFR declined by an average of 1.2% in the experimental group compared to an 11.2% decline in the control group at the 12-month follow-up; statistical significance and the method used to obtain the eGFR were not reported.

The eGFR was the targeted outcome in three other studies (Choi & Lee, 2012; Kazawa & Monyama, 2013; Williams et al., 2012) and a secondary outcome in another (Lin et al., 2013). None of the studies had significant improvements in eGFR. In the three studies reporting nonsignificant findings for eGFR, one assessed physiological outcomes at 8 weeks (Choi & Lee, 2012), another at 3 and 6 months following the intervention (Kazawa & Monyama, 2013), and another at 3, 6, and 12 months following the intervention (Lin et al., 2013).

Two studies (Choi & Lee, 2012; Lin et al., 2013) measured the estimated glomerular filtration rate (eGFR), derived from serum creatinine levels using the Modification of Diet in Renal Disease Equation (MDRD), two did not report method used (Flesher et al., 2011; Williams et al., 2012), and one used the formula by the Japanese Society of Nephrology (Kazawa & Monyama, 2013). It was not clear whether the metrics are similar in these different methods to allow comparisons.

Medication adherence was assessed in two studies (Kazawa & Monyama, 2013; Williams et al., 2012). Medication adherence significantly improved in a quasi-experimental study with 30 participants (Kazawa & Monyama, 2013). In this study, medication adherence was measured by computing the self-reported days per month they took prescribed oral or injectable medications. In the second study, an RCT with 75 participants (Williams et al., 2012), there was no significant difference in medication adherence when measured by either pill counts or self-report. The accuracy of using pill counts in this study was confounded by the fact that 30 of 75 participants had inaccurate or missing data.

Blood pressure was assessed in four studies with equivocal findings. In one RCT with 40 participants (Flesher et al., 2011), the mean baseline blood pressure in the experimental group was 139/78 mm Hg reducing to 127/69 at 12 months compared to the control group which had a mean baseline blood pressure of 140/76 and 144/74 at 12 months; statistical significance was not reported. In two additional RCTs (Byrne et al., 2011; Williams et al.,

2012) and one quasi-experimental study (Kazawa & Monyama, 2013), there were no significant improvements in blood pressure (see Table 2).

Hemoglobin A1C (HbA1C) was assessed by one investigative team and data were obtained from the medical record. In this quasi-experimental study of 30 participants, HbA1C significantly improved over time from baseline to 6-months, but was less than 7% at baseline using the Japan Diabetic Value (Kazawa & Monyama, 2013).

Dietary and exercise adherence were measured in one study and there was a significant increase in the frequency of exercise from 3- to 6-month follow-up, but no significant change in target dietary behaviors (Kazawa & Monyama, 2013). Adherence was assessed by computing the self-reported days per month engaged in dietary and exercise target behaviors.

Some investigators evaluated the effects of the interventions on disease-specific knowledge, self-management skills, and/or self-efficacy. The psychometric properties of the instruments were not fully described. Only one investigator evaluated change in knowledge using a dichotomous instrument. In this study, there were significant improvements in knowledge compared to controls (Choi & Lee, 2012).

Self-management was measured in four studies (Choi & Lee, 2012; Flesher et al., 2011; Lin et al., 2013; Walker et al., 2013) using four different self-report instruments. Only two of these investigators conceptually defined self-management (Flesher et al., 2011; Lin et al., 2013) and it was difficult to determine if the conceptual definitions were consistent with operational definitions because instruments were not fully described. Self-management significantly improved in a quasi-experimental study with 61 patients 4 weeks following the intervention (Choi & Lee, 2012). In another pretest/posttest study of 52 participants, there was a significant increase in self-management at 3 months that was sustained at 12 months (Walker et al., 2013). Self-management did not significantly improve in another quasi-experimental study of 27 patients (Lin et al., 2013) and was not statistically analyzed in an RCT of 40 patients although self-management was described qualitatively as improved (Flesher et al., 2011).

Self-efficacy was measured in three studies using three different instruments; significant improvements were reported in two. In one quasi-experimental study with 30 participants (Kazawa & Monyama, 2013), self-efficacy improved from baseline to 3 months and from baseline to 6 months when positive feedback was provided; additional improvement did not occur from 3 to 6 months. Self-efficacy also improved at 6- and 12-months in another quasi-experimental study of 27 participants (Lin et al., 2013) when using modeling of self-management behaviors and recognition of outcome performance as methods to enhance self-efficacy. Self-efficacy results were not reported in a RCT with 81 participants (Byrne et al., 2011).

As shown on Table 2, many other outcomes were assessed that included cardiovascular risk factors (Byrne et al., 2011); physiological indices, such as creatinine, hemoglobin, or blood urea nitrogen (Choi & Lee, 2012; Kazawa & Monyama, 2013; Lin et al, 2013; Williams et al., 2012), and quality of life (Kazawa & Monyama, 2013). Significant findings were

reported in only one. In this quasi-experimental study, there was a significant increase in serum sodium (Choi & Lee, 2012).

#### Discussion

The purpose of this paper was to review self-management interventions delivered to individuals with Stage 1-4 CKD to identify knowledge gaps and future directions for research. All seven of the reviewed studies were published between 2010 and 2013 and conducted outside of the U.S. The main findings were that (a) educational content was present in all, but was incomplete; (b) strategies to improve self-management varied and were limited in scope; (c) strategies to increase self-efficacy were largely undeveloped; (d) methodological limitations included flaws in design, sample size limitations, recruitment difficulties, attrition rates, and limited descriptions of the processes used in intervention delivery; and (e) outcomes varied across the studies and had equivocal findings. These findings are discussed below.

Interventions to improve acquisition of knowledge included some, but not all, of the key self-management behaviors associated with CKD. Content varied widely across studies and pharmacological content was included on a limited basis. Content on the avoidance of nonsteroidal anti-inflammatory drugs and tobacco avoidance was absent from all reports. Previous reports indicate patients with CKD want more information about their disease and how the underlying condition affects kidney function (Costantini et al., 2008; Mason, Stone, Khunti, Farooqi, & Carr, 2007), strategies to prolong function (Schatell, Ellstrom-Calder, Alt, & Garland, 2003), dietary modifications (Lewis, Stabler, & Welch, 2010; Mason et al., 2007), medications that help or harm the kidney (Costantini et al., 2008; Lewis et al., 2010), and strategies for blood pressure control (Mason et al., 2007). Consistent and inclusive content is recommended in future work.

Interventions to enhance self-management behaviors were limited in scope. Selfmanagement interventions directed at lifestyle and exercise were included in some interventions (Flesher et al., 2011; Kazawa & Monyama, 2013; Walker et al., 2013); content on smoking cessation was absent. These are important areas to emphasize so patients have the prerequisite knowledge to make important decisions for kidney health and engage in effective self-management behaviors. In a secondary analysis of data from 2,615 CKD patients (Tuot et al., 2013), 89% avoided tobacco and 24% engaged in frequent physical activity.

People with CKD have described self-management as active engagement in treatment requiring daily self-management decisions. These individuals reported lack of guidance on skill building as a major barrier to self-management (Costantini et al., 2008), suggesting self-management skills are important and needed by people with CKD. In our review, the self-management skills of action planning, problem-solving, and enhancing patient-provider partnerships were evident in some CKD self-management interventions; decision making, resource utilization, and self-tailoring were not evident. Moreover, the interventions focused on the self-management tasks associated with medical management, but tasks associated with role and emotional management were absent. Self-management interventions that

include skill development in these areas have improved patient outcomes in other patient populations (Bissonnette, Woodend, Davies, Stacey, & Knoll, 2013; Nuno, Coleman, Bengoa, & Sauto, 2012; Shively et al., 2013). Possible strategies to consider for inclusion in future CKD self-management interventions are (a) use of action planning tools or eHealth self-management applications (U.S. Department of Defense, 2012); (b) inclusion of methods to help patients remember what they need to ask their provider at routine visits, how to best report their problems or concerns and what they have done to alleviate the problem, and/or how to have serious discussions with their provider about health decisions; (c) providing a list of Web sites that include accurate and appropriate content and, as appropriate, teaching patients how to use and navigate through the sites; (d) providing resources where patients can find information, such as who to contact for help to learn to read food labels or quit smoking; and (e) providing a list of helpful smartphone apps, such as My MedSchedule, MyMeds, and RxmindMe (Dayer, Heldenbrand, Anderson, Gubbins, & Martin, 2013).

Prior research suggests patients with CKD want more information about decision making (Schatell et al., 2003). People with CKD must make daily decisions when taking care of themselves at home and must have accurate and complete information when responding to changing conditions (Lorig & Holman, 2003). The creation of important messages to support decision making is fundamental to self-management education (Lorig & Holman, 2003). Refinement of CKD self-management interventions should involve messages surrounding the following questions: (1) If I can no longer take NSAIDS, what options do I have when I experience minor aches and pains due to a headache, muscular aches, menstrual cramps, a backache, or arthritis? (2) What do I do if potassium or phosphorus content is not listed on a food label? (3) When should I contact my doctor for blood pressure or blood glucose readings that are higher or lower than normal? (4) What should I do if I become ill and am unable to take my ACE-I or ARB? (5) Should I continue taking my ACE-I or ARB even when my blood pressure is low? (6) What short-term strategies can I consider to begin a regular exercise regimen? (7) How do I know whether a new symptom is serious? Creation and use of decision aids (U.S. Department of Defense, 2012) may facilitate development of decision-making skills.

Strategies for increasing self-efficacy were largely underdeveloped or not described. Further development is needed, as supported by findings from a descriptive study of 174 CKD patients in which higher self-efficacy was associated with better self-care (Curtin et al., 2008). Because CKD often coexists with other chronic diseases, such as diabetes, heart failure, and hypertension (U.S. Renal Data System, 2013), an integration of interventions for all chronic conditions is suggested to help improve self-efficacy and self-management (Dickson, Buck, & Riegel, 2013).

There were numerous methodological limitations in the reviewed studies. Half of the studies were quasi-experimental and three of these used a pretest/posttest design. Although it was not clear why less rigorous designs were chosen, they may have been selected because many were pilot or feasibility studies. No further development of these trials, however, has been reported to date.

Recruitment was a major difficulty. Although lack of CKD awareness was cited as a reason for recruitment difficulties in only one study (Byrne et al., 2011), it may have been a factor affecting recruitment in other studies as well. In two large trials including a total of over 4,400 patient, 84-94% were unaware they had CKD (Tuot et al., 2013). Although prior research indicates that as CKD advances, CKD awareness and treatment improves (Sarafidis et al., 2008), slowing disease progression early is imperative. One promising strategy to improve awareness uses a one-page educational worksheet that physicians review with patients. Patients exposed to the worksheet were more likely to know they had CKD, their kidney function, and their stage of CKD (Nunes et al., 2013). A recent meta-analysis with older adults clearly showed that one-page succinct worksheets were effective for improving medication adherence (Conn et al., 2009).

Studies lasted for one year or less and were based on a single or short-term intervention designed to improve self-management in a slowly progressive disease. A recent report indicates that self-management behaviors do not develop in a uniform pattern (Audulv, 2013) suggesting that booster interventions may be needed throughout the course of a chronic illness.

Sample sizes were small and often had insufficient power. The racial composition of participants was seldom reported. Future researchers may want to consider enrolling adequate numbers of diverse participants to permit meaningful comparisons of intervention effects by race or ethnicity. Similarly, health literacy was not reported, although understanding health literacy in CKD patients would allow us to consider this factor during intervention refinement and testing.

Attrition was a problem in some studies which was particularly troublesome given the small sample sizes. It may be helpful in future studies to describe the activities to increase study participation. The use of incentives might be a beneficial way to thank participants for their time and effort given the significant time required for intervention delivery.

The self-management interventions in the studies reviewed were delivered on an individual or group level, and family members were not evident. No investigator examined whether one delivery mechanism was superior to another. Although interventionists were primarily and appropriately nurses, several other disciplines involved in nephrology care were omitted, such as pharmacists and social workers, who may need to be included in the future for their specialized knowledge and expertise. Consideration should be given to the inclusion of health coaches or use of peer mentors because they have been efficacious in previous chronic disease self-management investigations (Castro, Pruitt, Buman, & King, 2011; Long, Jahnle, Richardson, Loewenstein, & Volpp, 2012; Thom et al., 2013). Training of the interventionists was seldom described. Although presumably the interventionists had the technical and interpersonal skills to carry out intervention delivery, planned delivery of the intervention relies on the interveners' understanding of the essential features of the intervention and any variability may affect outcome achievement (Melnyk & Morrison-Beedy, 2012). Although the length of the intervention was often provided, no information was provided about actual attendance or whether participants received the entire intervention as planned. Future investigations may want to consider proactive development of strategies

to assess delivery, receipt, and enactment of the intervention because these data were often omitted from reports.

One of the principles for implementing self-management support is the use of diverse formats (Battersby et al., 2010). None of the interventions used information technology (IT). A recent report indicates that 76% of U.S. households have a computer and 72% have access to the Internet (File, 2013), suggesting that IT would be a viable option for delivery of chronic disease self-management interventions. Creative marketing approaches to make CKD self-management interventions available in rural areas, primary care, or family practice settings may be invaluable in slowing disease progression. Although one CKD self-management program has been designed using IT (Ong, Jassal, Porter, Logan, & Miller, 2013), its efficacy has not been tested.

Use of a health behavior theory guided study design or intervention development in four studies (Byrne et al., 2011; Kazawa & Monyama, 2013; Lin et al., 2013; Williams et al., 2012). Future work might want to consider use of the Self and Family Management Framework (Grey et al., 2006) or the Individual and Family Self-Management Theory (Ryan & Sawin, 2009). In addition, level of patient activation was not included in any investigation. Future researchers may want to consider tailoring or targeting interventions to activation level because changes in activation are often accompanied by changes in self-management behaviors (Hibbard, Mahoney, Stock, & Tusler, 2007; Shively et al., 2013; Solomon, Wagner, & Goes, 2012). Targeting interventions to activation level creates a level of self-management support that meets the needs of individuals at specific points in time, leading to more adherence to their healthcare providers' recommendations (Hibbard & Mahoney, 2010) and better health outcomes (Hibbard & Greene, 2013).

Outcomes varied and had equivocal findings across the reviewed studies. The primary outcome assessed in the studies was eGFR. Future investigations may want to consider the best time to measure this important outcome and conduct the study over a long enough period of time to assess the efficacy of the intervention. This will be an important consideration to help investigators decide if or when booster interventions are needed to assist participants as they live with and manage their CKD over time.

Strong evidence supports use of ACE-I and ARB therapy to slow progression to kidney failure (Fink et al., 2012). Medication adherence was included as an outcomes in only two studies (Kazawa & Monyama, 2013; Williams et al., 2012) and should be considered an important outcome associated with CKD self-management. Patients are often overwhelmed by the number of medications they must take, and the perceived barriers to medication taking often outweigh the benefits (Williams & Manias, 2014) as evidenced by 50% nonadherence to ACE-I or ARB therapy (Chang et al., 2012). Numerous approaches are available to measure medication adherence (Bosworth, 2006) and electronic monitoring is widely considered the best measure (Demonceau et al., 2013). Since medication taking is a dynamic behavior, electronic monitoring provides long-term information on the date and time medications are accessed for presumed medication administration (Dunbar-Jacob, Sereika, Foley, Bass, & Ness, 2004). Providing feedback on medication taking using printed

reports from electronic monitors shows great promise as an intervention for improving medication adherence (Demonceau et al., 2013).

Future investigators may want to examine the effects of the intervention on mechanism of action to validly interpret outcomes (Melnyk & Morrison-Beedy, 2012). The psychometric properties of the instruments used to measure knowledge, self-management, and self-efficacy were not completed reported and instruments may need additional psychometric testing.

In summary, the knowledge gaps identified following this review were as follows: (a) the focus of the papers reviewed were on medical self-management tasks and no attention was given to the role or emotional tasks that people may face when diagnosed with Stages 1-4 CKD, (b) there was lack of family involvement during intervention delivery, and (c) although there is considerable evidence that disease management interventions are effective and efficient (Hisashige, 2013); the ability to form conclusions about the efficacy of interventions designed for people with Stages 1-4 CKD was hampered because methodological rigor was insufficient. Despite the difficulties in drawing conclusions, recommendations for future work can be proposed. Further development and refinement of interventions are needed that consider acquisition of knowledge, development of selfmanagement skills, enhancement of confidence, and the role patient activation has for adherence. All core self-management skills should be addressed in future studies. Use of a theory to guide the studies or intervention development is recommended. Careful attention should be given to training of interventionists, length of interventions, and delivery, receipt, and enactment of the interventions. Future work should use rigorous methodologies such as use of randomized controlled trials, increased sample sizes with sufficient power to detect group mean differences, a sampling plan that allows recruitment of a large enough sample size, and use of strategies to minimize attrition. It would be helpful to determine if there are changes in intervention mechanisms following intervention delivery to allow a better evaluation of outcomes. Future work should pay particular attention to important clinical outcomes, such as eGFR, medication adherence, blood pressure, HbA1C, diet and exercise adherence, and health-related quality of life.

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				First Auth	or		
	Byrne	Choi	Flesher	Kazawa	Lin	Walker	Williams
Educational content associated with key components of CKD self-management:							
Avoidance of nonsteroidal anti-inflammatory drugs							
Nutrition, diet modifications, eating out, or reading labels		x	Х	x		Х	
Glycemic control				x			
Regular exercise			Х	x		Х	
Systolic blood pressure control	Х						х
Tobacco avoidance							
Angiotensin-converting enzyme inhibitors or angiotensin receptor blockers				x			x
Other educational content:							
CKD and kidney health		Х				Х	
Diabetes and nephropathy				x		Х	
Foot care				x			
Hypertension	Х					Х	X
Kidney replacement therapy		х					
Medication review						×	x
Self-management		Х	Х		х		
Stress or emotional management				x			
Core self-management skills:							
Problem-solving					x		Х
Decision making							
Resource utilization							
Patient-provider partnerships				x		Х	X
Action planning	Х		x	x	×	×	
Self-tailoring							
Strategies to enhance self-efficacy:							
Performance attainment					×		
Verbal persuasion				х			

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				First Autho	r		
	Byrne	Choi	Flesher	Kazawa	Lin	Walker	Williams
Vicarious experience (modeling)					x		х
Physiological state				x			
Not described	Х		х				

#### Table 2

## Methods and Outcomes of Self-Management Interventions Tested with People who have Stage 1-4 Chronic Kidney Disease (CKD)

First author	Design and sample	Characteristics of intervention	Outcomes
Byrne	Design: RCT; feasibility study (2 groups: intervention, control) Sample: $N = 81$ CKD Stage: 1-4	Dose of intervention Length of contact session: 2 ½ hour Number of contacts: 1 Groups of 2-6 participants Dose in comparison condition NR Setting Educational area within hospital <u>Interventionist</u> Study nurse <u>Theoretical model</u> Social cognitive theory	Significant difference: None <u>No statistical difference</u> : B/P (data not provided) Cardiovascular risk factors (data not provided) <u>Not reported</u> : Self-efficacy
Choi	Design: Quasi- experimental; nonequivalent control group non-synchronized design. (2 groups: intervention, control) Sample: <i>N</i> = 61 CKD Stage: 3-4	Dose of intervention   Education sessions   Length of contact session: 90 minutes   Number of contacts: 3 sessions   Groups of 3-5 people   Individualized consultation   Length of contact session: 20 minutes   Number of contacts: 1   Reinforcement of education following education and consultation 1 week later: length NR.   Dose of comparison condition   NR   Setting: Seminar room in hospital   Interventionist: CKD expert panel including 5 physicians, 3 nutritionists, and 5 nurses   Theoretical model: NR	Significant difference: CKD knowledge ( $p < .001$ ) Self-care ( $p = .001$ ) Serum sodium <u>No statistical difference</u> : Blood urea nitrogen Creatinine Serum sodium Serum potassium Serum potassium Serum phosphorus Hemoglobin GFR (using MDRD)
Flesher	Design: RCT (2 groups: intervention, control) Sample: <i>N</i> = 40 CKD Stage: 3-4	Dose of intervention Individualized nutrition counseling in both groups: length, number of contacts, and duration of contact NR Cooking class: Length of contact sessions: 2 hours Number of contacts: 4 Duration of contact over time: 4 weeks Group cooking class included a shopping tour led by dietitian Exercise class Length of contact session: 1 hour Number of contacts: 36 Duration of contact over time: 12 weeks Counseling: Length, number, and duration of contacts NR <u>Dose of comparison condition</u> Dose of standard nutritional care NR although a detailed description of standard nutritional care was provided. <u>Setting</u> : unknown for nutrition class; exercise class took place in a gym <u>Interventionist</u> : dietitian, cook educator, certified exercise physiologist, nurse. <u>Theoretical model</u> : NR	Significant difference 14 of 23 people in experimental group and 2 of 17 people in control group had improvement in 4 of 5 endpoints (B/P, GFR, total cholesterol, urinary protein, urinary sodium); ( $p = .03$ ) Self-management (qualitative): Experimental group indicated improvement in exercise frequency, concern over heath condition, frequency of visits to health care provider, and hospitalizations. Control group indicated improvement in communication with health providers. <u>No statistical difference</u> : None
Kazawa	Design: Quasi- experimental; one-group pretest/posttest Sample: <i>N</i> = 30 CKD Stage: 3-4	Dose of intervention: Session 1-4 face-to-face meetings Length of contact session: 1 hour Number of contact over time: 8 weeks Session 5-6 by telephone or e-mail Length of contact session: 30 minutes Number of contacts: 2 Duration of contact over time: 2 months Monthly telephone follow-up and length and number of contacts NR Duration: 6 months Consultation with a dietician provided when requested; length of contact, number of contacts, and number requesting NR Dose of comparison condition	Significant differenceSelf-efficacy ( $p < .01$ ).Exercise target behaviors ( $p < .05$ ).Frequency of self-monitoring( $p < .001$ ).Frequency of drug intake andinjection ( $p < .01$ ).HbA1C ( $p < .05$ )No statistical difference:AlbuminB/PBUNBody mass indexDietary behaviors

First author	Design and sample	Characteristics of intervention	Outcomes
		No control group <u>Setting</u> Individualized face-to face meetings occurred at participants' homes or the out-patient clinic. <u>Interventionist</u> Five nurses <u>Theoretical model</u> Social cognitive theory	Hemoglobin Lipid profile, Phosphorus Potassium Quality of life Serum creatinine Total protein
Lin	Design: Quasi- experimental; single- group pretest/posttest; pilot study Sample: <i>N</i> = 37 CKD Stage: 1-3a	Dose of intervention Length of contact session: 90 minutes Number of contacts: 5 Duration of contact over time: 5 weeks Groups of 6-8 participants each week Dose of comparison condition No control group Setting: NR Interventionist Lead investigator (a nurse) Theoretical model Self-regulation theory	Significant difference Self-efficacy ( $p < .05$ ) No statistical difference: eGFR using MDRD Self-management Serum creatinine
Walker	Design: Quasi- experimental; pre- and post-test design; pilot study Sample: $N = 52$ CKD Stage: 2	Dose of intervention Length of contact session: NR Number of contacts: 6 Duration of contact over time: 12 weeks <u>Dose of comparison condition</u> No control group Setting: primarily in clinic or in participants' homes if preferred <u>Interventionist</u> Nurse practitioner working with primary practice nurses and general practitioners. <u>Theoretical model</u> NR	Significant difference Self-management ( <i>p</i> < .001) <u>No statistical difference</u> : None <u>Not reported</u> : Secondary data analysis; main findings reported in another paper under review.
Williams	Design: RCT; feasibility study (2 groups; intervention, control) Sample: <i>N</i> = 75 CKD Stage: 3-4	Dose of intervention   Intervention home visit included a 20-minute DVD that used   interactive and psychosocial approach for motivating people to   take medications appealing to knowledge, thoughts, and   feelings based on Health Belief Model.   Length of contact session: mean 89 minutes   Number of contacts: 1   Motivational interviewing via telephone sessions   Length of contacts: 6   Duration of contact over time: 12 weeks   Dose of comparison condition   NR   Setting: Home of participant.   Interventionist: One doctorally prepared nephrology nurse who had training in motivational interviewing.   Theoretical model   Health Belief Model	Significant difference 87% adherence to taking B/P daily at 3 months in experimental group. <u>No statistical difference</u> : B/P Medication adherence <u>Not reported</u> : Improvement in eGFR and serum creatinine reported, but not statistically analyzed for group mean differences.

B/P = blood pressure; BUN = blood urea nitrogen; eGFR - estimated glomerular filtration rate; MDRD = Modification of Diet in Renal Disease Equation; NR = not reported; RCT = randomized controlled trial