

Bonner, A., Havas, K., Douglas, C., Thepha, T., Bennett, P., & Clark, R. (2014). Self-management programs in stage 1-4 chronic kidney disease: A literature review. *Journal of Renal Care*, 40(3), 194-204. DOI: 10.1111/jorc.12058.

## ABSTRACT

**Background:** Chronic kidney disease is a complex health problem which requires individuals to invest considerable time and energy in managing their health and adhering to multifaceted treatment regimens.

**Objectives:** To review studies delivering self-management interventions to people with chronic kidney disease (stages 1-4) and assess whether these interventions improve patient outcomes.

**Design:** Systematic review.

**Methods:** Nine electronic databases (MedLine, CINAHL, EMBASE, ProQuest Health & Medical Complete, ProQuest Nursing & Allied Health, The Cochrane Library, The Joanna Briggs Institute EBP Database, Web of Science, and PsycINFO) were searched using relevant terms for articles published between January 2003 and February 2013.

**Results:** The search strategy identified 2051 articles, of which 34 were retrieved in full with only five studies involving 274 patients meeting the inclusion criteria. Three studies were randomised controlled trials, a variety of methods were used to measure outcomes, and four studies included a nurse on the self-management intervention team. There was little consistency in the delivery, intensity, duration, and format of the self-management programs. There was some evidence that knowledge and health-related quality of life improved. Generally small effects were observed for levels of adherence and progression of chronic kidney disease according to physiologic measures.

**Conclusions:** The effectiveness of self-management programs in chronic kidney disease (stage 1-4) cannot be conclusively ascertained, and further research is required. It is desirable that individuals with chronic kidney disease are supported to effectively self-manage day-to-day aspects of their health.

**Key words:** chronic kidney disease, adherence, education, quality of life, self-care, systematic review

## INTRODUCTION

Chronic kidney disease (CKD) is increasing globally, affecting approximately 10% of the adult population (Eckardt *et al.* 2013). Increasing diabetes, hypertension and obesity (Eckardt *et al.* 2013, Johnson *et al.* 2013), has contributed to CKD becoming one of the most common chronic diseases. CKD is a progressive disease, classified into five stages based on declining glomerular filtration rate (GFR). Throughout these stages, people suffering with CKD need to invest considerable time into managing their health including modifying their diet and lifestyle, managing numerous medications, and attending medical appointments. Stage five or end-stage kidney disease (ESKD) places an even greater burden on individuals due to the addition of renal replacement therapies (RRT), and also places considerable demand on healthcare resources due to the cost of RRT.

Given the complex nature of the day-to-day routines that must be followed by individuals particularly with CKD stages 3-5, it is important that they engage in effective self-management. Self-management of chronic disease involves an individual taking responsibility for the day-to-day care of their illness (Lorig & Holman 2003). In order to minimise the impact of CKD upon the individual and slow the progression of the disease, individuals must adhere to strict treatment regimens. Education is important in assisting individuals to self-manage CKD (Novak *et al.* 2013). Increased disease-specific knowledge and knowledge regarding the importance of adhering to CKD treatment has been shown to be associated with better health outcomes (Cho *et al.* 2012). Knowledge of CKD among those with the disease, however, is low (Finklestein *et al.* 2008), with people reporting a lack of understanding of the importance of self-management (White *et al.* 2013). This lack of knowledge and understanding is cited as a barrier to treatment adherence (Griva *et al.* 2013) and, as such, it is important that targeted interventions are delivered in order to increase knowledge and understanding. Moreover, even assuming adequate knowledge, not all people are equally motivated and able to self-manage their health (e.g., Cramm *et al.* 2013).

In view of the need to enable people with chronic diseases to become successful self-managers, programs have been developed to provide individuals with a range of skills. Self-management programs are designed to increase the ability, confidence and self-efficacy of people to make decisions, engage in partnership with healthcare professionals, and take control of their health (Lorig & Holman 2003). Yet, while there are strong arguments for self-management support initiatives (Jordan *et al.* 2008), evidence regarding program effectiveness is mixed (Warsi *et al.* 2004). For example, there is evidence that self-management programs are beneficial for people with diabetes, asthma or heart failure (Warsi *et al.* 2004; Gonseth *et al.* 2005). In contrast, for example, reviews of programs delivered to people with arthritis (Nolte & Osborne 2012) generally show nil to small effects, suggesting that some patient groups may not gain benefits from self-management interventions. For many chronic conditions, reviews of self-management interventions generally find inadequate evidence (Coster & Norman 2009). Possible explanations are the heterogeneity observed among studies and reliance on subjective, patient-reported outcome measures (Nolte *et al.* 2012).

Despite the prevalence and burden of CKD, summaries of evidence for the effectiveness of self-management interventions for this population are lacking. To date, only two systematic reviews of self-management in CKD have been published. Mason *et al.*'s (2008) systematic review of educational interventions included only randomised controlled trials (RCTs) up until 2007 and only one study in this review involved pre-ESKD participants. In the other

systematic review, Reid *et al.* (2011) solely focused on nursing interventions for individuals receiving haemodialysis. The aim of this review was, therefore, to synthesise and critically appraise self-management interventions for adults with CKD stage 1-4, and assess whether these interventions improved adherence, knowledge, CKD progression, health literacy, self-efficacy, health-related quality of life (HRQoL) and/or hospitalisations.

## **METHODS**

The Joanna Briggs guidelines were used to guide the methodology of this review (The Joanna Briggs Institute (JBI) 2008). An electronic search of MedLine, CINAHL, EMBASE, ProQuest Health & Medical Complete, ProQuest Nursing & Allied Health, The Cochrane Library, The JBI EBP Database, Web of Science, and PsycINFO was conducted in March 2013. The search was limited to articles published between 1<sup>st</sup> January, 2003 and 28<sup>th</sup> February, 2013 that were available in English. A range of MeSH headings and key terms were combined using Boolean phrases (i.e. “and”, “or”). Tables 1 and 2 provide examples of the search strategies used. Articles were included if participants: (i) were adults ( $\geq 18$  years); (ii) had CKD stage 1-4; (iii) received a self-management/educational intervention targeting CKD; and (iv) reported at least one of the following outcomes - adherence, knowledge, renal function, hospitalisations, self-efficacy, health literacy, and/or HRQoL. Articles were excluded if they: (i) were not original research articles; (ii) did not assess an outcome of interest; (iii) did not focus on participants’ CKD and CKD-related outcomes; or (iv) only included participants with ESKD. The reference lists of full-text articles retrieved were also examined for further relevant articles.

[Insert table 1 and 2]

Two reviewers (AB and KH) identified potentially relevant studies and independently appraised full texts. Nine studies were initially thought to meet the inclusion criteria, however, upon closer inspection, four further studies were excluded. One of these studies (Pagels *et al.* 2008), indicated that it assessed the impact of a nurse-led clinic on self-care ability and disease-specific knowledge. However, the only results reported were: (1) the relationship between perceived self-care ability and dialysis modality choice (i.e., did the intervention increase the number of people willing to undertake home dialysis); and (2) participants’ disease-specific knowledge wants and needs (i.e., what disease-specific knowledge did people wish to acquire). Another excluded study (Allenet *et al.* 2007) recruited a highly heterogeneous and small sample, in that 11 participants were kidney transplant recipients (and, as such, would have previously received extensive self-management education) leaving only three who were naïve, CKD stage 4 participants. The final two articles (Devins *et al.* 2003, Devins *et al.* 2005) were excluded because they report results from data that was collected in the 1980s (Binik *et al.* 1993) and it was unclear whether all participants were CKD stages 1-4.

Given the heterogeneity of the data (types of self-management programs, outcome measures and follow-up periods) meta-analyses could not be conducted. Where possible, between-group effect sizes were calculated using Cohen’s *d*, which can be interpreted as small ( $d = .20$ ), medium ( $d = .50$ ) and large ( $d = .80$ ) (Cohen 1988). The characteristics and results of the studies are reported in narrative form.

## **RESULTS**

Figure 1 displays the review process, and the five studies that met the inclusion criteria for

this review are in Table 3. One study was conducted in Australia, one in Canada, one in Korea, and two in Taiwan. The total number of participants was 274. One study included only stage 3 participants, two studies included stages 3 and 4, one study included only stage 4 participants, and one study included stage 3-5 participants. Three studies were RCTs, although only two included a CONSORT diagram. One study employed a non-equivalent control group, non-synchronised design, but provided no information regarding whether participants were randomly allocated to conditions (experimental or control), or whether some or all participants participated in both conditions. The final included study used a one-group repeated-measures design. Groups were comparable at baseline in all studies where a two-group design was employed. For the most part, outcomes were measured objectively, although there was not always enough information to ascertain whether they were measured reliably. Data analysis was clearly described in four studies, although it was not always possible to determine whether the most appropriate analyses had been conducted. Follow-up periods varied widely, from eight weeks to 12 months after baseline assessment.

Four studies assessed knowledge as an outcome; three assessed HRQoL and three assessed self-management. Only one study directly assessed hospitalisation as an outcome. None of the studies measured health literacy, self-efficacy, or self-reported adherence, although four studies reported all-cause mortality and/or clinical indicators (i.e., blood pressure, serum biochemistry, estimated glomerular filtration rate (eGFR)) as objective adherence measures.

[Insert figure 1 here]

[Insert table 3 here]

### **Self-management/educational intervention outcomes**

There was little consistency between studies regarding mode of delivery, intensity, duration, and who provided the self-management program. The programs were delivered either face-to-face in an individual or group format, or included a combination of face-to-face and telephone sessions. Intensity varied greatly, ranging from multiple sessions per week to a single workshop with six-monthly follow-ups. Programs were delivered over five weeks to 12 months by a range of professionals, including nurses, dietitians/nutritionists, “cook educators” (p. 190, Flesher *et al.*), physicians, exercise physiologists and social workers.

#### *Knowledge*

Three studies assessed knowledge. Two studies (Yen *et al.* 2008; Chen *et al.* 2011) developed their own questionnaires to assess this outcome, and although neither study reported specific items, both questionnaires assessed knowledge of kidney function and dietary restrictions. Choi and Lee (2012) adapted an existing CKD knowledge instrument; however, the papers describing it are not available in English. The authors claimed the questionnaire assessed knowledge of normal kidney function, disease characteristics, lifestyle and dialysis. Two studies (Chen *et al.* 2011, Choi & Lee 2012) showed large effect sizes ( $d = 1.61 - 1.27$ ) for between-group differences at follow-up for knowledge, although Yen *et al.*'s (2008) within-group analysis found CKD knowledge was higher at six months than at baseline, but below baseline at 12 months.

#### *Quality of Life*

Two studies assessed HRQoL, using different tools. One study (Campbell *et al.* 2008) used the Kidney Disease Quality of Life Short Form version 1.3 (KDQOL-SF v1.3) and the other

(Yen *et al.* 2008) used the brief version of the World Health Organisation Quality of Life Questionnaire (WHOQOL-BREF). Both provide evidence that self-management programs may improve HRQoL in people with CKD. Campbell *et al.* (2008) found significant between-group effects on cognitive function ( $d = .90$ ) on the CKD-specific domains, as well as significantly greater vitality ( $d = .70$ ) and physical function ( $d = .30$ ) on the generic SF-36 domains. Yen *et al.* (2008) found that participants' overall level of HRQoL was higher at six months than at baseline, but dropped below baseline at 12 months. This same study did not find significant improvements following the intervention in the physical, psychological, social, or environmental domains of HRQoL. However, they did find that participants' satisfaction with their personal health was significantly higher at both six and 12 month follow-up than baseline.

### *Self-management*

Two studies assessed self-management as an outcome, with both suggesting that delivery of a self-management/educational intervention may lead to improvements. Again, measurement was inconsistent. Choi and Lee (2012) adapted an existing instrument that is not available in English. Flesher *et al.* (2011) used the Stanford School of Medicine Patient Education Research Centre questionnaire to assess self-management, although there are several questionnaires available which fit that description and they do not describe which scale was used. Choi and Lee (2012) reported that self-care within their experimental group increased significantly over time compared to the control group. However, inspection of means shows that the between-group difference in self-care was negligible at 8 weeks follow-up ( $d = .07$ ). Flesher *et al.* (2011) reported the findings of questionnaires in a qualitative manner, assessing "trends" rather than reporting quantitative data. They reported that the experimental group showed "improvement" in their exercise frequency, concern over health condition and frequency of visits to health providers or hospitalisation. The control group showed improvement in their communication with health providers in asking questions and discussing personal issues. It is unclear whether these were the only self-management parameters assessed, or if further data was collected but deemed insignificant.

### *Adherence*

No studies assessed patient-reported adherence. Four studies reported data on clinical indicators and one study (Chen *et al.* 2011) reported as end points ESKD that required RRT and all-cause mortality. Overall, evidence for the effect of interventions on clinical outcomes was weak. Only one study (Chen *et al.* 2011) found a clinically significant improvement in eGFR between groups at six and 12 months ( $d = .55 - .82$ ). Consistent with this, one patient (3.7%) in the intervention group, compared with nine (33.3%) in the control group had an eGFR reduction of >50% by the 12 month follow-up. In contrast, Choi and Lee (2012) found no between-group differences in terms of GFR ( $d = .06$ ), or any other clinical outcome. Flesher *et al.* (2011) reported that the experimental group showed improvement in more clinical indicators (i.e., eGFR, cholesterol, urinary sodium, urinary protein, and blood pressure) than the control group, yet incomplete reporting of data made it impossible to determine the significance of these results. Yen *et al.* (2008) found that only waist-hip ratio and BMI improved significantly over time, finding no significant differences for GFR or any other clinical outcome.

### *Hospitalisation*

Only one study directly investigated hospitalisation as an outcome (Chen *et al.* 2011), finding that participants who received the self-management program had significantly fewer

hospitalisations (18.50%) compared to controls (44.47%). Flesher *et al.* (2011) qualitatively reported a trend in improved self-reported frequency of visits to health providers or hospitalisation over a 12 month period in the intervention group.

## **DISCUSSION**

The aim of this review was to synthesise and critically appraise self-management interventions for people with CKD stage 1-4, and assess whether these interventions improved adherence, knowledge, progression of CKD, health literacy, self-efficacy, HRQoL, and/or hospitalisation. Surprisingly little research has been conducted in this area, although more research in self-management has been conducted with individuals who are receiving haemodialysis (Mason *et al.* 2008 Reid *et al.* 2011). Our search strategy returned only five studies which met the inclusion criteria for this review. The sheer number of articles which we were unable to include indicates that perhaps there is a need for guidelines regarding the way that self-management programs are evaluated, and that patient related outcomes ought to be routinely assessed and subsequently reported in the literature.

There was variation in the design of the five studies with regard to: study length; interventions delivered; outcomes assessed; assessment instruments used; and results obtained. All interventions included a face-to-face component and some also included telephone sessions. The intensity of the interventions delivered also varied widely, ranging from sessions several times a week to one session with six-monthly follow-ups. A wide range of professionals were employed to deliver the interventions, the most common element being that four of the studies included a nurse on their delivery team.

Outcomes measured varied, the most commonly reported being clinical indicators, which were included in four studies. Knowledge was measured differently across studies, and inadequate information was provided regarding the questions that participants were asked (Yen *et al.* 2008, Chen *et al.* 2011, Choi & Lee 2012). The two studies that assessed HRQoL (Campbell *et al.* 2008, Yen *et al.* 2008) used standardised (albeit different) measures. Self-management was assessed either via an author-adapted questionnaire (the original of which was not available in English; Choi & Lee, 2012) or using standardised assessment instruments developed by the Stanford School of Medicine, although it is unclear precisely which scales were included, as the authors only mentioned those items that yielded significant results (Flesher *et al.* 2011). Interestingly, none of the studies assessed patient-reported levels of adherence.

From this review, the effect of self-management programs in CKD (stage 1-4) cannot be conclusively ascertained. The largest effects observed were for increases in CKD-specific knowledge (Yen *et al.* 2008, Chen *et al.* 2011, Choi & Lee 2012), however, interpretation of these findings is difficult, due to measurement issues. One study found that, while knowledge was higher six-months post-intervention than at baseline, it was lower 12 months post-intervention than at baseline (Yen *et al.* 2008). It is worth noting the methodology employed by this study. The authors indicated that, after delivery of their initial educational intervention session, six- and 12-monthly follow-up/reinforcement consultations were conducted with participants. Participants' outcome measures were also assessed at these same sessions. There is no indication of whether the follow-up/reinforcement sessions were conducted: (1) before the assessments (which may have led to inflated knowledge scores, and even inflated estimations of HRQoL (see below), if this session made participants feel especially motivated and equipped to manage their CKD); (2) after the assessments (which may explain the poorer

participant outcomes at 12 months, but would be counter-intuitive, as participants were not followed up past this session); or if (3) this was not standardised. Knowledge about CKD can be measured with the Kidney Knowledge Survey (KiKS; Wright *et al.* 2011) designed to assess disease-specific knowledge in individuals with CKD. Initial investigations by the authors show it to be a reliable and valid measure for all stages of CKD (Wright *et al.* 2011).

Improved HRQoL is an important outcome for self-management interventions. Although limited data are available, results from one RCT suggested that self-management programs may have a positive impact on the HRQoL of people with CKD (stage 1-4), particularly cognitive function and vitality (Campbell *et al.* 2011). Yen *et al.* (2008) also reported improved HRQoL over time, but only at six months post-intervention. At 12 months, HRQoL was lower than baseline. As mentioned above, the findings from this study must be interpreted with caution. Future research into the effects of self-management programs for individuals with CKD ought to measure HRQoL using either the generic Short Form Health Survey questionnaire (SF-36; Ware & Sherbourne 1992) or the disease-specific Kidney Disease Quality of Life instrument (KDQOL; Pagels *et al.* 2012).

Only two studies measured whether self-management itself improved post-intervention. Although Choi and Lee (2012) reported that, post-intervention, self-management within the experimental group did increase significantly more than within the control group, calculation of effect size indicated that this difference was not clinically relevant. Furthermore, reporting of the study design lacked clarity regarding whether it was a cross-over research design, making it difficult to draw conclusions. Flesher *et al.* (2011) do not state why they interpreted their self-management data qualitatively, but reported that the experimental group showed improvement in some areas of self-management. However, the control group improved in different areas of self-management. Since it was not reported how many/what other areas were assessed, it is unclear whether the experimental group can be said to have improved “more” than the control group. Recently, Lin *et al.* (2012a) published a CKD-specific self-management instrument (the CKD-SM) with satisfactory psychometric properties among individuals with earlier stages of CKD which may provide a standardised measure of self-management in future research with this population.

There was only weak evidence that the delivery of self-management programs can improve adherence as measured objectively through clinical indicators. Only two studies reported between-group means and standard deviations for clinical outcomes (Chen *et al.* 2011, Choi & Lee, 2012). Chen *et al.* (2011) found clinically significant differences in eGFR which suggested that their intervention slowed the progression of CKD. They also reported reduced hospitalisations among the intervention group. In a systematic review, Matteson and Russell (2010) found that educational interventions led to some improvements in adherence to diet, fluid, medications and treatment, but this review was restricted to only clinical indicators of adherence in people receiving haemodialysis. Further research is needed to determine the effect of self-management support on clinical variables among people with CKD, and researchers are encouraged to routinely include physiologic measures as primary outcome measures.

Adherence to treatment regimens is multifactorial and cannot be assumed to be adequately measured through clinical indicators alone. Factors such as life contexts and events, socioeconomic, health literacy, cultural-religious, psychological and emotional issues, trust and communication with healthcare providers all contribute to an individual’s ability to

adhere to treatment (Novak *et al.* 2013). Using social cognitive theory to improve self-efficacy and thereby adherence behaviour could prove useful in designing self-management programs for CKD (Curtin *et al.* 2008). Self-efficacy is the belief that a person can undertake a task in a given situation (Bandura 1997) and it could be assessed by the CKD self-efficacy questionnaire (CKD-SE; Lin *et al.* 2012b). Furthermore, a section of the aforementioned CKD-SM (Lin *et al.* 2012) assesses adherence. Recently, an online tool for assessing diet adherence in people with CKD was developed (Murali *et al.* 2013). It is expected that online tools will continue to be developed and will make real-time measurement of self-care behaviours less challenging.

Self-management programs can increase the ability, confidence and problem-solving skills of people with chronic health conditions and thereby help them to effectively manage their illness (Lorig & Holman 2003). Educational programs have been shown to improve outcomes in other chronic diseases such as heart failure (Riegel *et al.* 2009), diabetes (Steinsbekk *et al.* 2012), and chronic obstructive pulmonary disease (Hurley *et al.* 2012). Additional strategies may add to the benefits gained from self-management interventions. In heart failure, for instance, incorporating a strategy to check that a person understands what is being taught (e.g., the teach-back method) leads to better outcomes (White *et al.* 2013). Given the increasing prevalence of CKD and that it is imperative to slow progression to ESKD; it is surprising that there is only limited evidence regarding self-management programs and how they should be delivered in this population. An article which did not meet the inclusion criteria for this review (Devins *et al.* 2005) reported that delivery of a pre-dialysis educational intervention significantly extended survival of participants after the initiation of dialysis therapy, highlighting the long-term benefits that can be gained from such programs.

## **IMPLICATIONS FOR PRACTICE**

It is necessary to intervene in a timely and effective way to support individuals with CKD to engage in self-management. Programs ought to take a systematic approach that focuses on facilitating, supporting and sustaining rather than directing, guiding or training individuals (Jordan *et al.* 2008). Self-management should be patient-centred, and this ought to include family members, who often support individuals to manage chronic health conditions in day-to-day life (Jonsdottir 2013). Appropriate, timely, tailored self-management programs which aim to maximise an individual's confidence to understand, cope, problem-solve and remain motivated with regards to adherence with diet, fluids, medications, and follow-up appointments is likely to contribute to a better HRQoL, and reduced hospitalisations and mortality. Nurses in primary health care are ideally placed to have a leading role in delivery of self-management programs for CKD stages 2-3a (Sargent *et al.* 2012). Quality improvement programs are beginning to be implemented in primary healthcare practice (Thomas & Loud 2012), and may prove effective in improving identification and treatment of CKD at an earlier stage, slowing the progression of the disease, and improving patient outcomes. However, such programs are a relatively recent development, and research which assesses their effect on important patient outcomes must be conducted. Coordinated and collaborative multidisciplinary teams in renal services would be well-placed to deliver such interventions to individuals whose renal function has deteriorated beyond this (Johnson *et al.* 2013).

## **CONCLUSION**

CKD is a growing problem, and it is essential that patients are taught to self-manage in the early stages of the disease. The evidence that is available suggests that self-management

programs may have some positive effects on outcomes for people with CKD (stages 1-4). However, the current literature on the topic is sparse, inconsistent, and contains significant methodological limitations. Future research should address limitations identified in previous studies by, for example, developing and testing different (clinically pragmatic) interventions with differences in mode of delivery, format, timeframe and who it is delivered by. The sooner CKD is identified and managed, the longer renal function can be preserved and progression to subsequent stages of CKD can be slowed.

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