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Self-management interventions for adults with chronic kidney disease: A scoping review

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Self-management interventions for adults with chronic kidney disease: A scoping review

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ABSTRACT

Objective: To systematically identify and describe self-management interventions for adult patients with CKD.

Setting: Community-based

Participants: Adults with CKD Stages 1 – 5 (not requiring kidney replacement therapy).

Interventions: Self-management strategies for adults with CKD.

Primary and secondary outcome measures: Using a scoping review, electronic databases and grey literature were searched to October 2016 to identify self-management interventions for adults with CKD Stages 1 – 5 (not requiring kidney replacement therapy). Randomized controlled trials (RCTs), non-RCTs, qualitative and mixed method studies were included and study selection and data extraction were independently performed by two reviewers. Outcomes included behaviors, cognitions, physiological measures, symptoms, health status and health care.

Results: 50 studies (19 RCTs, 7 quasi-experimental, 5 observational, 13 pre-post intervention, 1 mixed methods and 5 qualitative) reporting 45 interventions were included. The most common intervention topic was diet/nutrition and interventions were regularly delivered face to face. Interventions were administered by a variety of providers, with nursing professionals the most common health professional group. Cognitions (i.e. changes in general CKD knowledge, perceived self-management, and motivation) was the most frequently reported outcome domain that showed improvement. Less than 1% of the interventions were co-developed with patients and 20% were based on a theory or framework.

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Conclusions: There was a wide range of self-management interventions with considerable variability in outcomes for adults with CKD. Major gaps in the literature include lack of patient engagement in the design of the interventions, with the majority of interventions not applying a behavioral change theory to inform their development. This work highlights the need to involve patients to co-develop and evaluate a self-management intervention based on sound theories and clinical evidence.

Key words: Chronic kidney disease, scoping review, self-management, patient centred-care

Strengths and limitations of this study:

- A strength of this study is that it is the first scoping review to apply the principles of patient-oriented research, where patient partners where engaged in determining the research question, advising us on search terms and reviewing the results to ensure we captured and reported the data meaningfully.
- This scoping review is comprehensive in nature, inclusion of all study designs and consideration of self-management features that have not been investigated previously.
- Due to the heterogeneous nature of the literature, it was challenging to synthesize the data. To address this challenge the two reviewers used two standardized tools to independently extract data, and independently coded the outcomes into categories using the Self-and Family Management Framework.
- A limitation of this scoping review is that we were unable to assess the self-management outcomes in terms of sustained changes in behavior, physiological, and health status.

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- The scoping review was unable to draw conclusions regarding the most effective self-management intervention for adult patients with CKD, keeping in mind our aim was to review the breadth of the current literature and present the gaps that exist.

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INTRODUCTION

Chronic kidney disease (CKD) is associated with adverse health outcomes, poor quality of life and high health care costs (1). Patients with CKD often experience a number of comorbidities including diabetes, cardiovascular disease and depression (2). They must balance the medical management of their kidney disease and other chronic conditions with demands of their daily lives, including managing the emotional and psychosocial consequences of living with chronic disease. In a recent national research priority setting process, individuals with non-dialysis CKD, their caregivers, and clinicians and policy makers involved in their care, identified the need to develop optimal strategies to enable patients to manage their CKD and related comorbidities to slow or prevent the progression to end-stage kidney disease (ESKD) (3). International data in research priority setting for kidney disease also highlights self-management as a top priority to prevent progression (4).

Self-management interventions aim to facilitate an individual's ability to make lifestyle changes and manage symptoms, treatment, and the physical and psychosocial consequences inherent in living with CKD and associated comorbidities (5). Self-management of CKD involves focusing on illness needs (developing knowledge, skills and confidence to manage medical aspects), activating resources (identifying and accessing resources and supports) and living with the condition (learning to cope with the condition and its impact on their lives as well as the emotional consequences of the illness) (6). Self-management requires patient engagement, however, the degree to which patients are able or willing to participate in self-management can vary, and individual and health system factors may serve as facilitators or barriers to self-management processes (7).

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Despite the high prevalence of CKD and its impact on patient outcomes, there is limited evidence on the effectiveness of self-management interventions. A prior systematic review (8) and three integrative reviews (9-11) found that self-management interventions were variable in their effectiveness for managing and preventing progression of CKD. While these reviews add to the knowledge base, there has been limited information on describing complex self-management interventions in detail and providing structured accounts of the interventions and outcomes. In particular, features of self-management interventions such as patient centeredness, applicability to co-morbidities associated with CKD, physiological and non-physiological outcomes, and application of any behavioral change theories are often lacking. Self-management interventions need to be tailored to suit diverse patient needs and preferences, as well as the local health care context (7). Therefore, investigating the "who", "what" and the "how" of self-management interventions is crucial.

To our knowledge there is no literature synthesis that systematically and comprehensively summarizes the breadth of evidence found in primary quantitative, qualitative and mixed methods research regarding self-management interventions for adult patients with CKD. Using a scoping review methodology helps us to understand the range and types of interventions including both educational and support interventions for CKD to inform the future design of a self-management intervention. Therefore, we conducted a scoping review to identify and describe self-management interventions for adult patients with CKD (stages 1 – 5; non-dialysis, non-transplant).

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MATERIALS AND METHODS

We used a scoping review methodology to enable us to incorporate a broad range of studies and to summarize the knowledge from a variety of sources and types of evidence (12). Our aim was to identify the gaps within the literature for self-management interventions and inform future primary research in this area. A unique and important aspect was the involvement of "patient partners". Through a national initiative, Canadians Seeking Solutions and Innovations to Overcome CKD (Can-SOLVE CKD), patients work side by side with researchers, clinicians and decision makers to address patient-oriented research priorities (13). Our research team includes Can-SOLVE CKD patient partners with CKD and caregivers (13). Using the Joanna Briggs Institute framework for scoping reviews we undertook the following steps: (1) identified the research question, (2) identified relevant studies, (3) completed study selection, (4) charted, collated, summarized and reported the results, and (5) consulted with our patient partners (12, 14). These steps were iterative to ensure comprehensive inclusion of the literature and continued meaningful engagement with our patient partners. This study does not involve human participants and is exempt from ethics approval.

Research aim

Our scoping review aimed to determine the available self-management interventions for adults aged 18 years and over and diagnosed with CKD Stages 1 – 5 (not requiring dialysis or transplant).

Search and selection of studies

We worked with an information specialist (DL) to identify key words that represented the population (CKD) and the intervention (self-management). We searched a broad range of

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information sources including the following online databases: MEDLINE (OVID), EMBASE, PsycINFO, Cochrane Central Register of Controlled Trials, CINAHL Plus and Cochrane Database of Systematic Reviews for published studies, with no limits on date (inception to October 2016), language, age or study design. We also searched Web of Science from 2006 – October 2016 to capture recently published meeting abstracts and summaries. Using the Canadian Agency for Drugs and Technology (CADTH) Grey Matters approach, a "search tool for evidence-based searching on the Internet" (15) we searched Google Canada, Health Technology Assessment (HTA) agencies (Canada, Australia, Ireland, UK and US), and Clinical Trials databases (Biomed Central – ISRCTN Registry, US National Institutes of Health, ClinicalTrials.gov) during October 2016 with no language restrictions (Table S1). Our search strategy for grey literature was guided by the specific database (i.e. Google search operators, website search filters) and was completed within a single session for each search strategy to ensure consistency due to the dynamic nature of the Internet (Table S2). Two reviewers (BK and MD) also reviewed the reference lists of included studies, along with those identified in past systematic and integrative reviews of our research topic. We contacted authors of relevant protocols and conference abstracts to ascertain if their work and findings were published.

A study was included if the population involved adults with CKD (stages 1 – 5, non-dialysis, non-transplant). Self-management interventions included strategies, tools, or resources in any delivery format (print, electronic, face to face, etc.) that facilitated an individual's ability to make lifestyle changes or to manage symptoms, treatment, or the physical and psychosocial consequences inherent in living with CKD and other associated comorbidities. Interventions targeted only at selection of treatment for ESKD (i.e. dialysis, kidney transplant) were excluded. Other self-management interventions or standard care were considered as comparators. We did

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not define a primary outcome for the purposes of this scoping review. We included primary studies that used quantitative, qualitative or mixed methods. Systematic and integrative reviews were identified for the purpose of reviewing their included studies for potential relevant studies. We excluded case series, case studies, case reports, clinical practice guidelines, theses and opinion-driven reports (editorials, non-systematic or literature/narrative reviews).

Three reviewers (BK, MD, and BH) performed an initial screen of titles and abstracts using a citation screening tool. A calibration exercise was performed by the three reviewers through pilot testing a random sample of 50 citations with consistent screening achieved (kappa = 0.79) at which point the three reviewers screened the remaining titles and abstracts. Two reviewers (BK and MD) followed a similar procedure for identifying relevant full text studies, with good agreement between reviewers (kappa = 0.78). Disagreements were resolved by consensus or arbitration by a third reviewer (BH).

Charting, collating and summarizing the data

We developed a data extraction form based on the Template for Intervention Description and Replication (TIDierR) checklist (16) and the Effective Practice and Organization of Care (EPOC) data collection form (17). Study characteristics (e.g. study design, country of origin, publication year), population characteristics (e.g. CKD stage, comorbidities), and self-management intervention characteristics (e.g. topics, format, target audience, providers, location, dose, duration, etc.) were documented. For the study outcomes, the two reviewers (BK and MD) independently coded each outcome into categories identified by Grey et al (e.g. behaviors, cognitions, physiological measures, symptoms, health status, health care and other) (6). We pilot tested the form on a random sample of 10 eligible studies and once consensus between the two reviewers was reached, we independently abstracted data from the remaining eligible studies.

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Data was categorized and reported descriptively. For qualitative studies we identified the methodology and key concepts presented by the authors.

RESULTS

Search results

From 12,583 unique citations (Figure 1) we included 50 full text studies.

Description of studies

A summary of the 50 studies included in this review is provided in Table 1. The most common study designs were randomized controlled trials (RCTs) (38%). Non-RCTs consisted of quasi-experimental (14%), observational (10%), pre-post intervention (26%), qualitative (10%) and mixed methods (2%). The studies were conducted in 14 countries, including the United States (20%), United Kingdom (14%) and Australia (12%). Most studies were published in the last 5 years (64%).

Patient population characteristics

The target population in most studies was CKD (72%) and 15 studies mentioned CKD plus one or more associated comorbidities. The average ages of participants reported across studies were 50.2 to 74.3 years.

Description of self-management interventions

Table 2 summarizes the characteristics of the self-management interventions. Five studies reported the same self-management intervention (18-22), therefore 45 interventions were summarized. The most common intervention topic was diet/nutrition (64%) and the least common were symptom management and lifestyle (13% and 11% respectively). The most

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frequent modes of delivering the intervention were face to face (80%), multiple (i.e. more than one mode) (71%) and print (64%). Electronic was the least common delivery mode (16%). Interventions were administered by a variety of providers. The most common category of providers was "other" (56%), which was made up of various types of health professionals and lay people. However, the most common identifiable group of providers were nursing professionals (49%). Patient volunteer/mentor was the least common (9%). The outpatient setting was the most common location for providing the self-management intervention (51%), and the inpatient setting was the least popular (2%). Many studies did not report the intervention language (53%), but 12 languages were represented and 7 studies reported that they provided the intervention in multiple languages.

In terms of intervention development, only 20% of studies mentioned the use of evidence such as theories or frameworks. These included the transtheoretical model of behavior change, social cognitive theory and chronic care model (23-27). Less than 1% of the studies involved patients in the design of the intervention, where patients were interviewed regarding intervention content (23, 28-30).

Description of quantitative study outcomes and results

Characteristics of the quantitative study outcomes are presented in Table 3. Twenty-three (46%) studies measured physiological outcomes (i.e. laboratory tests, body composition, etc.). The least common outcomes reported by studies were health status and health care (each 10%) and symptoms (i.e. fatigue) (4%). Table 4 summarizes the details of the quantitative studies. We categorized the overall study results descriptively as improved, unchanged, or worse. Many studies had more than one outcome measure (i.e. one measure improved, another had no change) and they were reported as mixed results. Based on this method of categorization, 89 outcomes

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were reported, of which 61% improved, 20% had no change, 1% worsened, and 13% had mixed results. Four of the results were reported as not applicable as the outcomes were not relevant. Of the 54 outcome categories that improved, 15 were cognition, 9 were physiological measures, 8 were behaviors, 8 were individual outcomes, 5 were health status, 4 were health care, 4 were other, and 1 was symptom management.

Description of qualitative study outcomes and results

Table 5 summarizes the findings from 6 qualitative studies that look at patient perspectives, one of these being a mixed methods study. All studies used semi-structured interviews and one also used a questionnaire. The aims of all these studies were to examine patient perspectives' regarding the self-management interventions they were involved in. Due to the variety of interventions (i.e. intervention topics, delivery mode and providers of the intervention) it was difficult to summarize findings into meaningful categories. Overall, patients highlighted that interventions needed to be individualized and tailored to their specific situations and preferences (i.e. awareness of having CKD, stage of CKD, knowledge of the disease, access to resources, etc.).

DISCUSSION

To our knowledge, this is the first scoping review involving patient partners to identify and summarize self-management interventions for adults with CKD. The scoping review methodology enabled us to systematically summarize a broad range of self-management interventions, and describe their features. We identified 50 studies that investigated self-management interventions for adults with CKD, with considerable variation in interventions, outcomes assessed and results obtained (i.e. some improved and/or some worsened and/or some

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did not change). We found that self-management interventions for CKD is an emerging area with most studies published within the last 5 years, and may be related to the growing recognition of the importance of incorporating patients and their families in managing their disease to improve outcomes (7).

Our findings are similar to prior reviews reporting that the design of self-management interventions for CKD have not been theoretically driven and have been predominately designed by healthcare professionals without input from patients (10, 11). Patient-centred care is changing how healthcare professionals deliver care to patients, but more importantly how patients and their families are actively involved in self-managing their chronic conditions. Engaging patients by having them co-design self-management interventions will ensure that patient preferences based on their values, culture, and psychosocial needs will be addressed in the self-management intervention (9-11). Through our current national partnership with patients, researchers and clinicians we have the opportunity to obtain patient perspectives, along with incorporating a behavior change theory to inform the future design of a self-management intervention for CKD.

Only 28% of studies that we identified included patients with CKD plus other comorbidities, despite the common presence of comorbidities in this patient population. Less than one-quarter of included studies provided information on how to manage comorbid conditions such as tracking lab results and symptom management. This highlights the need to consider "whole person care", where the self-management intervention needs to encompass the physical, mental and emotional needs of the patient (31, 32).

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Forty-five different self-management interventions were identified, with one or more topics presented in a variety of formats and by a variety of providers. Symptom management and lifestyle topics were not included in many of the interventions. Based on prior work (3), non-dialysis patients with CKD have indicated that these were important topics for them in managing their CKD with an aim to slow the progression of CKD, and will be important to consider in the development of future interventions. Face to face was the most common delivery format while electronic (internet or mobile application) was least common, with many studies reporting multiple formats (i.e. face to face and printed materials). With the expansion of electronic platforms for supporting patients and providers in the uptake of evidence-based care, there is the potential to use an electronic format to support patients in self-managing their CKD and other co-morbidities (33). It is worth noting that there was variability in duration and frequency of face to face encounters, from a single session to multiple sessions over weeks to months. While varied options for in-person delivery is good if it meets the needs of the patients and their families, it may not be feasible on a larger scale due to the resources required. Only 5 studies looked at self-management health care cost-effectiveness, health care utilization and access, each measuring different end-points with mixed results. Future self-management interventions should include the essential principles to self-management (e.g. accessing relevant health information, adhering to multiple treatment protocols, changing health behaviors, shared decision making with healthcare providers) (7, 34), along with evaluation of the cost-effectiveness and resource utilization.

The majority of studies did not identify a single primary outcome but rather multiple outcomes. We found that physiological outcomes (i.e. blood pressure) were the most commonly reported and symptoms were the least mentioned. These findings demonstrate the lack of patient driven

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outcomes that may be important to them. For example, a patient's individual health goals across a variety of dimensions (i.e. symptoms, mobility, social and role function in the family or community) that could possibly maximize their quality of life. Work by Tong et al highlights this concept, where patients with CKD are more interested in treatment choices that influence non-traditional clinical outcomes such as impact on family and lifestyle (31). A holistic approach should be considered where mental and psychosocial outcomes are investigated, rather than just physiological endpoints.

Our findings from the qualitative studies looking at patient perspectives are inconclusive because of the limited number of studies and the heterogeneity of the interventions. Havas et al (9) in her integrative review similarly reported a lack of research related to patient perspectives on self-management in CKD. There is also a lack of qualitative studies overall, which could provide valuable information regarding attitudes and challenges of self-management interventions from the perspective of both providers and patients.

Strengths of our study include the comprehensive nature of our search, inclusion of all study designs and consideration of self-management features that have not been investigated previously. We also engaged patient partners in determining the research question, advising us on search terms and reviewing the results to ensure we captured and reported the data meaningfully. One of the main limitations was the challenge in synthesizing the data given its heterogeneous nature. To address this challenge the two reviewers used two standardized tools TIDieR (16) and the EPOC tool (17) to independently extract data, and independently coded the outcomes into categories using the Self-and Family Management Framework (6). Also, we were unable to assess the self-management outcomes in terms of sustained changes in behavior, physiological, and health status. A final limitation was our inability to draw conclusions

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regarding the most effective self-management intervention for adult patients with CKD, keeping in mind our aim was to review the breadth of the current literature and present the gaps that exist.

Overall, we found considerable variation in self-management interventions for adults with CKD with respect to their content and delivery, as well as the outcomes assessed and results obtained. Major gaps in the literature include the lack of patient engagement in the design of the self-management intervention, along with the lack of a behavioural change theory to inform their design. Our future research will incorporate intervention frameworks to co-develop and evaluate a self-management intervention based on a sound behavioral theory involving our national patient-partners, specialists, primary care providers, and decision makers.

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CONFLICT OF INTEREST STATEMENT

All authors certify that our manuscript has not been published in whole or in part elsewhere, nor is it currently being considered for publication elsewhere. All authors declare that they have no relevant conflicts of interest.

AUTHORS' CONTRIBUTIONS

Research idea and study design: all authors; data acquisition: MD, BK; data analysis/interpretation: MD, BK, BRH; supervision or mentorship: BRH, PR. Each author contributed important intellectual content during manuscript drafting and revisions and accepts

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accountability for the overall work by ensuring that questions to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

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DATA SHARING STATEMENT

The following data will be available, study protocol and analysis plan to anyone who wishes to access the data and will be available immediately following publication from the corresponding author.

TABLES

Table 1 Characteristics of studies

Table 2 Overall characteristics of self-management interventions

Table 3 Summary of quantitative outcomes

Table 4 summary of quantitative studies

Table 5 Summary of qualitative studies

FIGURES

Figure 1 Prisma flow diagram

SUPPLEMENTARY MATERIAL

Table S1. Search strategies used to search traditional databases

Table S2. Search strategies used to search Canadian Agency for Drugs and Technology (CADTH) databases

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Figure 1. PRISMA Flow Diagram

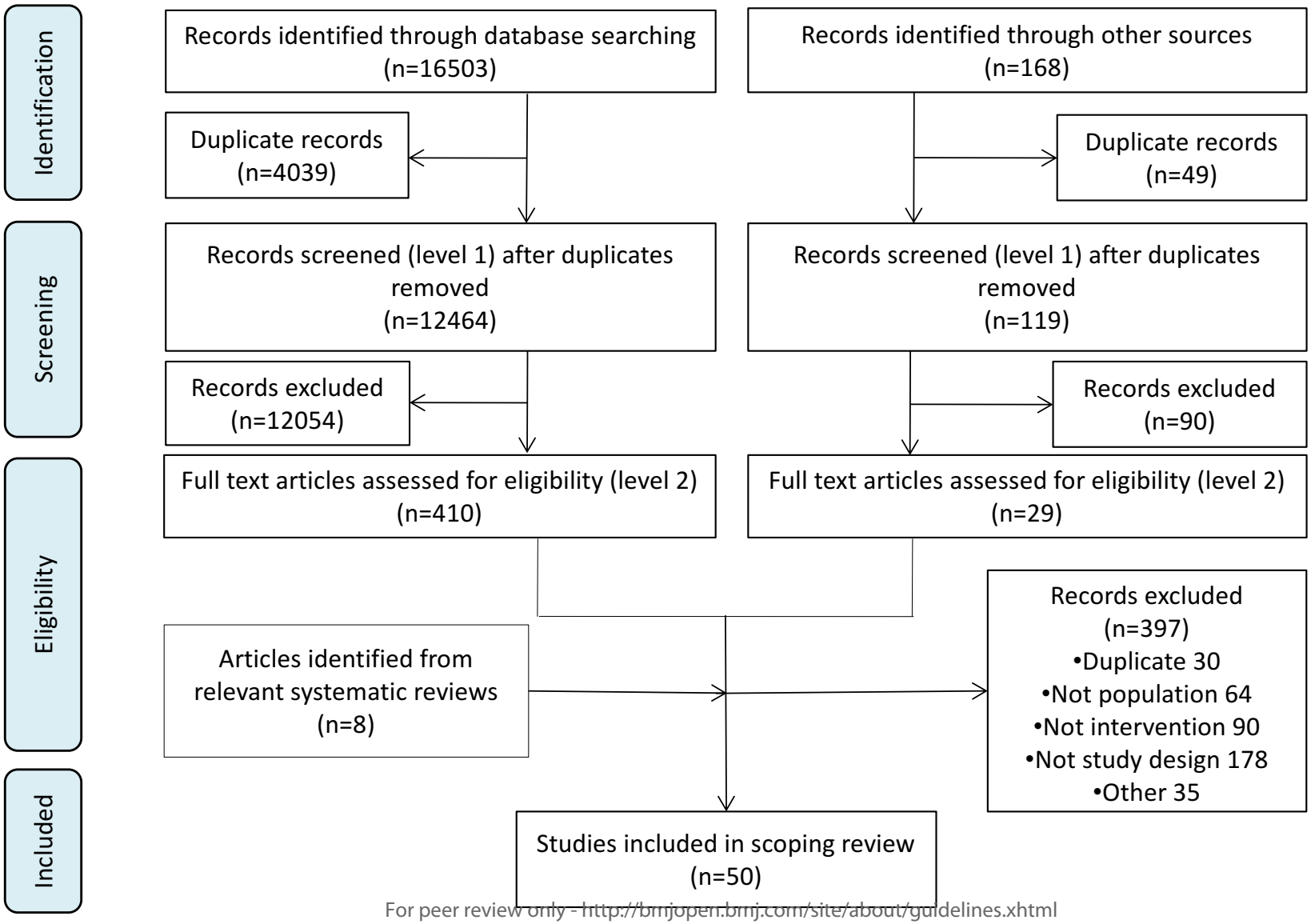

Table 1. Characteristics of the studies included in scoping review

Characteristic	Studies (N = 50)
Study design	
Randomized controlled trial	19
Pre-post test	13
Quasi-experimental (controlled/non-random)	7
Observational	5
Qualitative	5
Mixed methods	1
Origin of study	
United States	10
United Kingdom	7
Australia	6
Canada	5
Taiwan	5
Netherlands	3
Spain	3
Italy	2
Japan	2
New Zealand	2
Sweden	2
Brazil	1
Denmark	1
Korea	1
Year of publication	
2012 – 2016	32
2007 – 2011	11
Prior	7

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Table 2. Overall characteristics of self-management interventions

Variable	Intervention count (N = 45)
Intervention topics	
Diet/nutrition	29
General CKD knowledge	18
Other (i.e. advanced care planning, meditation)	18
Medication	17
Modalities	13
Physical activity	13
Comorbidities	11
Symptom management	6
Lifestyle	5
Mode of Delivery	
Face to face (i.e. group, one-on-one)	36
Multiple modes	32
Print	29
Distance (i.e. telephone, email)	13
Digital (i.e. DVD, PowerPoint, audio recording)	8
Electronic (i.e. website, mobile application)	7
Type of providers	
Other*	25
Nurse/nurse practitioner	22
Dietitian	14
Multiple providers	13
Social worker	6
Physician/primary care physician	6
Nephrologist/nephrology fellows	5
Patient volunteer/mentor	4
Pharmacist	1
Location of intervention	
Outpatient	23
Not specified	12
Community (non-clinic)**	10
Patient home	10
Multiple locations	7
Inpatient	1
Intervention languages	
Not Specified	24
English	10
Multiple languages	7
Mandarin	4
Spanish	3
Taiwanese	3
Dutch	2
Cantonese	1

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French	1
Greek	1
Italian	1
Japanese	1
Swedish	1
Vietnamese	1
Intervention development	
Use of framework or theory	9
Co-designed with patients	4

*Other providers: Trained research assistant, lay health worker, Bengali worker, Educators (health, cook, diabetic), online tool, physician assistant, exercise physiologist, technician, psychologist, employment expert, instructor, interpreter, physiotherapist, patient, principal investigator

**Community: gym, grocery store, “study room”

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Table 3. Summary of quantitative study outcomes*

Common outcomes	Description	Number of Studies
Physiologic measures	Changes in laboratory tests, blood pressure, body composition, functional/performance tests and cardiovascular risk.	23
Cognitions	Changes in general CKD knowledge, self-efficacy, self-management, motivation, perceived stress, anxiety and fear.	21
Behaviors	Adherence to diet, medication, physical activity, sleep, blood pressure control.	13
Individual Outcomes	QOL, well-being and general satisfaction.	11
Intervention specific	Reporting of general concepts regarding feasibility of intervention, enjoyment and interest in intervention.	9
Health care	Measurements of cost effectiveness, health care utilization and access.	5
Health status	Measurements of morbidity and mortality (i.e. time to dialysis, survival, all-cause mortality).	5
Symptoms	Changes in overall symptoms (i.e. pain, fatigue)	2

* Based on primary and distal outcomes from Grey et al (6)

CKD – chronic kidney disease; QOL – quality of life

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Table 4. Summary of quantitative studies

Study & Year (Reference)	Design	Target Population	Study Size Age (years)	Intervention Topic(s)	Provider(s)	Delivery Format	Description of Intervention	Study Outcomes	Study Results
RCT									
Binik 1993 (35)	RCT	Pre-RRT CKD (creatinine ≥350 µmol/L and rising rapidly)	204 (E = 87, C = 92, not part of education = 25) Age: 50.2	• General CKD knowledge • Diet/nutrition • Modalities	Trained research assistant	• Print • Face to face • PowerPoint slides	"Enhanced education": • 22-page booklet • Individual slide presentation (75 mins) *Duration* – one session *Comparator:* standard care	Health Status: • Duration between session & dialysis initiation – *patient in E group survived 4.6 months longer w/o requiring RRT*	
Gillis 1995 (36)	RCT	CKD 3-5	840 (unclear) Age: NR	• Diet/nutrition	Dietician	• Print • Face to face	"Modification of diet in renal disease": • "Keeping Track" booklet • Monthly meeting with dietician • Protein Wise Counter (lists protein content of foods) • "Shopping Wise": a guide to convenience and fast foods • Visited restaurants and shops *Duration* – 26 months *Comparator:* standard protein diet	Cognitions: • Patient reliance on dietician's feedback, support and modeling strategies - *decreased over time in E group* Individual Outcomes: • Top rated interventions by patients - *counseling, self-monitoring, protein counter*	
Devins 2003 (37)	RCT	CKD (creatinine ≤300 µmol/L and deemed to need RRT in 6-18 months)	297 (E = 149, C = 148) Age: 58.6	• General CKD knowledge • Diet/nutrition • Medication • Modalities • Lifestyles	Social worker	• Print • Face to face • Telephone	"Psychoeducation": • 60-page booklet • 90 min interactive educational intervention personalized for each patient • Supportive (10 min max) phone calls Q3 weeks	Health Status: • Time to dialysis – *E group had 3 month delay in dialysis compared to C group*	

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							Duration – 18 months or initiation of RRT *Comparator:* standard care		
Devins 2005 (38)	RCT	CKD with progressive reduction in kidney function	335 (E = 172, C = 163) Age: 47.4-53.9	• General CKD Knowledge • Diet/nutrition • Modalities	Health educator	• Print • Face to face • PowerPoint slides	"Psychoeducation session": • 22-page booklet • Individual slide presentation (60-75 min long) *Duration* – one visit *Comparator:* standard care	Health Status: • Survival pre-dialysis and after dialysis initiation – *significantly longer in the E group (2.25 years and 8 months respectively)*	
Campbell 2008 (39)	RCT	CKD 4-5	47 (E = 24, C = 23) Age: 68.5-72.6	• Diet/nutrition • Other (i.e. self-management principles)	Dietician	• Face to face • Telephone	"Individual nutritional counseling": • Initial individual consultation with dietician • Then phone follow-up Q2 weeks x 1 month then Q1 month *Duration*: 12 weeks *Comparator:* standard care	Individual outcomes: • QOL – *many components of KDQOLSF v1.3 improved: ↑CKD symptoms, ↑cognitive function, vitality**	
								Physiological measures: • Nutritional assessment PG-SGA – *in E group those who were malnourished at baseline improved, in C group malnourished from 12.5-25%*	
Byrne 2011 (23)	RCT	CKD 1-4 + HTN	81 (E = 40, C = 41) Age: 62.8-65.4	• Comorbidities (i.e. HTN management)	Nurse	• Print • Face to face • Telephone	"Structured education session": • Leaflet on HTN management • CHEERS patient education intervention, and standard care • 2.5 hour group session • Phone support from nurse *Duration:* one session *Comparator:* standard care	Intervention specific: • Feasibility (recruitment, retention, patient satisfaction, patient access of additional support) - *findings suggest delivering/evaluating an effective structured group educational intervention to promote better BP control would be challenging*	
Chen 2011 (40)	RCT	CKD 3-5	54 (E = 27, C = 27) Age: 68.2	• General CKD knowledge • Diet/nutrition • Medication • Lifestyle • Modality	Nurse, dietician, nephrologist, peers, volunteers	• Print • Face to face • Telephone	"Self-management Support": • Individual monthly health education • Weekly telephone based support • Aid of support group twice monthly (5 – 10 patients) *Duration*: 12 months	Physiological measures: • eGFR change – *higher in E group* • eGFR reduction of >50% - *less in E group* • ESRD requiring RRT and all-cause mortality – *no significant difference between groups*	

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				information for stage IV			*Comparator:* standard care	Health Status: • # Of hospitalizations in 1 year of follow-up – *less in E group*	
Flesher 2011 (41)	RCT	CKD 3-4 + HTN	40 (E = 23, C = 17) Age: 63.4	• Diet/nutrition • Physical activity	Nurse, exercise physiologist, dietician, cook educator	• Print • Face to face	"Cooking and exercise class": • Standard care and: • Group CKD nutrition class (with dietician and cook educator: 2 hour sessions over 4 weeks) plus 1 shopping tour led by a dietician • CKD cookbook • 12 week exercise program (3 X 1 hour sessions/week) led by a certified exercise physiologist & nurse *Duration:* 12 weeks *Comparator:* standard care	Physiological measures: • Improvement in 4/5 of the following: urinary protein, total cholesterol, eGFR decline, BP, urinary sodium – was considered a success – *61% in E group vs. 12% in C group*	
								Behaviors: • SM score – *some changes in some components in both groups*	
Joboshi 2012 (42)	RCT	CKD	31 (E = 19, C = 12) Age: 69.8	• Other	Nurse	• Face to face • Telephone • Email	"EASE (encourage autonomous self-enrichment) program": • Nurses listen to what patients have difficulties and discuss how they will try to improve • Face to face interview monthly • Telephone or email contact every 2 weeks *Duration*: 12 weeks *Comparator*: standard care	Cognitions: • Self-efficacy	
								Behaviors: • Medication adherence • Adherence to BP and weight measurements • Limiting salt intake • Alcohol consumption • Smoking	
								Physiological measures: • BP	
Williams 2012 (43)	RCT	CKD 2-4 (diabetic kidney disease) + DM + HTN	75 (E = 39, C = 41) Age: 67	• Medication • Comorbidities	Nurse	• Print • Face to face • Telephone • DVD	"Multifactorial intervention": • Individual medication review (draw chart) • Daily self-monitoring of BP x 3 months	Physiological measures: • BP – *no difference between groups*	

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							• 20 min DVD • Q2 week motivational interviewing follow up via phone x 12 weeks to support BP management and optimize medication SM *Duration:* 12 weeks *Comparator*: standard care	Behaviors: • Medication adherence – *no difference between groups*	
Williams 2012 (44)	RCT	CKD 2-4 + DM + cardio-vascular disease	78 (E = 40, C = 38) Age: 74.31	• Medication • Comorbidities • Other (i.e. self-efficacy)	Nurse, interpreter	• Print • Face to face • Telephone • PowerPoint slides	"Self-efficacy Medication Intervention (SEM)": • Individual medication review – chart in English but interpreter wrote on medication boxes in patients language or used symbols • Individual slide presentation (20 minutes) via interpreter (Greek, Italian, Vietnamese) • Q2 week motivational interviewing follow-up via phone x 12 weeks *Duration:* 12 weeks *Comparator:* standard care	Intervention specific: • Attrition rate to assess feasibility of study – *high attrition*	
								Cognitions: • Medication self-efficacy – *no difference between groups*	
								Health care: • Health care utilization – *no difference between groups*	
								Physiological measures: • Routine clinical lab surrogate measures – *no difference*	
								Behaviors: • Medication adherence – *no difference*	
								Individual outcomes: • General wellbeing – *no difference*	
De Brito 2013 (45)	RCT	CKD 3-5 + HTN (BP>130/80) + Bengali population	56 (E = 28, C = 28) Age: 55.7-60.7	• Diet/nutrition	Dietician and Bengali worker	• Face to face • Telephone	"Diet advice ": • Practical cooking & education sessions in the community facilitated by a Bengali worker • Followed by Q2 week phone calls to reinforce advice and set new targets *Duration:* 6 months *Comparator:* Standard care	Physiological measures: • BP – *decreased by 8mmHg in E group* • 24 hour urinary salt excretion – *decrease in E group* • eGFR – *no difference between groups*	

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Paes-Barreto 2013 (46)	RCT	CKD 3-5	89 (E = 43, C = 46) Age: 63.4	• Diet/nutrition	Dietician	• Print • Face to face • Telephone	"Nutrition Education Program': • Standard dietary counseling AND • Education folder with recipes to replace salt with sodium free seasoning blends • Individual 15-20 minute class • Hands on session about protein rich food • Hands on session using test tubes with the amount of salt in different foods • 4 monthly follow up visits • Telephone call to address any doubts with dietary plan *Duration*: 4 – 7 months *Comparator*: standard care	Behaviors: • Reduction in protein intake – *decreased* • Adherence to low protein diet – *effective*	
								Physiological measures: • Body composition: waist circumference, body fat, BMI, mid-arm muscle circumference – *no change* • Serum albumin – *no change*	
Blakeman 2014 (47)	RCT	CKD 3	436 (E = 215, C = 221) Age: 72.1	• General CKD knowledge • Comorbidities • Other (i.e. community resources	Lay health worker	• Print • Website • Telephone	"Information and telephone-guided access to community services": • Kidney Information Guidebook • Patient-Led Assessment for Network Support "PLANS" booklet and interactive website – tailored access to community resources • Telephone guided help from a lay health worker *Duration:* 6 months *Comparator:* standard care	Cognitions: • Positive & active engagement in life (heiQ) – *no difference between groups*	
								Physiological measures: • BP control – *better BP maintenance in E group*	
								Individual outcomes: • Health related QOL (EuroQoL EQ-5D index) – *higher in E group*	
McManus 2014 (48)	RCT	HTN (BP>130/80) + CKD3 or DM or CHD	555 (E = 277, C = 278) Age: 69.3-69.6	• Medication • Comorbidities	General practitioner, patient	• Print • Face to face	"Self-monitoring of BP and self-titration of medications": • Self-monitoring of BP • Self-titration of medications following a 3-step plan designed by general practitioner and patient *Duration:* 12 months	Physiological measures: • SBP at 12months – *no difference*	
								Health care: • Prescription of anti-hypertensive medications – *increased in both groups but*	

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							Comparator: standard care	*greater significance in E group*	
								Symptom mgmt.: • Adverse effects – *no significant difference between groups*	
								• Individual outcomes: • QOL - *no significant difference between groups*	
Park 2014 (49)	RCT	CKD3 + HTN + African American	15 Age: 58.7	• Other (i.e. meditation)	Principle investigator , patient	• Face to face • Audio recording	"Mindfulness meditation (MM)" • 14 min of pre-recorded guided MM using MP3 player & headphones *Duration*: one session *Comparator*: BP education	Physiological measures: • BP – *decrease in SBP/ DBP/ HR/ MAP* • Muscle sympathetic nerve activity – *decreased*	
Howden 2015 (50)	RCT	CKD 3-4 & >1 uncontrolled cardio-vascular risk factor	72 (E = 36, C = 36) Age 60.2-62.0	• Physical activity	Nurse practitioner, social worker, exercise physiologist, dietician, psychologist, diabetes educator	• Print • Face to face	"Exercise training and lifestyle intervention": • Standard care AND • Detailed medical/ surgical history taken by nurse practitioner • Education about exercising safely: maintaining hydration, signs/ symptoms of abnormal response to exercise • If diabetic – education on hypoglycemia • Exercise prescription individualized on patient's comorbid conditions • Goal = 150min/week of moderate intensity exercise plus resistance training • 8 weeks supervised, then 10 month home based • Patients got: exercise ball, resistance training booklet • Patients contacted regularly to monitor adherence to training	Physiological measures: • METS – *improved** • 6 minute walk distance – *improved** • BMI – *improved**	

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							Duration: 12 months *Comparator:* standard care		
Leehey 2016 (51)	RCT	CKD 2-4 + DM2 + BMI>30 + persistent proteinuria	36 (Exercise + diet = 18, Diet = 18) Age: 66	• Diet/nutrition • Physical activity	Personal trainer	• Face to face • Telephone	"Structured exercise program": • Dietary counseling = baseline nutritional counseling with 9 follow-up phone calls (both groups) AND • Supervised exercise program 3x.week (60 min cardio plus 25-30 min resistance training) • Followed by home exercise phase: 3x/week x 60 min with weekly follow-up phone calls & patient encouraged to meet trainer Q1 month *Duration:* 12 months *Comparator:* diet counseling only	Physiological measures: • Urine protein to creatinine ratio – *no change at 52 weeks* • Symptom limited and constant work rate treadmill time – *significant increase in diet + exercise group at 12 but not 52 weeks* • Urine albumin to creatinine ratio – *no change* • eGFR – *no change* • Inflammation – *no change* • Endothelial function – *no change* • Body composition – *no change*	
Montoya 2016 (27)	RCT	CKD 4	30 (E = 16, C = 14) Age: 67.9-68.3	• General CKD knowledge • Diet/nutrition • Medication • Modalities • Other (i.e. putting affairs in order)	Nephrologist, nurse practitioner, dietician, social worker	• Print • Face to face • PowerPoint slides	"Nurse practitioner facilitated CKD group visit": • Binder with section on individual labs, another section for topics of groups visits • Six 1.5-2 hour long monthly group visits of 8 patients (~1/2 had family members with them) • *3 visits done in conjunction with nephrologist's examinations (1st half = apt, 2nd half = education)* • *3 visits = education only* • Interactive discussion at each visit • Slide presentation (30 – 45 minutes) *Duration:* 9 months *Comparator*: standard care	Cognitions: • CKD knowledge – *improved in both groups* • Self-efficacy/disease SM – *upward trend in E group* Individual outcomes: • Satisfaction – *high*	
Non-RCT									

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Robinson 1988 (52)	Obs	CKD	25 Age: NR	• General CKD knowledge • Diet/nutrition • Medication • Other (i.e. self-care activities • Modalities	NR	• Face to face	"Renal Bingo": • Bingo game format/ group gaming technique • Provision of refreshments & prizes for motivation • Refreshments made with dietician consultation, reinforced dietary regimen *Duration:* one session *Comparator:* none	Cognitions: • Information was gained or reinforced – *desirable outcome* • Met a variety of learning needs – *desirable outcome* Intervention specific: • Participation was enjoyed – *desirable outcome* • Interest expressed for repeating the exercise – *desirable outcome*	
Klang 1998 (53)	QE	CKD 4-5	56 (E = 28, C = 28) Age: 54-58	• General CKD knowledge • Diet/nutrition • Physical activity • Modalities • Other (i.e. psychosocial - impact of CKD on economy, family, and social life)	Nurse, physician, social worker, dietician, physio-therapist	• Face to face	"Pre-dialysis patient education": • Four 2-hour sessions of group teaching with a classroom approach • Individual support follow-up by nephrology team member *Duration:* 4 sessions *Comparator:* standard care	Individual outcomes: • Functional and emotional wellbeing – *better in E group**	
Cupisiti 2002 (54)	PP	CKD 3b-5	20 Age: NR	• Diet/nutrition	NR	• Print	"Vegetarian diet": • Alternate between animal based conventional low protein diet & a vegetable based low protein diet • Booklets explaining general guidelines & features of the diet *Duration*: one session *Comparator*: conventional protein diet	Individual outcomes: • Opinions on diet – *90% enjoyed* Physiological measures: • Creatinine – *no change* • Albumin – *no change* • Total protein – *no change* • Lipids – *decreased* • Electrolytes – *no change* • Hematocrit – *no change* • Urinary protein excretion – *decreased* • Urinary urea excretion – *decreased*	

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								• Body weight – *no change*	
Gutierrez Vilaplana 2007 (58)	PP	CKD	24 Age: 64.5	• General CKD knowledge • Diet/nutrition • Modalities • Other	Nurse, patient volunteers	• Print • Face to face • PowerPoint slides	"Education Intervention" • 8 2-hour classes • Didactic and discussion *Duration*: 6 months *Comparator*: none	Cognitions: • Improvement in knowledge of CKD	
								Behaviors: • Modified lifestyle, diet	
								Intervention specific: • Reduction of stress, fear • Improvement in therapeutic relationships with healthcare providers, companions and multi-disciplinary team.	
Pagels 2008 (56)	Obs	CKD	58 Age: 65	• General CKD knowledge	Nurse	• Print	• A diary to promote disease related knowledge, involvement and self-care ability and to promote cooperation between patient and nurse *Duration*: 12 months *Comparator*: none	Cognitions: • Participation, self-care, and disease related knowledge	
								Intervention specific: • Use of diary • Suitability for teaching purposes	
Yen 2008 (57)	PP	CKD 3	66 Age: 67.4	• General CKD knowledge • Diet/nutrition • Physical activity • Medication	Nephrologist, nurse, dietician, social worker	• Print • Face to face • Telephone	"Educational intervention": • Handouts • One 150 min workshop • Individual consults Q6 month with nurse • Phone number provided to participants for questions • Desserts recommended by dietician given at workshop for educational purposes, lunch boxes designed by dietician given out at the end of the workshop *Duration:* 12 months *Comparator*: None	Cognitions: • QOL (WHOQOL-BREF Taiwan version) – *global increase* • Knowledge of renal function protection (checklist made by investigators) – *no change*	
								Physiological measures: • Creatinine – *no change* • BUN – *no change* • GFR – *no change* • Body weight – *no change* • Muscle weight – *no change*	

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								• % Body fat – *no change* • Waist to hip ratio – *significant decrease in E group* • BMI – *significant decrease in E group* • BP – *no change*	
Gutierrez Vilaplana 2009 (55)	PP	CKD 4-5	41 Age: 60.56	• General CKD knowledge • Diet/nutrition • Physical activity • Modalities • Other (i.e. psychosocial - impact of CKD family, finances, social life)	Nurse, physician, technician, 3 expert patients	• Print • Face to face	"Teaching group": • Six 2-hour monthly group education sessions • Booklet for future reference *Duration:* 6 months *Comparator:* None	Cognitions: • Anxiety – *decreased* • Fear – *more control of fear response* • Stress – *decreased*	
Wu 2009 (59)	QE	CKD 3-5	573 (E = 287, Cohort = 286) Age: 63.4	• General CKD knowledge • Diet/nutrition • Medication • Lifestyle	Nurse, social worker, dietician, HD/PD patient volunteers, physicians	• Face to face	"Multidisciplinary pre-dialysis education (MPE)": • Individual lectures, content based on CKD stage • Dietary counseling biannually *Duration:* 12 months *Comparator:* standard care	Health status: • ESRD warranting RRT – *13.9% in E group vs 43% in C group* • All cause mortality – *1.7% in E group vs 10.1% in C group*	
								Health care: • Hospitalization – *2.8% E group vs 16.4% in C group*	
Wierdsma 2011 (60)	QE	CKD	54 (E = 28, C = 26) Age: 55-59	• Medication	Nurse practitioner	• Face to face • Print	"Motivational interviewing": • Counseling by nurse practitioner (in addition to care by nephrologist) using motivational interviewing • Using the "Long-Term Medication Behavior Self-Efficacy Scale (LTMBSES)" – areas with score <5 were identified and then up to 5 areas (picked by patient) were discussed and	Cognitions: • LTMBSES – *difference in mean self-efficacy score at post-test*	

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							solutions and goals were set *Duration:* 6 months *Comparator:* standard care		
Aguilera Florez 2012 (61)	Obs	CKD	19 Age: 58	• General CKD knowledge • Diet/nutrition • Medication • Symptom management • Physical activity • Modalities • Other	Nurse, physio-therapist, dietician, pharmacist, psychologist, coordinators, nephrologist, patient mentors	• Face to face	"Escuela ERCA": • 7 1.5-hour multi-disciplinary group education sessions held biweekly • Up to 10 patients per group with family members • Didactic plus discussion format *Duration*: Not reported *Comparator*: None	Cognitions: • Knowledge • Anxiety - i*ncreased* Individual outcomes: • Satisfaction in group therapy	
Choi 2012 (62)	QE	CKD 1-5	61 (E = 31, C = 30) Age: 53.93-58.33	• General CKD knowledge • Diet/nutrition • Modalities • Other (i.e. understanding and compliance with SM)	Physician, nurse, dietician	• Face to face • PowerPoint slides	"Face-to-face SM program": • 90 minute lecture with slides (3 – 5 people/group) • 20 minute individual consult • 1 week later individual reinforcement education and consultation *Duration:* 2 sessions *Comparator:* general maintenance	Cognitions: • Knowledge of CKD scale – *increase > in E group* Behaviors: • Self-care practice scale for CKD patients – *no difference between E group and C group but did increase over time for both groups* Physiological measures: • BUN/Creatinine – *no change* • Na/K – *no change* • Ca/PO4 – *no change* • Hemoglobin – *no change* • GFR – *no change*	
Kao 2012 (24)	QE	CKD 1-4	94 (E = 45, C = 49) Age: 73.17	• General CKD knowledge • Physical activity	Instructor	• Print • Face to face • Telephone	"Exercise education intervention": • Manual • 1.5 hour exercise/ health education course • Drafted exercise contract &	Behaviors: • Exercise behavior – *improved in E group*	

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							exercise programs • Follow up phone calls • 1x/month for patients in maintenance phase • 2x/month for patients in action/ prep stages • 4x/month for patients at pre-contemplation/ contemplation stages • Goal: workout 3-5x/week x 30min for 3 months *Duration*: 4 months *Comparator:* standard care	Cognitions: • Depression – *score decreased (i.e. improved) in E group* Symptom management: • Fatigue - *score decreased in E group*	
Diamantidis 2013 (63)	PP	CKD 3-5	108 Age: 64	• Diet/nutrition • Medication	Online tool	• Website	"Disease-specific safety information": • Safe kidney care website – patient/family member and provider portals • Education modules displayed in circular distribution to avoid prioritization of topics *Duration:* Not applicable *Comparator:* None	Intervention specific: • First entry into website - *<30% of participants entered within 365 days (total follow up period*) • Average dwell time on the website – *7 minutes* • Modules were ranked by frequency of selection - *The three most frequently visited pages were "Renal function calculator", "Pills to avoid", and "Foods to avoid"*	
Kazawa 2013 (28)	PP	CKD 3-4 (diabetic nephropathy)	30 Age: 67	• Diet/nutrition • Medications • Physical activity • Comorbidities	Nurse	• Print • Face to face • Telephone • Email	"SM skills program": • Textbook • Daily journal • Four 1-hour face-to-face sessions Q2 weeks at outpatient clinic or	Individual outcomes: • QOL – *self-efficacy and SM behaviors improved*	

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				• Other (i.e. stress management, identify supporters (family) & how they can contribute, goal setting)			in home • Two 30 minute phone or email sessions Q1 month • Then Q1 month phone calls *Duration:* 6 months *Comparator*: None	Physiological measures: • Renal function – *no change* • Hemoglobin A1c – *decreased post intervention*	
Lin 2013 (64)	PP	CKD 1-3a	37 Age 67.42	• Other (i.e. self-regulation/ self-management topics)	Nurse	• Print • Face to face • Video	"SM program": • Self-monitoring workbook • 5 week SM program • Weekly 90 minute face- to-face group sessions (6-8 patients) • CKD SM video about self-regulation *Duration:* 5 weeks *Comparator*: None	Cognitions: • CKD self-efficacy – *increased*	
								Behaviors: • CKD SM – *no change*	
								Physiological measures: • Creatinine – *marginally significant decrease* • GFR – *remained stable*	
Murali 2013 (25)	PP	CKD 4	12 Age: 68	• Diet/nutrition	Online tool	• Website	"Dietary assessment and evaluation tool": • Self -administered • Obtains 24 hour food history • Then evaluates diet based on KDOQI GL • Then share general tips for success • A report is generated for the nephrologist to guide discussion with patients *Duration:* single exposure *Comparator:* None	Cognitions: • Change in patients' self-efficacy to adhere to KDOQI GL after single exposure to the tool – *3 worsened, 3 improved, 6 no change*	
								Intervention specific: • Tool acceptability – *well accepted* • Congruence of patient and provider attitudes – *incongruence in 4/10 cases where provider states used report but patient doesn't verify*	
Nauta 2013 (29)	PP	CKD	22 Age: 55.2-59.8	• Diet/nutrition • Physical	Online tool	• Print • Website	"Lifestyle management tool": • 33-page quick start guide provided	Cognitions: • Self-efficacy – *limited effectiveness*	

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				• activity • Lifestyle			• Patients had access to site for 4 months – patient choice to frequency of visits to website • *Duration*: 4 months • *Comparator*: None	Behaviors: • SM – *limited effectiveness*	
Thomas 2013 (30)	MM	Diabetic nephropathy (DM + micro-albuminuria)	176 (E = 116, C = 60) Age: NR	• General CKD knowledge • Comorbidities • Lifestyle	NR	• Print • DVD	"SM package": • Written materials • 20 minute DVD • Self-monitoring diary • Fridge magnet with key messages • BP monitor if needed *Duration*: One session *Comparator*: standard care	Physiological measures: • BP – *no statistically sig difference* • Hemoglobin A1c– *no change* • BMI – *no change*	
Walker 2013 (65)	PP	CKD with high risk of progression + DM2 + HTN + albuminuria	52 Age: 57.5	• Diet/nutrition • Medication • Symptom management • Physical activity • Other (i.e. compliance)	Nurse, nurse practitioner	• Print • Face to face	"Nurse practitioner intervention in primary care setting": • SM booklet • Initial assessment of lifestyle behaviors, SM practice, health/medication knowledge • Individual education • Individualized patient management plan given at end of 12 weeks • Q2 week 30 minute long assessments & review x 12 weeks *Duration:* 12 weeks *Comparator:* None	Behaviors: • SM (Partners in Health (PIH) instrument) – *had change in certain domains*	
Wright Nunes 2013 (66)	QE	CKD 1-5	556 (E = 155, Cohort = 401)	• General CKD knowledge • Diet/nutrition	Nephrology fellows	• Print • Face to face	"Physician-delivered education too'" • 1-page intervention worksheet delivered during clinic visits –	Cognitions: • Kidney specific knowledge – *associated with increase in knowledge*	

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			Age: 57	• Medication • Physical activity • Lifestyle • Comorbidities • Other (i.e. compliance)			take 1-2 minutes to administer *Duration*: one session *Comparator*: "historical group" – who developed sheet	Intervention specific: • Feasibility of intervention – *physicians found it useful and efficient but had concern regarding some of the talking points*	
Walker 2014 (21)	PP	CKD with high risk of progression + DM2 + HTN + albuminuria	52 Age: 57.5	• See Walker (65)	Nurse, nurse practitioner	• See Walker (65)	• See Walker (65)	Physiological measures: • Albuminuria – *improved* • GFR – *no change* • 5 year absolute cardiovascular risk – *improved* • BP – *improved* • Total cholesterol – *improved* • Hemoglobin A1c – *improved*	
								Cognitions: • Knowledge of medications/ conditions – *improved*	
								Behaviors: • Medication adherence, adherence to healthy lifestyle – *improved*	
Enworom 2015 (67)	QE	CKD 1-4	49 (E = 25, C = 24) Age: 73	• General CKD knowledge • Symptoms management • Modalities • Comorbidities • Other (i.e. advanced care planning)	Nurse practitioner, physician assistants, clinical nurse specialist	• Face to face	"Kidney Disease Education (KDE)" • 6 education classes on one on one or group basis *Duration*: unclear *Comparator*: no KDE	Physiological measures: • GFR decline – *slower in E group* • Hemoglobin – *E group maintained more stable level compared to non-KDE group who lost 1g/dL from baseline*	
								Cognitions: • Kidney disease knowledge (KiKS survey) – *no change*	

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Vann 2015 (26)	PP	CKD 3b-4	9 Age: mean NR	• General CKD knowledge • Diet/nutrition • Symptom management • Modalities • Comorbidities • Other (i.e. self-care management strategies and behaviors)	Nurse practitioner	• Print • Website • Face to face • White board	"CKD Education Program" • CKD education sessions • Assessment of readiness to change • CKD toolkit individualized for each participant • Collaborative goal setting between nurse practitioner and patient • Information booklet with websites listed • Patients met with nurse practitioner for 60 min *Duration*: over 6 visits *Comparator*: none	Cognitions: • CKD related knowledge – *improved*	
								Behaviors: • Self reported behavior change - *improved*	
Cupisiti 2016 (68)	Obs	CKD 3b-5	823 (E = 305, C = 518) Age: 69-74	• Diet/nutrition	Dietician	• Face to face	"Nutritional Treatment" • Renal dietician assessed dietary habits using 3 day dietary recall & performed an intervention tailored to the needs/clinical features of the patient • Progressed from "normal" diet → low protein diet → very low protein diet depending on needs *Duration*: at least 6 months *Comparator*: standard care	Physiological measures: • Phosphaturia – *lower in E group*	
								Health care: • Furosemide use – *lower in E group* • Calcium free phosphate bind use – *lower in E group* • ESA use – *lower in E group* • Active vitamin D preparation use – *lower in E group*	
								Individual outcomes: • Dietary satisfaction questionnaire – *majority of E group patients were satisfied with their diet*	
Ong 2016 (69)	PP	CKD 4-5	45 Age: 59.4	• Medications • Symptom management • Comorbidities	Mobile application	• Smart phone application	"Smartphone based SM system" • Application generated personalized patient messages based on pre-built algorithms	Physiological measures: • BP – *change in home BP readings*	

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				• Other (i.e. tracking lab results)			*Duration*: 6 months *Comparator*: none	Intervention specific: • Medications – *127 medication discrepancies identified*	
Penaloza-Ramos 2016 (22)	Obs	HTN (BP>130/80) + CKD stage 3 or CVA/TIA or DM or MI or angina, or CABG	NR Age: NA	• See McManus (48)	General practitioner, patient	• See McManus (48)	• See McManus (48)	Health care: • Cost effective – *yes*	

Abbreviations: BP – blood pressure; E – experimental; C – control; CHD – coronary heart disease; CHEERS – Controlling Hypertension: Education and Empowerment Renal Study; DM – diabetes mellitus; HTN – hypertension; NR – not reported; RRT – renal replacement therapy; TIA – transient ischemic attack; QOL – quality of life; RCT = randomized controlled trial; QE = quasi-experimental; PP = pre-post intervention; Obs = observational; MM = mixed methods; SM – self-management

Key:

Not applicable

Outcome improved post intervention

Outcome worsened post intervention

Outcome unchanged post intervention

Outcome had mixed results (some improved and/or some worsened and/or some did not change)

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Table 5. Summary of qualitative studies

Study (Reference)	Target population	Number of participants	Aim/Intervention	Methods	Summary of findings
Blickem (18)	CKD Stage 3	20	"To explore the experience of patient-led assessment for network support (PLANS) from the perspectives of participants and telephone support workers." (p.1) Intervention: see Table 4 Blakeman (47)	Interviews and focus groups: No analytic methodology discussed	• Mixed reception from participants • Formulation of "health" in everyday life (i.e. participants unaware of having CKD or its significance - confused about relevance of PLANS) • Trajectories and tipping points (i.e. engagement in PLANS depended on participants' stage of life – either could influence trying new things or disrupt routines) • Trust in networks (i.e. unwillingness to seek support, intrusive, others saw improved awareness/access to local resources; tailored support)
Heiden (70)	CKD pre-dialysis, dialysis, transplant	5	To identify participant's perspective regarding a "web application prototype to help make decisions regarding diet restrictions and phosphate binder dosage." (p.544) Intervention: Website tool for patients that included 3 components – diet/fluid education; diet registry; and	Interviews: no analytic methodology discussed	• Benefits: ○ Education tool increased insight and understanding ○ Assisted in tracking and choosing best food alternative ○ Decision support for binder dosage • Limitations: ○ Targeted users familiar with using computers ○ Users had different information needs ○ One-way communication ○ Need self-care resources in place to carry out recommendations

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			phosphate binder decision support tool.		
Jansen (71)	CKD Stages 4 – 5	7	Feasibility of "a psychosocial intervention to assist ESRD patients and their partners in integrating renal disease and treatment into daily activities, primary work and thereby increasing autonomy." (p.280) Intervention: Group teaching and handbook regarding coping strategies and goals based on self-regulation, social learning and self-determination theories.	Interviews: no analytic methodology discussed	• Benefits: ○ Group included pre-dialysis and dialysis patients ○ Leaders addressed individual needs, situations and questions • Limitations: ○ Patient preferences for information differed by stages of CKD ○ Patient schedules need to be considered when intervention offered ○ Consider offering intervention shortly after diagnosis of CKD
Thomas (30)	Type 1 or 2 DM with microalbuminuria	5 (3 face-to-face interviews)	To evaluate "whether patients understood the content of the pack and whether they could make any recommendations." (p.275) Intervention: See Table 4 Thomas (30)	Questionnaire and interview: no analytic methodology discussed	• Mixed responses • DVD – content distressing and took effort to use • Written material useful, but need to elaborate on seriousness of disease • Package helped change behavior – stop smoking, monitoring DM
Williams (19)	CKD Stages 2 – 4 with diabetes and	26	"Examine the perceptions of a	Interviews: Ritchie and	• Attitudes towards taking medications (i.e.

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	cardiovascular disease		group of CALD participants with comorbid diabetes, chronic kidney disease and cardiovascular disease … using an intervention to influence their medication self-efficacy." (p. 1271) Intervention: see Table 4 Williams (44)	Spencer thematic approach	appreciate importance of taking; medication burden; concern with the number of medications, effectiveness and side effects of medications • Having to take medications (i.e. behaviors and family support to assist taking medications; forgetting and non-adherent; motivation to take to prevent becoming worse) • Impediments to chronic illness medication self-efficacy (i.e. lack of knowledge regarding medication; strong faith in physician's advice; multiple medications too overwhelming; cost)
Williams (20)	CKD Stages 2 – 4, with coexisting diabetes and hypertension	39	Individual perceptions of a "telephone call using a motivational interviewing approach to improve medication adherence in participants with co-existing diabetes, CKD and hypertension." (p.472) Intervention: see Table 4 Williams (43)	Interviews: Ritchie and Spencer thematic approach	• Importance of health (i.e. determined the degree of health behavior; altered medications or use of alternative medicine to control health) • Perceived seriousness of disease (i.e. thinking about mortality; comorbidities complicate care; acute illness with chronic conditions) • Perceived threat of disease (i.e. want to learn about disease control earlier; symptom management; looking for reasons to explain why ill)

BP – blood pressure; CKD – chronic kidney disease; DM – diabetes mellitus

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Self-management interventions for adults with chronic kidney disease: A scoping review

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Manuscripts

Self-management interventions for adults with chronic kidney disease: A scoping review

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ABSTRACT

Objective: To systematically identify and describe self-management interventions for adult patients with CKD.

Setting: Community-based

Participants: Adults with CKD Stages 1 – 5 (not requiring kidney replacement therapy).

Interventions: Self-management strategies for adults with CKD.

Primary and secondary outcome measures: Using a scoping review, electronic databases and grey literature were searched in October 2016 to identify self-management interventions for adults with CKD Stages 1 – 5 (not requiring kidney replacement therapy). Randomized controlled trials (RCTs), non-RCTs, qualitative and mixed method studies were included and study selection and data extraction were independently performed by two reviewers. Outcomes included behaviors, cognitions, physiological measures, symptoms, health status and health care.

Results: Fifty studies (19 RCTs, 7 quasi-experimental, 5 observational, 13 pre-post intervention, 1 mixed methods and 5 qualitative) reporting 45 interventions were included. The most common intervention topic was diet/nutrition and interventions were regularly delivered face to face. Interventions were administered by a variety of providers, with nursing professionals the most common health professional group. Cognitions (i.e. changes in general CKD knowledge, perceived self-management, and motivation) was the most frequently reported outcome domain that showed improvement. Less than 1% of the interventions were co-developed with patients and 20% were based on a theory or framework.

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Conclusions: There was a wide range of self-management interventions with considerable variability in outcomes for adults with CKD. Major gaps in the literature include lack of patient engagement in the design of the interventions, with the majority of interventions not applying a behavioral change theory to inform their development. This work highlights the need to involve patients to co-develop and evaluate a self-management intervention based on sound theories and clinical evidence.

Key words: Chronic kidney disease, scoping review, self-management, person centered-care

Strengths and limitations of this study:

- A strength of our study is that it is the first scoping review to apply the principles of patient-oriented research, where patient partners where engaged in determining the research question, advising us on search terms and reviewing the results to ensure we captured and reported the data meaningfully.
- Our scoping review is comprehensive in nature, inclusion of all study designs and consideration of self-management features that have not been investigated previously.
- Due to the heterogeneous nature of the literature, it was challenging to synthesize the data. To address this challenge the two reviewers used two standardized tools to independently extract data, and independently coded the outcomes into categories using the Self-and Family Management Framework.
- A limitation of our scoping review is that we were unable to assess the self-management outcomes in terms of sustained changes in behavior, physiological, and health status.

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- We were unable to draw conclusions regarding the most effective self-management intervention for adult patients with CKD, keeping in mind our aim was to review the breadth of the current literature and present the gaps that exist.

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INTRODUCTION

Chronic kidney disease (CKD) is associated with adverse health outcomes, poor quality of life and high health care costs (1). Patients with CKD often experience a number of comorbidities including diabetes, cardiovascular disease and depression (2). They must balance the medical management of their kidney disease and other chronic conditions with demands of their daily lives, including managing the emotional and psychosocial consequences of living with chronic disease. In a recent CKD research priority setting study, individuals with non-dialysis CKD, their caregivers, clinicians and policy makers identified the need to develop optimal strategies to enable patients to manage their CKD and related comorbidities to slow or prevent the progression to end-stage kidney disease (ESKD) (3). International data in research priority setting for kidney disease also highlights self-management as a top priority to prevent progression (4).

Self-management interventions aim to facilitate an individual's ability to make lifestyle changes and manage symptoms, treatment, and the physical and psychosocial consequences inherent in living with CKD and associated comorbidities (5). Self-management of CKD involves focusing on illness needs (developing knowledge, skills and confidence to manage medical aspects), activating resources (identifying and accessing resources and supports) and living with the condition (learning to cope with the condition and its impact on their lives as well as the emotional consequences of the illness) (6). Self-management requires patient engagement, however, the degree to which patients are able or willing to participate in self-management can vary, and individual and health system factors may serve as facilitators or barriers to self-management processes (7).

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Despite the high prevalence of CKD and its impact on patient outcomes, there is limited evidence on the effectiveness of self-management interventions. Prior systematic reviews (8 - 11) and three integrative reviews (12-14) found that self-management interventions were variable in their effectiveness for managing and preventing progression of CKD. While these reviews add to the knowledge base, they have restricted inclusion criteria (e.g. study type, patient population) and unclear reporting strategies (i.e. describing complex self-management interventions in detail and providing structured accounts of the interventions and outcomes). In particular, features of self-management interventions such as person centeredness, applicability to co-morbidities associated with CKD, physiological and non-physiological outcomes, and application of any behavioral change theories are often lacking. Self-management interventions need to be tailored to suit diverse patient needs and preferences, as well as the local health care context (7). Therefore, investigating the "who", "what" and the "how" of self-management interventions is crucial. We used recognized literature synthesis and reporting guidelines, along with engagement of our patient partners in determining the research question and search terms, as well as reviewing the results to ensure we captured and reported the data meaningfully.

To our knowledge there is no literature synthesis that systematically and comprehensively summarizes the breadth of evidence found in primary quantitative, qualitative and mixed methods research regarding self-management interventions for adult patients with CKD. We used a scoping review methodology to understand the range and types of interventions including both educational and support interventions for CKD to inform the future design of a self-management intervention. Specifically, we conducted a scoping review to identify and describe self-management interventions for adult patients with CKD (stages 1 – 5; non-dialysis, non-transplant).

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MATERIALS AND METHODS

We used a scoping review methodology to enable us to incorporate a broad range of studies and to summarize the knowledge from a variety of sources and types of evidence (15). Our aim was to identify gaps in literature related to CKD self-management interventions and inform future research. A unique and important aspect was the involvement of "patient partners". Through a national initiative, Canadians Seeking Solutions and Innovations to Overcome CKD (Can-SOLVE CKD), patients work side by side with researchers, clinicians and decision makers to address patient-oriented research priorities (16). Our research team includes Can-SOLVE CKD patient partners with CKD and caregivers (16). Using the Joanna Briggs Institute framework for scoping reviews we undertook the following steps: (1) identified the research question, (2) identified relevant studies, (3) completed study selection, (4) charted, collated, summarized and reported the results, and (5) consulted with our patient partners (15, 17). These steps were iterative to ensure comprehensive inclusion of the literature and continued meaningful engagement with our patient partners. This work involves identifying, reviewing and categorizing data from primary articles and does not involve human participants and is exempt from ethics approval.

Research aim

Our scoping review aimed to determine the available self-management interventions for adults aged 18 years and over and diagnosed with CKD Stages 1 – 5 (not requiring dialysis or transplant).

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Search and selection of studies

We worked with an information specialist (DL) to identify key words that represented the population (CKD) and the intervention (self-management). We searched a broad range of information sources including the following online databases: MEDLINE (OVID), EMBASE, PsycINFO, Cochrane Central Register of Controlled Trials, CINAHL Plus and Cochrane Database of Systematic Reviews for published studies, with no limits on date (inception to October 2016), language, age or study design. We also searched Web of Science from 2006 – October 2016 to capture recently published meeting abstracts and summaries. Using the Canadian Agency for Drugs and Technology (CADTH) Grey Matters approach, (18) we searched Google Canada, Health Technology Assessment (HTA) agencies (Canada, Australia, Ireland, UK and US), and Clinical Trials databases (Biomed Central – ISRCTN Registry, US National Institutes of Health, ClinicalTrials.gov) during October 2016 with no language restrictions (Table S1). Our search strategy for grey literature was guided by the specific database (i.e. Google search operators, website search filters) and was completed within a single session for each search strategy to ensure consistency due to the dynamic nature of the Internet (Table S2). Two reviewers (BK and MD) also reviewed the reference lists of included studies, along with those identified in past systematic and integrative reviews of our research topic. We contacted authors of relevant protocols and conference abstracts to ascertain if their work and findings were published.

A study was included if the population involved adults with CKD (stages 1 – 5, non-dialysis, non-transplant). Self-management interventions included strategies, tools, or resources in any delivery format (print, electronic, face to face, etc.) that facilitated an individual's ability to make

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lifestyle changes or to manage symptoms, treatment, or the physical and psychosocial consequences inherent in living with CKD and other associated comorbidities. Interventions targeted only at selection of treatment for ESKD (i.e. dialysis, kidney transplant) were excluded. Other self-management interventions or standard care were considered as a comparison. We included primary studies that used quantitative, qualitative or mixed methods. Systematic and integrative reviews were identified for the purpose of reviewing their included studies for potential relevant studies. We excluded case series, case studies, case reports, clinical practice guidelines, theses and opinion-driven reports (editorials, non-systematic or literature/narrative reviews).

Three reviewers (BK, MD, and BH) performed an initial screen of titles and abstracts using a citation screening tool. To determine inter-rater reliability, a calibration exercise was performed by the three reviewers. Pilot testing a random sample of 50 citations achieved good agreement (kappa = 0.79) at which point the three reviewers screened the remaining titles and abstracts. Two reviewers (BK and MD) followed a similar procedure for identifying relevant full text studies, with good agreement between the two reviewers (kappa = 0.78). Disagreements were resolved by discussion and obtaining consensus between the three reviewers.

Charting, collating and summarizing the data

We developed a data extraction form based on the Template for Intervention Description and Replication (TIDierR) checklist (19).This checklist provides a template to structure accounts of an intervention (e.g. goal of intervention, materials used, who delivered the intervention and how, where, when and how much, and how well the intervention was delivered). We also used the Effective Practice and Organization of Care (EPOC) data collection form (20) to ensure we were comprehensive in extracting relevant study characteristics as outlined by Cochrane EPOC

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group. Study characteristics (e.g. study design, country of origin, publication year), population characteristics (e.g. CKD stage, comorbidities), and self-management intervention characteristics (e.g. topics, format, target audience, providers, location, dose, duration, etc.) were documented. For the study outcomes, the two reviewers (BK and MD) independently coded each outcome into categories identified by Grey et al (e.g. behaviors, cognitions, physiological measures, symptoms, health status, health care and other) (6). We pilot tested the form on a random sample of 10 eligible studies and once consensus between the two reviewers was reached, we independently abstracted data from the remaining eligible studies. Data was categorized and reported descriptively (i.e. counts and frequencies). For qualitative studies we identified the methodology and key concepts presented by the authors.

Consultation with patient partners

Patient partners were engaged throughout this work, specifically to provide input on the research question, search strategies (e.g. grey literature sources) and reviewing the final results. The results were presented and discussed at the national Can-SOLVE CKD meeting.

RESULTS

Search results

From 12,583 unique citations (Figure 1) we included 50 full text studies (21-70).

Description of studies

A summary of the 50 studies included in this review is provided in Table 1.

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Table 1 Characteristics of the studies included in scoping review

Characteristic	Studies (N = 50)
Study design	
Randomized controlled trial	19
Pre-post test	13
Quasi-experimental (controlled/non-random)	7
Observational	5
Qualitative	5
Mixed methods	1
Origin of study	
United States	10
United Kingdom	7
Australia	6
Canada	5
Taiwan	5
Netherlands	3
Spain	3
Italy	2
Japan	2
New Zealand	2
Sweden	2
Brazil	1
Denmark	1
Korea	1
Year of publication	
2012 – 2016	32
2007 – 2011	11
Prior	7

The most common study designs were randomized controlled trials (RCTs) (38%). Non-RCTs consisted of quasi-experimental (14%), observational (10%), pre-post intervention (26%), qualitative (10%) and mixed methods (2%). The studies were conducted in 14 countries, including the United States (20%), United Kingdom (14%) and Australia (12%). Most studies were published in the last 5 years (64%).

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Patient population characteristics

The target population in most studies was CKD (72%) and 15 studies mentioned CKD plus one or more associated comorbidities. The average ages of participants reported across studies were 50.2 to 74.3 years.

Description of self-management interventions

Table 2 summarizes the characteristics of the self-management interventions. Five studies reported the same self-management intervention (21-25), therefore 45 interventions were summarized. The most common intervention topic was diet/nutrition (64%) and the least common were symptom management and lifestyle (13% and 11% respectively). The most frequent modes of delivering the intervention were face to face (80%), multiple (i.e. more than one mode) (71%) and print (64%). Electronic was the least common delivery mode (16%). Interventions were administered by a variety of providers. The most common category of providers was "other" (56%), which was made up of various types of health professionals and lay people. However, the most common identifiable group of providers were nursing professionals (49%). Patient volunteer/mentor was the least common (9%). The outpatient setting was the most common location for providing the self-management intervention (51%), and the inpatient setting was the least popular (2%). Many studies did not report the intervention language (53%), but 12 languages were represented and 7 studies reported that they provided the intervention in multiple languages.

In terms of intervention development, only 20% of studies mentioned the use of evidence such as theories or frameworks. These included the transtheoretical model of behavior change, social cognitive theory and chronic care model (26-30). Less than 1% of the studies involved patients in

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the design of the intervention, where patients were interviewed regarding intervention content (26, 31-33).

Table 2 Overall characteristics of self-management interventions

Variable	Intervention count (N = 45)
Intervention topics	
Diet/nutrition	29
General CKD knowledge	18
Other (i.e. advanced care planning, meditation)	18
Medication	17
Modalities	13
Physical activity	13
Comorbidities	11
Symptom management	6
Lifestyle	5
Mode of Delivery	
Face to face (i.e. group, one-on-one)	36
Multiple modes	32
Print	29
Distance (i.e. telephone, email)	13
Digital (i.e. DVD, PowerPoint, audio recording)	8
Electronic (i.e. website, mobile application)	7
Type of providers	
Other*	25
Nurse/nurse practitioner	22
Dietitian	14
Multiple providers	13
Social worker	6
Physician/primary care physician	6
Nephrologist/nephrology fellows	5
Patient volunteer/mentor	4
Pharmacist	1
Location of intervention	
Outpatient	23
Not specified	12
Community (non-clinic)**	10
Patient home	10
Multiple locations	7
Inpatient	1
Intervention languages	
Not Specified	24

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English	10
Multiple languages	7
Mandarin	4
Spanish	3
Taiwanese	3
Dutch	2
Cantonese	1
French	1
Greek	1
Italian	1
Japanese	1
Swedish	1
Vietnamese	1
Intervention development	
Use of framework or theory	9
Co-designed with patients	4

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Description of quantitative study outcomes and results

Characteristics of the quantitative study outcomes are presented in Table 3. Twenty-three (46%) studies measured physiological outcomes (i.e. laboratory tests, body composition, etc.). The least common outcomes reported by studies were health status and health care (each 10%) and symptoms (i.e. fatigue) (4%). Table 4 summarizes the details of the quantitative studies. We categorized the overall study results descriptively as improved, unchanged, or worse. Many studies had more than one outcome measure (e.g.. one measure improved, another had no change) and they were reported as mixed results. Based on this method of categorization, 89 outcomes were reported, of which 61% improved, 20% had no change, 1% worsened, and 13% had mixed results. Four of the results were reported as not applicable as the outcomes were not relevant. Of the 54 outcome categories that improved, 15 were cognition, 9 were physiological measures, 8 were behaviors, 8 were individual outcomes, 5 were health status, 4 were health care, 4 were intervention specific, and 1 was symptom management.

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Table 3 Summary of quantitative study outcomes*

Common outcomes	Description	Number of studies	Number of studies in which outcome improved
Physiologic measures	Changes in laboratory tests, blood pressure, body composition, functional/performance tests and cardiovascular risk.	23	9
Cognitions	Changes in general CKD knowledge, self-efficacy, self-management, motivation, perceived stress, anxiety and fear.	21	15
Behaviors	Adherence to diet, medication, physical activity, sleep, blood pressure control.	13	8
Individual outcomes	QOL, well-being and general satisfaction.	11	8
Intervention specific	Reporting of general concepts regarding feasibility of intervention, enjoyment and interest in intervention.	9	4
Health care	Measurements of cost effectiveness, health care utilization and access.	5	4
Health status	Measurements of morbidity and mortality (i.e. time to dialysis, survival, all-cause mortality).	5	5
Symptoms	Changes in overall symptoms (i.e. pain, fatigue)	2	1

* Based on primary and distal outcomes from Grey et al (6)
CKD – chronic kidney disease; QOL – quality of life

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Table 4 Summary of quantitative studies

Study & Year (Reference)	Design	Target Population	Study Size Age (years)	Intervention Topic(s)	Provider(s)	Delivery Format	Description of Intervention	Study Outcomes	Study Results
RCT									
Binik 1993 (34)	RCT	Pre-RRT CKD (creatinine ≥350 µmol/L and rising rapidly)	204 (E = 87, C = 92, not part of education = 25) Age: 50.2	• General CKD knowledge • Diet/nutrition • Modalities	Trained research assistant	• Print • Face to face • PowerPoint slides	"Enhanced education": • 22-page booklet • Individual slide presentation (75 mins) *Duration* – one session *Comparator:* standard care	Health Status: • Duration between session & dialysis initiation – *patient in E group survived 4.6 months longer w/o requiring RRT*	
Gillis 1995 (35)	RCT	CKD 3-5	840 (unclear) Age: NR	• Diet/nutrition	Dietician	• Print • Face to face	"Modification of diet in renal disease": • "Keeping Track" booklet • Monthly meeting with dietician • Protein Wise Counter (lists protein content of foods) • "Shopping Wise": a guide to convenience and fast foods • Visited restaurants and shops *Duration* – 26 months *Comparator:* standard protein diet	Cognitions: • Patient reliance on dietician's feedback, support and modeling strategies - *decreased over time in E group* Individual Outcomes: • Top rated interventions by patients - *counseling, self-monitoring, protein counter*	
Devins 2003 (36)	RCT	CKD (creatinine ≤300 µmol/L and deemed to need RRT in 6-18 months)	297 (E = 149, C = 148) Age: 58.6	• General CKD knowledge • Diet/nutrition • Medication • Modalities • Lifestyles	Social worker	• Print • Face to face • Telephone	"Psychoeducation": • 60-page booklet • 90 min interactive educational intervention personalized for each patient • Supportive (10 min max) phone calls Q3 weeks *Duration* – 18 months or initiation of RRT	Health Status: • Time to dialysis – *E group had 3 month delay in dialysis compared to C group*	

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CKD self-management interventions

							Comparator: standard care		
Devins 2005 (37)	RCT	CKD with progressive reduction in kidney function	335 (E = 172, C = 163) Age: 47.4-53.9	• General CKD Knowledge • Diet/nutrition • Modalities	Health educator	• Print • Face to face • PowerPoint slides	"Psychoeducation session": • 22-page booklet • Individual slide presentation (60-75 min long) *Duration* – one visit *Comparator:* standard care	Health Status: • Survival pre-dialysis and after dialysis initiation – *significantly longer in the E group (2.25 years and 8 months respectively)*	
Campbell 2008 (38)	RCT	CKD 4-5	47 (E = 24, C = 23) Age: 68.5-72.6	• Diet/nutrition • Other (i.e. self-management principles)	Dietician	• Face to face • Telephone	"Individual nutritional counseling": • Initial individual consultation with dietician • Then phone follow-up Q2 weeks x 1 month then Q1 month *Duration*: 12 weeks *Comparator:* standard care	Individual outcomes: • QOL – *many components of KDQOLSF v1.3 improved: □CKD symptoms, □cognitive function, vitality**	
								Physiological measures: • Nutritional assessment PG-SGA – *in E group those who were malnourished at baseline improved, in C group malnourished from 12.5-25%*	
Byrne 2011 (26)	RCT	CKD 1-4 + HTN	81 (E = 40, C = 41) Age: 62.8-65.4	• Comorbidities (i.e. HTN management)	Nurse	• Print • Face to face • Telephone	"Structured education session": • Leaflet on HTN management • CHEERS patient education intervention, and standard care • 2.5 hour group session • Phone support from nurse *Duration:* one session *Comparator:* standard care	Intervention specific: • Feasibility (recruitment, retention, patient satisfaction, patient access of additional support) - *findings suggest delivering/evaluating an effective structured group educational intervention to promote better BP control would be challenging*	
Chen 2011 (39)	RCT	CKD 3-5	54 (E = 27, C = 27) Age: 68.2	• General CKD knowledge • Diet/nutrition • Medication • Lifestyle • Modality information for stage IV	Nurse, dietician, nephrologist, peers, volunteers	• Print • Face to face • Telephone	"Self-management Support": • Individual monthly health education • Weekly telephone based support • Aid of support group twice monthly (5 – 10 patients) *Duration*: 12 months *Comparator:* standard care	Physiological measures: • eGFR change – *higher in E group* • eGFR reduction of >50% - *less in E group* • ESRD requiring RRT and all-cause mortality – *no significant difference between groups*	
								Health Status: • # Of hospitalizations in 1 year of follow-up – *less in E group*	
Flesher 2011 (40)	RCT	CKD 3-4 + HTN	40 (E = 23, C = 17) Age: 63.4	• Diet/nutrition • Physical activity	Nurse, exercise physiologist, dietician, cook educator	• Print • Face to face	"Cooking and exercise class": • Standard care and: • Group CKD nutrition class (with dietician and cook educator: 2 hour	Physiological measures: • Improvement in 4/5 of the following: urinary protein, total cholesterol, eGFR decline, BP, urinary sodium – was considered a	

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							sessions over 4 weeks) plus 1 shopping tour led by a dietician • CKD cookbook • 12 week exercise program (3 X 1 hour sessions/week) led by a certified exercise physiologist & nurse *Duration:* 12 weeks *Comparator:* standard care	success – *61% in E group vs. 12% in C group* Behaviors: • SM score – *some changes in some components in both groups*	
Joboshi 2012 (41)	RCT	CKD	31 (E = 19, C = 12) Age: 69.8	• Other	Nurse	• Face to face • Telephone • Email	"EASE (encourage autonomous self-enrichment) program": • Nurses listen to what patients have difficulties and discuss how they will try to improve • Face to face interview monthly • Telephone or email contact every 2 weeks *Duration*: 12 weeks *Comparator*: standard care	Cognitions: • Self-efficacy Behaviors: • Medication adherence • Adherence to BP and weight measurements • Limiting salt intake • Alcohol consumption • Smoking Physiological measures: • BP	
Williams 2012 (42)	RCT	CKD 2-4 (diabetic kidney disease) + DM + HTN	75 (E = 39, C = 41) Age: 67	• Medication • Comorbidities	Nurse	• Print • Face to face • Telephone • DVD	"Multifactorial intervention": • Individual medication review (draw chart) • Daily self-monitoring of BP x 3 months • 20 min DVD • Q2 week motivational interviewing follow up via phone x 12 weeks to support BP management and optimize medication SM *Duration:* 12 weeks *Comparator*: standard care	Physiological measures: • BP – *no difference between groups* Behaviors: • Medication adherence – *no difference between groups*	
Williams 2012 (43)	RCT	CKD 2-4 + DM + cardio-vascular disease	78 (E = 40, C = 38) Age: 74.31	• Medication • Comorbidities • Other (i.e. self-efficacy)	Nurse, interpreter	• Print • Face to face • Telephone • PowerPoint slides	"Self-efficacy Medication Intervention (SEM)": • Individual medication review – chart in English but interpreter wrote on medication boxes in patients language or used symbols	Intervention specific: • Attrition rate to assess feasibility of study – *high attrition* Cognitions: • Medication self-efficacy – *no difference between groups*	

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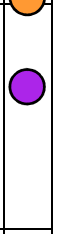
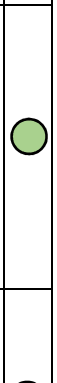
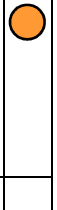
CKD self-management interventions

							• Individual slide presentation (20 minutes) via interpreter (Greek, Italian, Vietnamese) • Q2 week motivational interviewing follow-up via phone x 12 weeks *Duration:* 12 weeks *Comparator:* standard care	Health care: • Health care utilization – *no difference between groups* Physiological measures: • Routine clinical lab surrogate measures – *no difference* Behaviors: • Medication adherence – *no difference* Individual outcomes: • General wellbeing – *no difference*	
De Brito 2013 (44)	RCT	CKD 3-5 + HTN (BP>130/80) + Bengali population	56 (E = 28, C = 28) Age: 55.7-60.7	• Diet/nutrition	Dietician and Bengali worker	• Face to face • Telephone	"Diet advice ": • Practical cooking & education sessions in the community facilitated by a Bengali worker • Followed by Q2 week phone calls to reinforce advice and set new targets *Duration:* 6 months *Comparator:* Standard care	Physiological measures: • BP – *decreased by 8mmHg in E group* • 24 hour urinary salt excretion – *decrease in E group* • eGFR – *no difference between groups*	
Paes-Barreto 2013 (45)	RCT	CKD 3-5	89 (E = 43, C = 46) Age: 63.4	• Diet/nutrition	Dietician	• Print • Face to face • Telephone	"Nutrition Education Program': • Standard dietary counseling AND • Education folder with recipes to replace salt with sodium free seasoning blends • Individual 15-20 minute class • Hands on session about protein rich food • Hands on session using test tubes with the amount of salt in different foods • 4 monthly follow up visits • Telephone call to address any doubts with dietary plan *Duration*: 4 – 7 months *Comparator*: standard care	Behaviors: • Reduction in protein intake – *decreased* • Adherence to low protein diet – *effective* Physiological measures: • Body composition: waist circumference, body fat, BMI, mid-arm muscle circumference – *no change* • Serum albumin – *no change*	 
Blakeman 2014 (46)	RCT	CKD 3	436 (E = 215, C = 221) Age: 72.1	• General CKD knowledge • Comorbidities	Lay health worker	• Print • Website • Telephone	"Information and telephone-guided access to community services": • Kidney Information Guidebook	Cognitions: • Positive & active engagement in life (heiQ) – *no difference between groups*	

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				• Other (i.e. community resources			• Patient-Led Assessment for Network Support "PLANS" booklet and interactive website – tailored access to community resources • Telephone guided help from a lay health worker *Duration:* 6 months *Comparator:* standard care	Physiological measures: • BP control – *better BP maintenance in E group*	
								Individual outcomes: • Health related QOL (EuroQoL EQ-5D index) – *higher in E group*	
McManus 2014 (47)	RCT	HTN (BP>130/80) + CKD3 or DM or CHD	555 (E = 277, C = 278) Age: 69.3-69.6	• Medication • Comorbidities	General practitioner, patient	• Print • Face to face	"Self-monitoring of BP and self-titration of medications": • Self-monitoring of BP • Self-titration of medications following a 3-step plan designed by general practitioner and patient *Duration:* 12 months *Comparator:* standard care	Physiological measures: • SBP at 12months – *no difference*	
								Health care: • Prescription of anti-hypertensive medications – *increased in both groups but greater significance in E group*	
								Symptom mgmt.: • Adverse effects – *no significant difference between groups*	
								• Individual outcomes: • QOL - *no significant difference between groups*	
Park 2014 (48)	RCT	CKD3 + HTN + African American	15 Age: 58.7	• Other (i.e. meditation)	Principle investigator , patient	• Face to face • Audio recording	"Mindfulness meditation (MM)" • 14 min of pre-recorded guided MM using MP3 player & headphones *Duration*: one session *Comparator*: BP education	Physiological measures: • BP – *decrease in SBP/ DBP/ HR/ MAP* • Muscle sympathetic nerve activity – *decreased*	
Howden 2015 (49)	RCT	CKD 3-4 & >1 uncontrolled cardio-vascular risk factor	72 (E = 36, C = 36) Age 60.2-62.0	• Physical activity	Nurse practitioner, social worker, exercise physiologist, dietician, psychologist, diabetes educator	• Print • Face to face	"Exercise training and lifestyle intervention": • Standard care AND • Detailed medical/ surgical history taken by nurse practitioner • Education about exercising safely: maintaining hydration, signs/ symptoms of abnormal response to exercise • If diabetic – education on hypoglycemia • Exercise prescription individualized on patient's comorbid conditions • Goal = 150min/week of moderate	Physiological measures: • METS – *improved** • 6 minute walk distance – *improved** • BMI – *improved**	

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							intensity exercise plus resistance training • 8 weeks supervised, then 10 month home based • Patients got: exercise ball, resistance training booklet • Patients contacted regularly to monitor adherence to training *Duration:* 12 months *Comparator:* standard care		
Leehey 2016 (50)	RCT	CKD 2-4 + DM2 + BMI>30 + persistent proteinuria	36 (Exercise + diet = 18, Diet = 18) Age: 66	• Diet/nutrition • Physical activity	Personal trainer	• Face to face • Telephone	"Structured exercise program": • Dietary counseling = baseline nutritional counseling with 9 follow-up phone calls (both groups) AND • Supervised exercise program 3x.week (60 min cardio plus 25-30 min resistance training) • Followed by home exercise phase: 3x/week x 60 min with weekly follow-up phone calls & patient encouraged to meet trainer Q1 month *Duration:* 12 months *Comparator:* diet counseling only	Physiological measures: • Urine protein to creatinine ratio – *no change at 52 weeks* • Symptom limited and constant work rate treadmill time – *significant increase in diet + exercise group at 12 but not 52 weeks* • Urine albumin to creatinine ratio – *no change* • eGFR – *no change* • Inflammation – *no change* • Endothelial function – *no change* • Body composition – *no change*	
Montoya 2016 (30)	RCT	CKD 4	30 (E = 16, C = 14) Age: 67.9-68.3	• General CKD knowledge • Diet/nutrition • Medication • Modalities • Other (i.e. putting affairs in order)	Nephrologist, nurse practitioner, dietician, social worker	• Print • Face to face • PowerPoint slides	"Nurse practitioner facilitated CKD group visit": • Binder with section on individual labs, another section for topics of groups visits • Six 1.5-2 hour long monthly group visits of 8 patients (~1/2 had family members with them) • *3 visits done in conjunction with nephrologist's examinations (1st half = apt, 2nd half = education)* • *3 visits = education only* • Interactive discussion at each visit • Slide presentation (30 – 45 minutes) *Duration:* 9 months *Comparator*: standard care	Cognitions: • CKD knowledge – *improved in both groups* • Self-efficacy/disease SM – *upward trend in E group* Individual outcomes: • Satisfaction – *high*	
Non-RCT									

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Robinson 1988 (51)	Obs	CKD	25 Age: NR	• General CKD knowledge • Diet/nutrition • Medication • Other (i.e. self-care activities • Modalities	NR	• Face to face	"Renal Bingo": • Bingo game format/ group gaming technique • Provision of refreshments & prizes for motivation • Refreshments made with dietician consultation, reinforced dietary regimen *Duration:* one session *Comparator:* none	Cognitions: • Information was gained or reinforced – *desirable outcome* • Met a variety of learning needs – *desirable outcome* Intervention specific: • Participation was enjoyed – *desirable outcome* • Interest expressed for repeating the exercise – *desirable outcome*	
Klang 1998 (52)	QE	CKD 4-5	56 (E = 28, C = 28) Age: 54-58	• General CKD knowledge • Diet/nutrition • Physical activity • Modalities • Other (i.e. psychosocial - impact of CKD on economy, family, and social life)	Nurse, physician, social worker, dietician, physio-therapist	• Face to face	"Pre-dialysis patient education": • Four 2-hour sessions of group teaching with a classroom approach • Individual support follow-up by nephrology team member *Duration:* 4 sessions *Comparator:* standard care	Individual outcomes: • Functional and emotional wellbeing – *better in E group**	
Cupisiti 2002 (53)	PP	CKD 3b-5	20 Age: NR	• Diet/nutrition	NR	• Print	"Vegetarian diet": • Alternate between animal based conventional low protein diet & a vegetable based low protein diet • Booklets explaining general guidelines & features of the diet *Duration*: one session *Comparator*: conventional protein diet	Individual outcomes: • Opinions on diet – *90% enjoyed* Physiological measures: • Creatinine – *no change* • Albumin – *no change* • Total protein – *no change* • Lipids – *decreased* • Electrolytes – *no change* • Hematocrit – *no change* • Urinary protein excretion – *decreased* • Urinary urea excretion – *decreased* • Body weight – *no change*	
Gutierrez Vilaplana 2007 (57)	PP	CKD	24 Age: 64.5	• General CKD knowledge • Diet/nutrition • Modalities	Nurse, patient volunteers	• Print • Face to face • PowerPoint slides	"Education Intervention" • 8 2-hour classes • Didactic and discussion *Duration*: 6 months	Cognitions: • Improvement in knowledge of CKD	

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				• Other			*Comparator*: none		
								Behaviors: • Modified lifestyle, diet	
								Intervention specific: • Reduction of stress, fear • Improvement in therapeutic relationships with healthcare providers, companions and multi-disciplinary team.	
Pagels 2008 (55)	Obs	CKD	58 Age: 65	• General CKD knowledge	Nurse	• Print	• A diary to promote disease related knowledge, involvement and self-care ability and to promote cooperation between patient and nurse *Duration*: 12 months *Comparator*: none	Cognitions: • Participation, self-care, and disease related knowledge	
								Intervention specific: • Use of diary • Suitability for teaching purposes	
Yen 2008 (61)	PP	CKD 3	66 Age: 67.4	• General CKD knowledge • Diet/nutrition • Physical activity • Medication	Nephrologist, nurse, dietician, social worker	• Print • Face to face • Telephone	"Educational intervention": • Handouts • One 150 min workshop • Individual consults Q6 month with nurse • Phone number provided to participants for questions • Desserts recommended by dietician given at workshop for educational purposes, lunch boxes designed by dietician given out at the end of the workshop *Duration:* 12 months *Comparator*: None	Cognitions: • QOL (WHOQOL-BREF Taiwan version) – *global increase* • Knowledge of renal function protection (checklist made by investigators) – *no change*	
								Physiological measures: • Creatinine – *no change* • BUN – *no change* • GFR – *no change* • Body weight – *no change* • Muscle weight – *no change* • % Body fat – *no change* • Waist to hip ratio – *significant decrease in E group* • BMI – *significant decrease in E group* • BP – *no change*	

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Gutierrez Vilaplana 2009 (54)	PP	CKD 4-5	41 Age: 60.56	• General CKD knowledge • Diet/nutrition • Physical activity • Modalities • Other (i.e. psychosocial - impact of CKD family, finances, social life)	Nurse, physician, technician, 3 expert patients	• Print • Face to face	"Teaching group": • Six 2-hour monthly group education sessions • Booklet for future reference *Duration:* 6 months *Comparator:* None	Cognitions: • Anxiety – *decreased* • Fear – *more control of fear response* • Stress – *decreased*	
Wu 2009 (58)	QE	CKD 3-5	573 (E = 287, Cohort = 286) Age: 63.4	• General CKD knowledge • Diet/nutrition • Medication • Lifestyle	Nurse, social worker, dietician, HD/PD patient volunteers, physicians	• Face to face	"Multidisciplinary pre-dialysis education (MPE)": • Individual lectures, content based on CKD stage • Dietary counseling biannually *Duration:* 12 months *Comparator:* standard care	Health status: • ESRD warranting RRT – *13.9% in E group vs 43% in C group* • All cause mortality – *1.7% in E group vs 10.1% in C group* Health care: • Hospitalization – *2.8% E group vs 16.4% in C group*	
Wierdsma 2011 (59)	QE	CKD	54 (E = 28, C = 26) Age: 55-59	• Medication	Nurse practitioner	• Face to face • Print	"Motivational interviewing": • Counseling by nurse practitioner (in addition to care by nephrologist) using motivational interviewing • Using the "Long-Term Medication Behavior Self-Efficacy Scale (LTMBSES)" – areas with score <5 were identified and then up to 5 areas (picked by patient) were discussed and solutions and goals were set *Duration:* 6 months *Comparator:* standard care	Cognitions: • LTMBSES – *difference in mean self-efficacy score at post-test*	
Aguilera Florez 2012 (60)	Obs	CKD	19 Age: 58	• General CKD knowledge • Diet/nutrition • Medication • Symptom management • Physical activity • Modalities • Other	Nurse, physio-therapist, dietician, pharmacist, psychologist, coordinators, nephrologist, patient mentors	• Face to face	"Escuela ERCA": • 7 1.5-hour multi-disciplinary group education sessions held biweekly • Up to 10 patients per group with family members • Didactic plus discussion format *Duration*: Not reported *Comparator*: None	Cognitions: • Knowledge • Anxiety - *increased* Individual outcomes: • Satisfaction in group therapy	

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CKD self-management interventions

Choi 2012 (61)	QE	CKD 1-5	61 (E = 31, C = 30) Age: 53.93-58.33	• General CKD knowledge • Diet/nutrition • Modalities • Other (i.e. understanding and compliance with SM)	Physician, nurse, dietician	• Face to face • PowerPoint slides	"Face-to-face SM program": • 90 minute lecture with slides (3 – 5 people/group) • 20 minute individual consult • 1 week later individual reinforcement education and consultation *Duration:* 2 sessions *Comparator:* general maintenance	Cognitions: • Knowledge of CKD scale – *increase > in E group*	
								Behaviors: • Self-care practice scale for CKD patients – *no difference between E group and C group but did increase over time for both groups*	
								Physiological measures: • BUN/Creatinine – *no change* • Na/K – *no change* • Ca/PO4 – *no change* • Hemoglobin – *no change* • GFR – *no change*	
Kao 2012 (27)	QE	CKD 1-4	94 (E = 45, C = 49) Age: 73.17	• General CKD knowledge • Physical activity	Instructor	• Print • Face to face • Telephone	"Exercise education intervention": • Manual • 1.5 hour exercise/ health education course • Drafted exercise contract & exercise programs • Follow up phone calls • 1x/month for patients in maintenance phase • 2x/month for patients in action/ prep stages • 4x/month for patients at pre-contemplation/ contemplation stages • Goal: workout 3-5x/week x 30min for 3 months *Duration*: 4 months *Comparator:* standard care	Behaviors: • Exercise behavior – *improved in E group*	
								Cognitions: • Depression – *score decreased (i.e. improved) in E group*	
								Symptom management: • Fatigue - *score decreased in E group*	
Diamantidis 2013 (62)	PP	CKD 3-5	108 Age: 64	• Diet/nutrition • Medication	Online tool	• Website	"Disease-specific safety information": • Safe kidney care website – patient/family member and provider portals • Education modules displayed in circular distribution to avoid prioritization of topics *Duration:* Not applicable	Intervention specific: • First entry into website - *<30% of participants entered within 365 days (total follow up period)* • Average dwell time on the website – *7 minutes* • Modules were ranked by frequency of selection - *The three most*	

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							Comparator: None	*frequently visited pages were "Renal function calculator", "Pills to avoid", and "Foods to avoid"*	
Kazawa 2013 (31)	PP	CKD 3-4 (diabetic nephropathy)	30 Age: 67	• Diet/nutrition • Medications • Physical activity • Comorbidities • Other (i.e. stress management, identify supporters (family) & how they can contribute, goal setting)	Nurse	• Print • Face to face • Telephone • Email	"SM skills program": • Textbook • Daily journal • Four 1-hour face-to-face sessions Q2 weeks at outpatient clinic or in home • Two 30 minute phone or email sessions Q1 month • Then Q1 month phone calls *Duration:* 6 months *Comparator*: None	Individual outcomes: • QOL – *self-efficacy and SM behaviors improved*	
								Physiological measures: • Renal function – *no change* • Hemoglobin A1c – *decreased post intervention*	
Lin 2013 (63)	PP	CKD 1-3a	37 Age 67.42	• Other (i.e. self-regulation/ self-management topics)	Nurse	• Print • Face to face • Video	"SM program": • Self-monitoring workbook • 5 week SM program • Weekly 90 minute face- to-face group sessions (6-8 patients) • CKD SM video about self-regulation *Duration:* 5 weeks *Comparator*: None	Cognitions: • CKD self-efficacy – *increased*	
								Behaviors: • CKD SM – *no change*	
								Physiological measures: • Creatinine – *marginally significant decrease* • GFR – *remained stable*	
Murali 2013 (28)	PP	CKD 4	12 Age: 68	• Diet/nutrition	Online tool	• Website	"Dietary assessment and evaluation tool": • Self -administered • Obtains 24 hour food history • Then evaluates diet based on KDOQI GL • Then share general tips for success	Cognitions: • Change in patients' self-efficacy to adhere to KDOQI GL after single exposure to the tool – *3 worsened, 3 improved, 6 no change*	

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CKD self-management interventions

							• A report is generated for the nephrologist to guide discussion with patients *Duration:* single exposure *Comparator:* None	Intervention specific: • Tool acceptability – *well accepted* • Congruence of patient and provider attitudes – *incongruence in 4/10 cases where provider states used report but patient doesn't verify*	
Nauta 2013 (32)	PP	CKD	22 Age: 55.2-59.8	• Diet/nutrition • Physical activity • Lifestyle	Online tool	• Print • Website	"Lifestyle management tool": • 33-page quick start guide provided • Patients had access to site for 4 months – patient choice to frequency of visits to website • *Duration*: 4 months • *Comparator*: None	Cognitions: • Self-efficacy – *limited effectiveness* Behaviors: • SM – *limited effectiveness*	
Thomas 2013 (33)	MM	Diabetic nephropathy (DM + micro-albuminuria)	176 (E = 116, C = 60) Age: NR	• General CKD knowledge • Comorbidities • Lifestyle	NR	• Print • DVD	"SM package": • Written materials • 20 minute DVD • Self-monitoring diary • Fridge magnet with key messages • BP monitor if needed *Duration*: One session *Comparator*: standard care	Physiological measures: • BP – *no statistically sig difference* • Hemoglobin A1c– *no change* • BMI – *no change*	
Walker 2013 (64)	PP	CKD with high risk of progression + DM2 + HTN + albuminuria	52 Age: 57.5	• Diet/nutrition • Medication • Symptom management • Physical activity • Other (i.e. compliance)	Nurse, nurse practitioner	• Print • Face to face	"Nurse practitioner intervention in primary care setting": • SM booklet • Initial assessment of lifestyle behaviors, SM practice, health/medication knowledge • Individual education • Individualized patient management plan given at end of 12 weeks • Q2 week 30 minute long assessments & review x 12 weeks *Duration:* 12 weeks *Comparator:* None	Behaviors: • SM (Partners in Health (PIH) instrument) – *had change in certain domains*	
Wright Nunes 2013 (65)	QE	CKD 1-5	556 (E = 155, Cohort = 401)	• General CKD knowledge • Diet/nutrition • Medication	Nephrology fellows	• Print • Face to face	"Physician-delivered education too'" • 1-page intervention worksheet delivered during clinic visits – take 1-2 minutes to administer	Cognitions: • Kidney specific knowledge – *associated with increase in knowledge*	

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			Age: 57	• Physical activity • Lifestyle • Comorbidities • Other (i.e. compliance)			*Duration*: one session *Comparator*: "historical group" – who developed sheet	Intervention specific: • Feasibility of intervention – *physicians found it useful and efficient but had concern regarding some of the talking points*	
Walker 2014 (24)	PP	CKD with high risk of progression + DM2 + HTN + albuminuria	52 Age: 57.5	• See Walker (65)	Nurse, nurse practitioner	• See Walker (65)	• See Walker (65)	Physiological measures: • Albuminuria – *improved* • GFR – *no change* • 5 year absolute cardiovascular risk – *improved* • BP – *improved* • Total cholesterol – *improved* • Hemoglobin A1c – *improved*	
								Cognitions: • Knowledge of medications/ conditions – *improved*	
								Behaviors: • Medication adherence, adherence to healthy lifestyle – *improved*	
Enworom 2015 (66)	QE	CKD 1-4	49 (E = 25, C = 24) Age: 73	• General CKD knowledge • Symptoms management • Modalities • Comorbidities • Other (i.e. advanced care planning)	Nurse practitioner, physician assistants, clinical nurse specialist	• Face to face	"Kidney Disease Education (KDE)" • 6 education classes on one on one or group basis *Duration*: unclear *Comparator*: no KDE	Physiological measures: • GFR decline – *slower in E group* • Hemoglobin – *E group maintained more stable level compared to non-KDE group who lost 1g/dL from baseline*	
								Cognitions: • Kidney disease knowledge (KiKS survey) – *no change*	
Vann 2015 (29)	PP	CKD 3b-4	9 Age: mean NR	• General CKD knowledge • Diet/nutrition • Symptom management • Modalities • Comorbidities • Other (i.e. self-	Nurse practitioner	• Print • Website • Face to face • White board	"CKD Education Program" • CKD education sessions • Assessment of readiness to change • CKD toolkit individualized for each participant • Collaborative goal setting between nurse practitioner and patient • Information booklet with websites	Cognitions: • CKD related knowledge – *improved*	

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				care management strategies and behaviors)			listed • Patients met with nurse practitioner for 60 min *Duration*: over 6 visits *Comparator*: none	Behaviors: • Self reported behavior change - *improved*	
Cupisiti 2016 (67)	Obs	CKD 3b-5	823 (E = 305, C = 518) Age: 69-74	• Diet/nutrition	Dietician	• Face to face	"Nutritional Treatment" • Renal dietician assessed dietary habits using 3 day dietary recall & performed an intervention tailored to the needs/clinical features of the patient • Progressed from "normal" diet → low protein diet → very low protein diet depending on needs *Duration*: at least 6 months *Comparator*: standard care	Physiological measures: • Phosphaturia – *lower in E group*	
								Health care: • Furosemide use – *lower in E group* • Calcium free phosphate bind use – *lower in E group* • ESA use – *lower in E group* • Active vitamin D preparation use – *lower in E group*	
								Individual outcomes: • Dietary satisfaction questionnaire – *majority of E group patients were satisfied with their diet*	
Ong 2016 (68)	PP	CKD 4-5	45 Age: 59.4	• Medications • Symptom management • Comorbidities • Other (i.e. tracking lab results)	Mobile application	• Smart phone application	"Smartphone based SM system" • Application generated personalized patient messages based on pre-built algorithms *Duration*: 6 months *Comparator*: none	Physiological measures: • BP – *change in home BP readings*	
								Intervention specific: • Medications – *127 medication discrepancies identified*	
Penaloza-Ramos 2016 (25)	Obs	HTN (BP>130/80) + CKD stage 3 or CVA/TIA or DM or MI or angina, or CABG	NR Age: NA	• See McManus (48)	General practitioner, patient	• See McManus (48)	• See McManus (48)	Health care: • Cost effective – *yes*	

Abbreviations: BP – blood pressure; E – experimental; C – control; CHD – coronary heart disease; CHEERS – Controlling Hypertension: Education and Empowerment Renal Study; DM – diabetes mellitus; HTN – hypertension; NR – not reported; RRT – renal replacement therapy; TIA – transient ischemic attack; QOL – quality of life; RCT = randomized controlled trial; QE = quasi-experimental; PP = pre-post intervention; Obs = observational; MM = mixed methods; SM – self-management

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Key:

Not applicable

Outcome improved post intervention

Outcome worsened post intervention

Outcome unchanged post intervention

Outcome had mixed results (some improved and/or some worsened and/or some did not change)

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Description of qualitative study outcomes and results

Table 5 summarizes the findings from 6 qualitative studies that explored patient perspectives, one of these being a mixed methods study. All studies used semi-structured interviews and one also used a questionnaire. The aims of all these studies were to examine patient perspectives' regarding the self-management interventions they were involved in. Due to the variety of interventions (e.g. intervention topics, delivery mode and providers of the intervention) it was difficult to summarize findings into meaningful categories. Overall, patients highlighted that interventions needed to be individualized and tailored to their specific situations and preferences (e.g. awareness of having CKD, stage of CKD, knowledge of the disease, access to resources, etc.).

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Table 5 Summary of qualitative studies

Study (Reference)	Target population	Number of participants	Aim/Intervention	Methods	Summary of findings
Blickem (21)	CKD Stage 3	20	"To explore the experience of patient-led assessment for network support (PLANS) from the perspectives of participants and telephone support workers." (p.1) Intervention: see Table 4 Blakeman (47)	Interviews and focus groups: No analytic methodology discussed	• Mixed reception from participants • Formulation of "health" in everyday life (i.e. participants unaware of having CKD or its significance - confused about relevance of PLANS) • Trajectories and tipping points (i.e. engagement in PLANS depended on participants' stage of life – either could influence trying new things or disrupt routines) • Trust in networks (i.e. unwillingness to seek support, intrusive, others saw improved awareness/access to local resources; tailored support)
Heiden (69)	CKD pre-dialysis, dialysis, transplant	5	To identify participant's perspective regarding a "web application prototype to help make decisions regarding diet restrictions and phosphate binder dosage." (p.544) Intervention: Website tool for patients that included 3 components – diet/fluid	Interviews: no analytic methodology discussed	• Benefits: o Education tool increased insight and understanding o Assisted in tracking and choosing best food alternative o Decision support for binder dosage • Limitations: o Targeted users familiar with using computers o Users had different information needs o One-way communication o Need self-care resources in place to carry out recommendations

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			education; diet registry; and phosphate binder decision support tool.		
Jansen (70)	CKD Stages 4 – 5	7	Feasibility of "a psychosocial intervention to assist ESRD patients and their partners in integrating renal disease and treatment into daily activities, primary work and thereby increasing autonomy." (p.280) Intervention: Group teaching and handbook regarding coping strategies and goals based on self-regulation, social learning and self-determination theories.	Interviews: no analytic methodology discussed	• Benefits: o Group included pre-dialysis and dialysis patients o Leaders addressed individual needs, situations and questions • Limitations: o Patient preferences for information differed by stages of CKD o Patient schedules need to be considered when intervention offered o Consider offering intervention shortly after diagnosis of CKD
Thomas (33)	Type 1 or 2 DM with microalbuminuria	5 (3 face-to-face interviews)	To evaluate "whether patients understood the content of the pack and whether they could make any recommendations."	Questionnaire and interview: no analytic methodology discussed	• Mixed responses • DVD – content distressing and took effort to use • Written material useful, but need to elaborate on seriousness of disease • Package helped change behavior – stop smoking, monitoring DM

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			(p.275) Intervention: See Table 4 Thomas (30)		
Williams (22)	CKD Stages 2 – 4 with diabetes and cardiovascular disease	26	"Examine the perceptions of a group of CALD participants with comorbid diabetes, chronic kidney disease and cardiovascular disease … using an intervention to influence their medication self-efficacy." (p. 1271) Intervention: see Table 4 Williams (44)	Interviews: Ritchie and Spencer thematic approach	• Attitudes towards taking medications (i.e. appreciate importance of taking; medication burden; concern with the number of medications, effectiveness and side effects of medications • Having to take medications (i.e. behaviors and family support to assist taking medications; forgetting and non-adherent; motivation to take to prevent becoming worse) • Impediments to chronic illness medication self-efficacy (i.e. lack of knowledge regarding medication; strong faith in physician's advice; multiple medications too overwhelming; cost)
Williams (23)	CKD Stages 2 – 4, with coexisting diabetes and hypertension	39	Individual perceptions of a "telephone call using a motivational interviewing approach to improve medication adherence in participants with co-existing diabetes, CKD and hypertension."	Interviews: Ritchie and Spencer thematic approach	• Importance of health (i.e. determined the degree of health behavior; altered medications or use of alternative medicine to control health) • Perceived seriousness of disease (i.e. thinking about mortality; comorbidities complicate care; acute illness with chronic conditions) • Perceived threat of disease (i.e. want to learn about disease control earlier; symptom management; looking for reasons to explain why ill)

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			(p.472) Intervention: see Table 4 Williams (43)		

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DISCUSSION

To our knowledge, this is the first scoping review involving patients as research partners to identify and summarize self-management interventions for adults with CKD. The scoping review methodology enabled us to systematically summarize a broad range of self-management interventions, and describe their features. We identified 50 studies that investigated self-management interventions for adults with CKD, with considerable variation in interventions, outcomes assessed and results obtained (i.e. some improved and/or some worsened and/or some did not change). We found that self-management interventions for CKD is an emerging area with most studies published within the last 5 years, and may be related to the growing recognition of the importance of incorporating patients and their families in managing their disease to improve outcomes (7).

Our findings are similar to prior reviews reporting that the design of self-management interventions for CKD have not been theoretically driven and have been predominately designed by healthcare professionals without input from patients (13, 14). Person-centered care is changing how healthcare professionals deliver care to patients, but more importantly how patients and their families are actively involved in self-managing their chronic conditions (71). Engaging patients by having them co-design self-management interventions will ensure that patient preferences based on their values, culture, and psychosocial needs will be addressed in the self-management intervention (12-14). Through our current national partnership with patients, researchers and clinicians we have the opportunity to obtain patient perspectives, along with incorporating a behavior change theory to inform the future design of a self-management intervention for CKD.

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Only 28% of studies that we identified included patients with CKD plus other comorbidities, despite the common presence of comorbidities in this patient population. Less than one-quarter of included studies provided information on how to manage comorbid conditions such as tracking lab results and symptom management. This highlights the need to consider "whole person care", where the self-management intervention needs to encompass the physical, mental and emotional needs of the patient (72, 73) that are important to them, as well as meeting the individuals desires by collaboration between relevant providers (71).

Forty-five different self-management interventions were identified, with one or more topics presented in a variety of formats and by a variety of providers. Symptom management and lifestyle topics were not included in many of the interventions. Based on prior work (3), non-dialysis patients with CKD have indicated that these were important topics for them in managing their CKD with an aim to slow the progression of CKD, and will be important to consider in the development of future interventions. Face to face was the most common delivery format while electronic (internet or mobile application) was least common, with many studies reporting multiple formats (i.e. face to face and printed materials). With the expansion of electronic platforms for supporting patients and providers in the uptake of evidence-based care, there is the potential to use an electronic format to support patients in self-managing their CKD and other co-morbidities (74). It is worth noting that there was variability in duration and frequency of face to face encounters, from a single session to multiple sessions over weeks to months. While varied options for in-person delivery is good if it meets the needs of the patients and their families, it may not be feasible on a larger scale due to the resources required. Only 5 studies looked at self-management health care cost-effectiveness, health care utilization and access, each measuring different end-points with mixed results. Future self-management interventions should

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include the essential principles to self-management (e.g. accessing relevant health information, adhering to multiple treatment protocols, changing health behaviors, shared decision making with healthcare providers) (7, 75), along with evaluation of the cost-effectiveness and resource utilization.

The majority of studies did not identify a single primary outcome but rather multiple outcomes. We found that physiological outcomes (i.e. blood pressure) were the most commonly reported and symptoms were the least mentioned. These findings demonstrate the lack of patient driven outcomes that may be important to them. For example, a patient's individual health goals across a variety of dimensions (i.e. symptoms, mobility, social and role function in the family or community) that could possibly maximize their quality of life. Work by Tong et al. (2015) highlights this concept, where patients with CKD are more interested in treatment choices that influence non-traditional clinical outcomes such as impact on family and lifestyle (72). A holistic approach should be considered where mental and psychosocial outcomes are investigated, rather than just physiological endpoints.

Our findings from the qualitative studies looking at patient perspectives are inconclusive because of the limited number of studies and the heterogeneity of the interventions. Havas et al. (2016) similarly reported a lack of research related to patient perspectives on self-management in CKD (12). There is also a lack of qualitative studies overall, which could provide valuable information regarding attitudes and challenges of self-management interventions from the perspective of both providers and patients.

Strengths of our study include the comprehensive nature of our search, inclusion of all study designs and consideration of self-management features that have not been investigated previously. We also engaged patient partners in determining the research question, advising us

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on search terms, grey literature sources and reviewing the results to ensure we captured and reported the data meaningfully. One of the main limitations was the challenge in synthesizing the data given its heterogeneous nature. To address this challenge the two reviewers used two standardized tools TIDieR (19) and the EPOC tool (20) to independently extract data, and independently coded the outcomes into categories using the Self-and Family Management Framework (6). Also, we were unable to assess the self-management outcomes in terms of sustained changes in behavior, physiological, and health status. A final limitation was our inability to draw conclusions regarding the most effective self-management intervention for adult patients with CKD, keeping in mind our aim was to review the breadth of the current literature and present the gaps that exist.

Overall, we found considerable variation in self-management interventions for adults with CKD with respect to their content and delivery, as well as the outcomes assessed and results obtained. Major gaps in the literature include the lack of patient engagement in the design of the self-management intervention, along with the lack of a behavioral change theory to inform their design. Our future research will incorporate intervention frameworks to co-develop and evaluate a self-management intervention based on a sound behavioral theory involving our national patient partners, specialists, primary care providers, and decision makers.

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CONFLICT OF INTEREST STATEMENT

All authors certify that our manuscript has not been published in whole or in part elsewhere, nor is it currently being considered for publication elsewhere. All authors declare that they have no relevant conflicts of interest.

AUTHORS' CONTRIBUTIONS

Research idea and study design: all authors; data acquisition: MD, BK; data analysis/interpretation: MD, BK, BRH; supervision or mentorship: BRH, PR. Each author contributed important intellectual content during manuscript drafting and revisions and accepts accountability for the overall work by ensuring that questions to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

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DATA SHARING STATEMENT

The following data will be available, study protocol and analysis plan to anyone who wishes to access the data and will be available immediately following publication from the corresponding author.

TABLES

Table 1 Characteristics of studies

Table 2 Overall characteristics of self-management interventions

Table 3 Summary of quantitative outcomes

Table 4 summary of quantitative studies

Table 5 Summary of qualitative studies

FIGURES

Figure 1 Prisma flow diagram

SUPPLEMENTARY MATERIAL

Table S1. Search strategies used to search traditional databases

Table S2. Search strategies used to search Canadian Agency for Drugs and Technology (CADTH) databases

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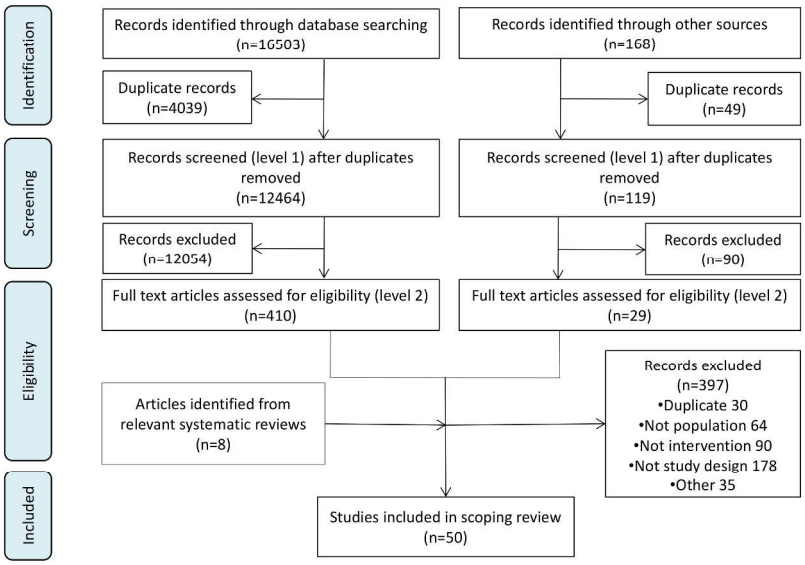
Figure 1. PRISMA Flow Diagram



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Self-management interventions for adults with chronic kidney disease: A scoping review

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ABSTRACT

Objective: To systematically identify and describe self-management interventions for adult patients with CKD.

Setting: Community-based

Participants: Adults with CKD Stages 1 – 5 (not requiring kidney replacement therapy).

Interventions: Self-management strategies for adults with CKD.

Primary and secondary outcome measures: Using a scoping review, electronic databases and grey literature were searched in October 2016 to identify self-management interventions for adults with CKD Stages 1 – 5 (not requiring kidney replacement therapy). Randomized controlled trials (RCTs), non-RCTs, qualitative and mixed method studies were included and study selection and data extraction were independently performed by two reviewers. Outcomes included behaviors, cognitions, physiological measures, symptoms, health status and health care.

Results: Fifty studies (19 RCTs, seven quasi-experimental, five observational, 13 pre-post intervention, one mixed methods and five qualitative) reporting 45 interventions were included. The most common intervention topic was diet/nutrition and interventions were regularly delivered face to face. Interventions were administered by a variety of providers, with nursing professionals the most common health professional group. Cognitions (i.e. changes in general CKD knowledge, perceived self-management, and motivation) was the most frequently reported outcome domain that showed improvement. Less than 1% of the interventions were co-developed with patients and 20% were based on a theory or framework.

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Conclusions: There was a wide range of self-management interventions with considerable variability in outcomes for adults with CKD. Major gaps in the literature include lack of patient engagement in the design of the interventions, with the majority of interventions not applying a behavioral change theory to inform their development. This work highlights the need to involve patients to co-develop and evaluate a self-management intervention based on sound theories and clinical evidence.

Key words: Chronic kidney disease, scoping review, self-management, person centered-care

Strengths and limitations of this study:

- A strength of our study is that it is the first scoping review to apply the principles of patient-oriented research, where patient partners where engaged in determining the research question, advising us on search terms and reviewing the results to ensure we captured and reported the data meaningfully.
- Our scoping review is comprehensive in nature, inclusion of all study designs and consideration of self-management features that have not been investigated previously.
- Due to the heterogeneous nature of the literature, it was challenging to synthesize the data. To address this challenge the two reviewers used two standardized tools to independently extract data, and independently coded the outcomes into categories using the Self-and Family Management Framework.
- A limitation of our scoping review is that we were unable to assess the self-management outcomes in terms of sustained changes in behavior, physiological, and health status.

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- We were unable to draw conclusions regarding the most effective self-management intervention for adult patients with CKD, keeping in mind our aim was to review the breadth of the current literature and present the gaps that exist.

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INTRODUCTION

Chronic kidney disease (CKD) is associated with adverse health outcomes, poor quality of life and high health care costs (1). Patients with CKD often experience a number of comorbidities including diabetes, cardiovascular disease and depression (2). They must balance the medical management of their kidney disease and other chronic conditions with demands of their daily lives, including managing the emotional and psychosocial consequences of living with chronic disease. In a recent CKD research priority setting study, individuals with non-dialysis CKD, their caregivers, clinicians and policy makers identified the need to develop optimal strategies to enable patients to manage their CKD and related comorbidities to slow or prevent the progression to end-stage kidney disease (ESKD) (3). International data in research priority setting for kidney disease also highlights self-management as a top priority to prevent progression (4).

Self-management interventions aim to facilitate an individual's ability to make lifestyle changes and manage symptoms, treatment, and the physical and psychosocial consequences inherent in living with CKD and associated comorbidities (5). Self-management of CKD involves focusing on illness needs (developing knowledge, skills and confidence to manage medical aspects), activating resources (identifying and accessing resources and supports) and living with the condition (learning to cope with the condition and its impact on their lives as well as the emotional consequences of the illness) (6). Self-management requires patient engagement, however, the degree to which patients are able or willing to participate in self-management can vary, and individual and health system factors may serve as facilitators or barriers to self-management processes (7).

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Despite the high prevalence of CKD and its impact on patient outcomes, there is limited evidence on the effectiveness of self-management interventions. Prior systematic reviews (8 - 11) and three integrative reviews (12-14) found that self-management interventions were variable in their effectiveness for managing and preventing progression of CKD. While these reviews add to the knowledge base, they have restricted inclusion criteria (e.g. study type, patient population) and unclear reporting strategies (i.e. describing complex self-management interventions in detail and providing structured accounts of the interventions and outcomes). In particular, features of self-management interventions such as person centeredness, applicability to co-morbidities associated with CKD, physiological and non-physiological outcomes, and application of any behavioral change theories are often lacking. Self-management interventions need to be tailored to suit diverse patient needs and preferences, as well as the local health care context (7). Therefore, investigating the "who", "what" and the "how" of self-management interventions is crucial. We used recognized literature synthesis and reporting guidelines, along with engagement of our patient partners in determining the research question and search terms, as well as reviewing the results to ensure we captured and reported the data meaningfully.

To our knowledge there is no literature synthesis that systematically and comprehensively summarizes the breadth of evidence found in primary quantitative, qualitative and mixed methods research regarding self-management interventions for adult patients with CKD. We used a scoping review methodology to understand the range and types of interventions including both educational and support interventions for CKD to inform the future design of a self-management intervention. Specifically, we conducted a scoping review to identify and describe self-management interventions for adult patients with CKD (stages 1 – 5; non-dialysis, non-transplant).

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MATERIALS AND METHODS

We used a scoping review methodology to enable us to incorporate a broad range of studies and to summarize the knowledge from a variety of sources and types of evidence (15). Our aim was to identify gaps in literature related to CKD self-management interventions and inform future research. A unique and important aspect was the involvement of "patient partners". Through a national initiative, Canadians Seeking Solutions and Innovations to Overcome CKD (Can-SOLVE CKD), patients work side by side with researchers, clinicians and decision makers to address patient-oriented research priorities (16). Our research team includes Can-SOLVE CKD patient partners with CKD and caregivers (16). Using the Joanna Briggs Institute framework for scoping reviews we undertook the following steps: (1) identified the research question, (2) identified relevant studies, (3) completed study selection, (4) charted, collated, summarized and reported the results, and (5) consulted with our patient partners (15, 17). These steps were iterative to ensure comprehensive inclusion of the literature and continued meaningful engagement with our patient partners. This work involves identifying, reviewing and categorizing data from primary articles and does not involve human participants and is exempt from ethics approval.

Research aim

Our scoping review aimed to determine the available self-management interventions for adults aged 18 years and over and diagnosed with CKD Stages 1 – 5 (not requiring dialysis or transplant).

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Search and selection of studies

We worked with an information specialist (DL) to identify key words that represented the population (CKD) and the intervention (self-management). We searched a broad range of information sources including the following online databases: MEDLINE (OVID), EMBASE, PsycINFO, Cochrane Central Register of Controlled Trials, CINAHL Plus and Cochrane Database of Systematic Reviews for published studies, with no limits on date (inception to October 2016), language, age or study design. We also searched Web of Science from 2006 – October 2016 to capture recently published meeting abstracts and summaries. Using the Canadian Agency for Drugs and Technology (CADTH) Grey Matters approach, (18) we searched Google Canada, Health Technology Assessment (HTA) agencies (Canada, Australia, Ireland, UK and US), and Clinical Trials databases (Biomed Central – ISRCTN Registry, US National Institutes of Health, ClinicalTrials.gov) during October 2016 with no language restrictions (Table S1). Our search strategy for grey literature was guided by the specific database (i.e. Google search operators, website search filters) and was completed within a single session for each search strategy to ensure consistency due to the dynamic nature of the Internet (Table S2). Two reviewers (BK and MD) also reviewed the reference lists of included studies, along with those identified in past systematic and integrative reviews of our research topic. We contacted authors of relevant protocols and conference abstracts to ascertain if their work and findings were published.

A study was included if the population involved adults with CKD (stages 1 – 5, non-dialysis, non-transplant). Self-management interventions included strategies, tools, or resources in any delivery format (print, electronic, face to face, etc.) that facilitated an individual's ability to make

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lifestyle changes or to manage symptoms, treatment, or the physical and psychosocial consequences inherent in living with CKD and other associated comorbidities. Interventions targeted only at selection of treatment for ESKD (i.e. dialysis, kidney transplant) were excluded. Other self-management interventions or standard care were considered as a comparison. We included primary studies that used quantitative, qualitative or mixed methods. Systematic and integrative reviews were identified for the purpose of reviewing their included studies for potential relevant studies. We excluded case series, case studies, case reports, clinical practice guidelines, theses and opinion-driven reports (editorials, non-systematic or literature/narrative reviews).

Three reviewers (BK, MD, and BH) performed an initial screen of titles and abstracts using a citation screening tool. To determine inter-rater reliability, a calibration exercise was performed by the three reviewers. Pilot testing a random sample of 50 citations achieved good agreement (kappa = 0.79) at which point the three reviewers screened the remaining titles and abstracts. Two reviewers (BK and MD) followed a similar procedure for identifying relevant full text studies, with good agreement between the two reviewers (kappa = 0.78). Disagreements were resolved by discussion and obtaining consensus between the three reviewers.

Charting, collating and summarizing the data

We developed a data extraction form based on the Template for Intervention Description and Replication (TIDierR) checklist (19).This checklist provides a template to structure accounts of an intervention (e.g. goal of intervention, materials used, who delivered the intervention and how, where, when and how much, and how well the intervention was delivered). We also used the Effective Practice and Organization of Care (EPOC) data collection form (20) to ensure we were comprehensive in extracting relevant study characteristics as outlined by Cochrane EPOC

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group. Study characteristics (e.g. study design, country of origin, publication year), population characteristics (e.g. CKD stage, comorbidities), and self-management intervention characteristics (e.g. topics, format, target audience, providers, location, dose, duration, etc.) were documented. For the study outcomes, the two reviewers (BK and MD) independently coded each outcome into categories identified by Grey et al (e.g. behaviors, cognitions, physiological measures, symptoms, health status, health care and other) (6). We pilot tested the form on a random sample of 10 eligible studies and once consensus between the two reviewers was reached, we independently abstracted data from the remaining eligible studies. Data was categorized and reported descriptively (i.e. counts and frequencies). For qualitative studies we identified the methodology and key concepts presented by the authors.

Consultation with patient partners

Patient partners were engaged throughout this work, specifically to provide input on the research question, search strategies (e.g. grey literature sources) and reviewing the final results. The results were presented and discussed at the national Can-SOLVE CKD meeting.

RESULTS

Search results

From 12,583 unique citations (Figure 1) we included 50 full text studies (21-70).

Description of studies

A summary of the 50 studies included in this review is provided in Table 1.

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Table 1 Characteristics of the studies included in scoping review

Characteristic	Studies (N = 50)
Study design	
Randomized controlled trial	19
Pre-post test	13
Quasi-experimental (controlled/non-random)	7
Observational	5
Qualitative	5
Mixed methods	1
Origin of study	
United States	10
United Kingdom	7
Australia	6
Canada	5
Taiwan	5
Netherlands	3
Spain	3
Italy	2
Japan	2
New Zealand	2
Sweden	2
Brazil	1
Denmark	1
Korea	1
Year of publication	
2012 – 2016	32
2007 – 2011	11
Prior	7

The most common study designs were randomized controlled trials (RCTs) (38%). Non-RCTs consisted of quasi-experimental (14%), observational (10%), pre-post intervention (26%), qualitative (10%) and mixed methods (2%). The studies were conducted in 14 countries, including the United States (20%), United Kingdom (14%) and Australia (12%). Most studies were published in the last five years (64%).

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Patient population characteristics

The target population in most studies was CKD (72%) and 15 studies mentioned CKD plus one or more associated comorbidities. The average ages of participants reported across studies were 50.2 to 74.3 years.

Description of self-management interventions

Table 2 summarizes the characteristics of the self-management interventions. Five studies reported the same self-management intervention (21-25), therefore 45 interventions were summarized. The most common intervention topic was diet/nutrition (64%) and the least common were symptom management and lifestyle (13% and 11% respectively). The most frequent modes of delivering the intervention were face to face (80%), multiple (i.e. more than one mode) (71%) and print (64%). Electronic was the least common delivery mode (16%). Interventions were administered by a variety of providers. The most common category of providers was "other" (56%), which was made up of various types of health professionals and lay people. However, the most common identifiable group of providers were nursing professionals (49%). Patient volunteer/mentor was the least common (9%). The outpatient setting was the most common location for providing the self-management intervention (51%), and the inpatient setting was the least popular (2%). Many studies did not report the intervention language (53%), but 12 languages were represented and seven studies reported that they provided the intervention in multiple languages.

In terms of intervention development, only 20% of studies mentioned the use of evidence such as theories or frameworks. These included the transtheoretical model of behavior change, social cognitive theory and chronic care model (26-30). Less than 1% of the studies involved patients in

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the design of the intervention, where patients were interviewed regarding intervention content (26, 31-33).

Table 2 Overall characteristics of self-management interventions

Variable	Intervention count (N = 45)
Intervention topics	
Diet/nutrition	29
General CKD knowledge	18
Other (i.e. advanced care planning, meditation)	18
Medication	17
Modalities	13
Physical activity	13
Comorbidities	11
Symptom management	6
Lifestyle	5
Mode of Delivery	
Face to face (i.e. group, one-on-one)	36
Multiple modes	32
Print	29
Distance (i.e. telephone, email)	13
Digital (i.e. DVD, PowerPoint, audio recording)	8
Electronic (i.e. website, mobile application)	7
Type of providers	
Other*	25
Nurse/nurse practitioner	22
Dietitian	14
Multiple providers	13
Social worker	6
Physician/primary care physician	6
Nephrologist/nephrology fellows	5
Patient volunteer/mentor	4
Pharmacist	1
Location of intervention	
Outpatient	23
Not specified	12
Community (non-clinic)**	10
Patient home	10
Multiple locations	7
Inpatient	1
Intervention languages	
Not Specified	24

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English	10
Multiple languages	7
Mandarin	4
Spanish	3
Taiwanese	3
Dutch	2
Cantonese	1
French	1
Greek	1
Italian	1
Japanese	1
Swedish	1
Vietnamese	1
Intervention development	
Use of framework or theory	9
Co-designed with patients	4

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Description of quantitative study outcomes and results

Characteristics of the quantitative study outcomes are presented in Table 3. Twenty-three (46%) studies measured physiological outcomes (i.e. laboratory tests, body composition, etc.). The least common outcomes reported by studies were health status and health care (each 10%) and symptoms (i.e. fatigue) (4%). Table 4 summarizes the details of the quantitative studies. We categorized the overall study results descriptively as improved, unchanged, or worse. Many studies had more than one outcome measure (e.g. one measure improved, another had no change) and they were reported as mixed results. Based on this method of categorization, 89 outcomes were reported, of which 61% improved, 20% had no change, 1% worsened, and 13% had mixed results. Four of the results were reported as not applicable as the outcomes were not relevant. Of the 54 outcome categories that improved, 15 were cognition, nine were physiological measures, eight were behaviors, eight were individual outcomes, five were health status, four were health care, four were intervention specific, and one was symptom management.

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Table 3 Summary of quantitative study outcomes*

Common outcomes	Description	Number of studies	Number of studies in which outcome improved
Physiologic measures	Changes in laboratory tests, blood pressure, body composition, functional/performance tests and cardiovascular risk.	23	9
Cognitions	Changes in general CKD knowledge, self-efficacy, self-management, motivation, perceived stress, anxiety and fear.	21	15
Behaviors	Adherence to diet, medication, physical activity, sleep, blood pressure control.	13	8
Individual outcomes	QOL, well-being and general satisfaction.	11	8
Intervention specific	Reporting of general concepts regarding feasibility of intervention, enjoyment and interest in intervention.	9	4
Health care	Measurements of cost effectiveness, health care utilization and access.	5	4
Health status	Measurements of morbidity and mortality (i.e. time to dialysis, survival, all-cause mortality).	5	5
Symptoms	Changes in overall symptoms (i.e. pain, fatigue)	2	1

* Based on primary and distal outcomes from Grey et al (6)
CKD – chronic kidney disease; QOL – quality of life

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Table 4 Summary of quantitative studies

Study & Year (Reference)	Design	Target Population	Study Size Age (years)	Intervention Topic(s)	Provider(s)	Delivery Format	Description of Intervention	Study Outcomes	Study Results
RCT									
Binik 1993 (34)	RCT	Pre-RRT CKD (creatinine ≥350 µmol/L and rising rapidly)	204 (E = 87, C = 92, not part of education = 25) Age: 50.2	• General CKD knowledge • Diet/nutrition • Modalities	Trained research assistant	• Print • Face to face • PowerPoint slides	"Enhanced education": • 22-page booklet • Individual slide presentation (75 mins) *Duration* – one session *Comparator:* standard care	Health Status: • Duration between session & dialysis initiation – *patient in E group survived 4.6 months longer w/o requiring RRT*	
Gillis 1995 (35)	RCT	CKD 3-5	840 (unclear) Age: NR	• Diet/nutrition	Dietician	• Print • Face to face	"Modification of diet in renal disease": • "Keeping Track" booklet • Monthly meeting with dietician • Protein Wise Counter (lists protein content of foods) • "Shopping Wise": a guide to convenience and fast foods • Visited restaurants and shops *Duration* – 26 months *Comparator:* standard protein diet	Cognitions: • Patient reliance on dietician's feedback, support and modeling strategies - *decreased over time in E group* Individual Outcomes: • Top rated interventions by patients - *counseling, self-monitoring, protein counter*	
Devins 2003 (36)	RCT	CKD (creatinine ≤300 µmol/L and deemed to need RRT in 6-18 months)	297 (E = 149, C = 148) Age: 58.6	• General CKD knowledge • Diet/nutrition • Medication • Modalities • Lifestyles	Social worker	• Print • Face to face • Telephone	"Psychoeducation": • 60-page booklet • 90 min interactive educational intervention personalized for each patient • Supportive (10 min max) phone calls Q3 weeks *Duration* – 18 months or initiation of RRT	Health Status: • Time to dialysis – *E group had 3 month delay in dialysis compared to C group*	

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CKD self-management interventions

							Comparator: standard care		
Devins 2005 (37)	RCT	CKD with progressive reduction in kidney function	335 (E = 172, C = 163) Age: 47.4-53.9	• General CKD Knowledge • Diet/nutrition • Modalities	Health educator	• Print • Face to face • PowerPoint slides	"Psychoeducation session": • 22-page booklet • Individual slide presentation (60-75 min long) *Duration* – one visit *Comparator:* standard care	Health Status: • Survival pre-dialysis and after dialysis initiation – *significantly longer in the E group (2.25 years and 8 months respectively)*	
Campbell 2008 (38)	RCT	CKD 4-5	47 (E = 24, C = 23) Age: 68.5-72.6	• Diet/nutrition • Other (i.e. self-management principles)	Dietician	• Face to face • Telephone	"Individual nutritional counseling": • Initial individual consultation with dietician • Then phone follow-up Q2 weeks x 1 month then Q1 month *Duration*: 12 weeks *Comparator:* standard care	Individual outcomes: • QOL – *many components of KDQOLSF v1.3 improved: □CKD symptoms, □cognitive function, vitality**	
								Physiological measures: • Nutritional assessment PG-SGA – *in E group those who were malnourished at baseline improved, in C group malnourished from 12.5-25%*	
Byrne 2011 (26)	RCT	CKD 1-4 + HTN	81 (E = 40, C = 41) Age: 62.8-65.4	• Comorbidities (i.e. HTN management)	Nurse	• Print • Face to face • Telephone	"Structured education session": • Leaflet on HTN management • CHEERS patient education intervention, and standard care • 2.5 hour group session • Phone support from nurse *Duration:* one session *Comparator:* standard care	Intervention specific: • Feasibility (recruitment, retention, patient satisfaction, patient access of additional support) - *findings suggest delivering/evaluating an effective structured group educational intervention to promote better BP control would be challenging*	
Chen 2011 (39)	RCT	CKD 3-5	54 (E = 27, C = 27) Age: 68.2	• General CKD knowledge • Diet/nutrition • Medication • Lifestyle • Modality information for stage IV	Nurse, dietician, nephrologist, peers, volunteers	• Print • Face to face • Telephone	"Self-management Support": • Individual monthly health education • Weekly telephone based support • Aid of support group twice monthly (5 – 10 patients) *Duration*: 12 months *Comparator:* standard care	Physiological measures: • eGFR change – *higher in E group* • eGFR reduction of >50% - *less in E group* • ESRD requiring RRT and all-cause mortality – *no significant difference between groups*	
								Health Status: • # Of hospitalizations in 1 year of follow-up – *less in E group*	
Flesher 2011 (40)	RCT	CKD 3-4 + HTN	40 (E = 23, C = 17) Age: 63.4	• Diet/nutrition • Physical activity	Nurse, exercise physiologist, dietician, cook educator	• Print • Face to face	"Cooking and exercise class": • Standard care and: • Group CKD nutrition class (with dietician and cook educator: 2 hour	Physiological measures: • Improvement in 4/5 of the following: urinary protein, total cholesterol, eGFR decline, BP, urinary sodium – was considered a	

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							sessions over 4 weeks) plus 1 shopping tour led by a dietician • CKD cookbook • 12 week exercise program (3 X 1 hour sessions/week) led by a certified exercise physiologist & nurse *Duration:* 12 weeks *Comparator:* standard care	success – *61% in E group vs. 12% in C group* Behaviors: • SM score – *some changes in some components in both groups*	
Joboshi 2012 (41)	RCT	CKD	31 (E = 19, C = 12) Age: 69.8	• Other	Nurse	• Face to face • Telephone • Email	"EASE (encourage autonomous self-enrichment) program": • Nurses listen to what patients have difficulties and discuss how they will try to improve • Face to face interview monthly • Telephone or email contact every 2 weeks *Duration*: 12 weeks *Comparator*: standard care	Cognitions: • Self-efficacy Behaviors: • Medication adherence • Adherence to BP and weight measurements • Limiting salt intake • Alcohol consumption • Smoking Physiological measures: • BP	
Williams 2012 (42)	RCT	CKD 2-4 (diabetic kidney disease) + DM + HTN	75 (E = 39, C = 41) Age: 67	• Medication • Comorbidities	Nurse	• Print • Face to face • Telephone • DVD	"Multifactorial intervention": • Individual medication review (draw chart) • Daily self-monitoring of BP x 3 months • 20 min DVD • Q2 week motivational interviewing follow up via phone x 12 weeks to support BP management and optimize medication SM *Duration:* 12 weeks *Comparator*: standard care	Physiological measures: • BP – *no difference between groups* Behaviors: • Medication adherence – *no difference between groups*	
Williams 2012 (43)	RCT	CKD 2-4 + DM + cardio-vascular disease	78 (E = 40, C = 38) Age: 74.31	• Medication • Comorbidities • Other (i.e. self-efficacy)	Nurse, interpreter	• Print • Face to face • Telephone • PowerPoint slides	"Self-efficacy Medication Intervention (SEM)": • Individual medication review – chart in English but interpreter wrote on medication boxes in patients language or used symbols	Intervention specific: • Attrition rate to assess feasibility of study – *high attrition* Cognitions: • Medication self-efficacy – *no difference between groups*	

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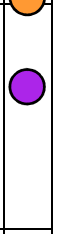
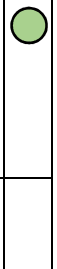
CKD self-management interventions

							• Individual slide presentation (20 minutes) via interpreter (Greek, Italian, Vietnamese) • Q2 week motivational interviewing follow-up via phone x 12 weeks *Duration:* 12 weeks *Comparator:* standard care	Health care: • Health care utilization – *no difference between groups* Physiological measures: • Routine clinical lab surrogate measures – *no difference* Behaviors: • Medication adherence – *no difference* Individual outcomes: • General wellbeing – *no difference*	
De Brito 2013 (44)	RCT	CKD 3-5 + HTN (BP>130/80) + Bengali population	56 (E = 28, C = 28) Age: 55.7-60.7	• Diet/nutrition	Dietician and Bengali worker	• Face to face • Telephone	"Diet advice ": • Practical cooking & education sessions in the community facilitated by a Bengali worker • Followed by Q2 week phone calls to reinforce advice and set new targets *Duration:* 6 months *Comparator:* Standard care	Physiological measures: • BP – *decreased by 8mmHg in E group* • 24 hour urinary salt excretion – *decrease in E group* • eGFR – *no difference between groups*	
Paes-Barreto 2013 (45)	RCT	CKD 3-5	89 (E = 43, C = 46) Age: 63.4	• Diet/nutrition	Dietician	• Print • Face to face • Telephone	"Nutrition Education Program': • Standard dietary counseling AND • Education folder with recipes to replace salt with sodium free seasoning blends • Individual 15-20 minute class • Hands on session about protein rich food • Hands on session using test tubes with the amount of salt in different foods • 4 monthly follow up visits • Telephone call to address any doubts with dietary plan *Duration*: 4 – 7 months *Comparator*: standard care	Behaviors: • Reduction in protein intake – *decreased* • Adherence to low protein diet – *effective* Physiological measures: • Body composition: waist circumference, body fat, BMI, mid-arm muscle circumference – *no change* • Serum albumin – *no change*	
Blakeman 2014 (46)	RCT	CKD 3	436 (E = 215, C = 221) Age: 72.1	• General CKD knowledge • Comorbidities	Lay health worker	• Print • Website • Telephone	"Information and telephone-guided access to community services": • Kidney Information Guidebook	Cognitions: • Positive & active engagement in life (heiQ) – *no difference between groups*	

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				• Other (i.e. community resources			• Patient-Led Assessment for Network Support "PLANS" booklet and interactive website – tailored access to community resources • Telephone guided help from a lay health worker *Duration:* 6 months *Comparator:* standard care	Physiological measures: • BP control – *better BP maintenance in E group*	
								Individual outcomes: • Health related QOL (EuroQoL EQ-5D index) – *higher in E group*	
McManus 2014 (47)	RCT	HTN (BP>130/80) + CKD3 or DM or CHD	555 (E = 277, C = 278) Age: 69.3-69.6	• Medication • Comorbidities	General practitioner, patient	• Print • Face to face	"Self-monitoring of BP and self-titration of medications": • Self-monitoring of BP • Self-titration of medications following a 3-step plan designed by general practitioner and patient *Duration:* 12 months *Comparator:* standard care	Physiological measures: • SBP at 12months – *no difference*	
								Health care: • Prescription of anti-hypertensive medications – *increased in both groups but greater significance in E group*	
								Symptom mgmt.: • Adverse effects – *no significant difference between groups*	
								• Individual outcomes: • QOL - *no significant difference between groups*	
Park 2014 (48)	RCT	CKD3 + HTN + African American	15 Age: 58.7	• Other (i.e. meditation)	Principle investigator , patient	• Face to face • Audio recording	"Mindfulness meditation (MM)" • 14 min of pre-recorded guided MM using MP3 player & headphones *Duration*: one session *Comparator*: BP education	Physiological measures: • BP – *decrease in SBP/ DBP/ HR/ MAP* • Muscle sympathetic nerve activity – *decreased*	
Howden 2015 (49)	RCT	CKD 3-4 & >1 uncontrolled cardio-vascular risk factor	72 (E = 36, C = 36) Age 60.2-62.0	• Physical activity	Nurse practitioner, social worker, exercise physiologist, dietician, psychologist, diabetes educator	• Print • Face to face	"Exercise training and lifestyle intervention": • Standard care AND • Detailed medical/ surgical history taken by nurse practitioner • Education about exercising safely: maintaining hydration, signs/ symptoms of abnormal response to exercise • If diabetic – education on hypoglycemia • Exercise prescription individualized on patient's comorbid conditions • Goal = 150min/week of moderate	Physiological measures: • METS – *improved** • 6 minute walk distance – *improved** • BMI – *improved**	

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							intensity exercise plus resistance training • 8 weeks supervised, then 10 month home based • Patients got: exercise ball, resistance training booklet • Patients contacted regularly to monitor adherence to training *Duration:* 12 months *Comparator:* standard care		
Leehey 2016 (50)	RCT	CKD 2-4 + DM2 + BMI>30 + persistent proteinuria	36 (Exercise + diet = 18, Diet = 18) Age: 66	• Diet/nutrition • Physical activity	Personal trainer	• Face to face • Telephone	"Structured exercise program": • Dietary counseling = baseline nutritional counseling with 9 follow-up phone calls (both groups) AND • Supervised exercise program 3x.week (60 min cardio plus 25-30 min resistance training) • Followed by home exercise phase: 3x/week x 60 min with weekly follow-up phone calls & patient encouraged to meet trainer Q1 month *Duration:* 12 months *Comparator:* diet counseling only	Physiological measures: • Urine protein to creatinine ratio – *no change at 52 weeks* • Symptom limited and constant work rate treadmill time – *significant increase in diet + exercise group at 12 but not 52 weeks* • Urine albumin to creatinine ratio – *no change* • eGFR – *no change* • Inflammation – *no change* • Endothelial function – *no change* • Body composition – *no change*	
Montoya 2016 (30)	RCT	CKD 4	30 (E = 16, C = 14) Age: 67.9-68.3	• General CKD knowledge • Diet/nutrition • Medication • Modalities • Other (i.e. putting affairs in order)	Nephrologist, nurse practitioner, dietician, social worker	• Print • Face to face • PowerPoint slides	"Nurse practitioner facilitated CKD group visit": • Binder with section on individual labs, another section for topics of groups visits • Six 1.5-2 hour long monthly group visits of 8 patients (~1/2 had family members with them) • *3 visits done in conjunction with nephrologist's examinations (1st half = apt, 2nd half = education)* • *3 visits = education only* • Interactive discussion at each visit • Slide presentation (30 – 45 minutes) *Duration:* 9 months *Comparator*: standard care	Cognitions: • CKD knowledge – *improved in both groups* • Self-efficacy/disease SM – *upward trend in E group* Individual outcomes: • Satisfaction – *high*	
Non-RCT									

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Robinson 1988 (51)	Obs	CKD	25 Age: NR	• General CKD knowledge • Diet/nutrition • Medication • Other (i.e. self-care activities • Modalities	NR	• Face to face	"Renal Bingo": • Bingo game format/ group gaming technique • Provision of refreshments & prizes for motivation • Refreshments made with dietician consultation, reinforced dietary regimen *Duration:* one session *Comparator:* none	Cognitions: • Information was gained or reinforced – *desirable outcome* • Met a variety of learning needs – *desirable outcome* Intervention specific: • Participation was enjoyed – *desirable outcome* • Interest expressed for repeating the exercise – *desirable outcome*	
Klang 1998 (52)	QE	CKD 4-5	56 (E = 28, C = 28) Age: 54-58	• General CKD knowledge • Diet/nutrition • Physical activity • Modalities • Other (i.e. psychosocial - impact of CKD on economy, family, and social life)	Nurse, physician, social worker, dietician, physio-therapist	• Face to face	"Pre-dialysis patient education": • Four 2-hour sessions of group teaching with a classroom approach • Individual support follow-up by nephrology team member *Duration:* 4 sessions *Comparator:* standard care	Individual outcomes: • Functional and emotional wellbeing – *better in E group**	
Cupisiti 2002 (53)	PP	CKD 3b-5	20 Age: NR	• Diet/nutrition	NR	• Print	"Vegetarian diet": • Alternate between animal based conventional low protein diet & a vegetable based low protein diet • Booklets explaining general guidelines & features of the diet *Duration*: one session *Comparator*: conventional protein diet	Individual outcomes: • Opinions on diet – *90% enjoyed* Physiological measures: • Creatinine – *no change* • Albumin – *no change* • Total protein – *no change* • Lipids – *decreased* • Electrolytes – *no change* • Hematocrit – *no change* • Urinary protein excretion – *decreased* • Urinary urea excretion – *decreased* • Body weight – *no change*	
Gutierrez Vilaplana 2007 (57)	PP	CKD	24 Age: 64.5	• General CKD knowledge • Diet/nutrition • Modalities	Nurse, patient volunteers	• Print • Face to face • PowerPoint slides	"Education Intervention" • 8 2-hour classes • Didactic and discussion *Duration*: 6 months	Cognitions: • Improvement in knowledge of CKD	

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				• Other			*Comparator*: none		
								Behaviors: • Modified lifestyle, diet	
								Intervention specific: • Reduction of stress, fear • Improvement in therapeutic relationships with healthcare providers, companions and multi-disciplinary team.	
Pagels 2008 (55)	Obs	CKD	58 Age: 65	• General CKD knowledge	Nurse	• Print	• A diary to promote disease related knowledge, involvement and self-care ability and to promote cooperation between patient and nurse *Duration*: 12 months *Comparator*: none	Cognitions: • Participation, self-care, and disease related knowledge	
								Intervention specific: • Use of diary • Suitability for teaching purposes	
Yen 2008 (61)	PP	CKD 3	66 Age: 67.4	• General CKD knowledge • Diet/nutrition • Physical activity • Medication	Nephrologist, nurse, dietician, social worker	• Print • Face to face • Telephone	"Educational intervention": • Handouts • One 150 min workshop • Individual consults Q6 month with nurse • Phone number provided to participants for questions • Desserts recommended by dietician given at workshop for educational purposes, lunch boxes designed by dietician given out at the end of the workshop *Duration:* 12 months *Comparator*: None	Cognitions: • QOL (WHOQOL-BREF Taiwan version) – *global increase* • Knowledge of renal function protection (checklist made by investigators) – *no change*	
								Physiological measures: • Creatinine – *no change* • BUN – *no change* • GFR – *no change* • Body weight – *no change* • Muscle weight – *no change* • % Body fat – *no change* • Waist to hip ratio – *significant decrease in E group* • BMI – *significant decrease in E group* • BP – *no change*	

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Gutierrez Vilaplana 2009 (54)	PP	CKD 4-5	41 Age: 60.56	• General CKD knowledge • Diet/nutrition • Physical activity • Modalities • Other (i.e. psychosocial - impact of CKD family, finances, social life)	Nurse, physician, technician, 3 expert patients	• Print • Face to face	"Teaching group": • Six 2-hour monthly group education sessions • Booklet for future reference *Duration:* 6 months *Comparator:* None	Cognitions: • Anxiety – *decreased* • Fear – *more control of fear response* • Stress – *decreased*	
Wu 2009 (58)	QE	CKD 3-5	573 (E = 287, Cohort = 286) Age: 63.4	• General CKD knowledge • Diet/nutrition • Medication • Lifestyle	Nurse, social worker, dietician, HD/PD patient volunteers, physicians	• Face to face	"Multidisciplinary pre-dialysis education (MPE)": • Individual lectures, content based on CKD stage • Dietary counseling biannually *Duration:* 12 months *Comparator:* standard care	Health status: • ESRD warranting RRT – *13.9% in E group vs 43% in C group* • All cause mortality – *1.7% in E group vs 10.1% in C group* Health care: • Hospitalization – *2.8% E group vs 16.4% in C group*	
Wierdsma 2011 (59)	QE	CKD	54 (E = 28, C = 26) Age: 55-59	• Medication	Nurse practitioner	• Face to face • Print	"Motivational interviewing": • Counseling by nurse practitioner (in addition to care by nephrologist) using motivational interviewing • Using the "Long-Term Medication Behavior Self-Efficacy Scale (LTMBSES)" – areas with score <5 were identified and then up to 5 areas (picked by patient) were discussed and solutions and goals were set *Duration:* 6 months *Comparator:* standard care	Cognitions: • LTMBSES – *difference in mean self-efficacy score at post-test*	
Aguilera Florez 2012 (60)	Obs	CKD	19 Age: 58	• General CKD knowledge • Diet/nutrition • Medication • Symptom management • Physical activity • Modalities • Other	Nurse, physio-therapist, dietician, pharmacist, psychologist, coordinators, nephrologist, patient mentors	• Face to face	"Escuela ERCA": • 7 1.5-hour multi-disciplinary group education sessions held biweekly • Up to 10 patients per group with family members • Didactic plus discussion format *Duration*: Not reported *Comparator*: None	Cognitions: • Knowledge • Anxiety - *increased* Individual outcomes: • Satisfaction in group therapy	

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CKD self-management interventions

Choi 2012 (61)	QE	CKD 1-5	61 (E = 31, C = 30) Age: 53.93-58.33	• General CKD knowledge • Diet/nutrition • Modalities • Other (i.e. understanding and compliance with SM)	Physician, nurse, dietician	• Face to face • PowerPoint slides	"Face-to-face SM program": • 90 minute lecture with slides (3 – 5 people/group) • 20 minute individual consult • 1 week later individual reinforcement education and consultation *Duration:* 2 sessions *Comparator:* general maintenance	Cognitions: • Knowledge of CKD scale – *increase > in E group*	
								Behaviors: • Self-care practice scale for CKD patients – *no difference between E group and C group but did increase over time for both groups*	
								Physiological measures: • BUN/Creatinine – *no change* • Na/K – *no change* • Ca/PO4 – *no change* • Hemoglobin – *no change* • GFR – *no change*	
Kao 2012 (27)	QE	CKD 1-4	94 (E = 45, C = 49) Age: 73.17	• General CKD knowledge • Physical activity	Instructor	• Print • Face to face • Telephone	"Exercise education intervention": • Manual • 1.5 hour exercise/ health education course • Drafted exercise contract & exercise programs • Follow up phone calls • 1x/month for patients in maintenance phase • 2x/month for patients in action/ prep stages • 4x/month for patients at pre-contemplation/ contemplation stages • Goal: workout 3-5x/week x 30min for 3 months *Duration*: 4 months *Comparator:* standard care	Behaviors: • Exercise behavior – *improved in E group*	
								Cognitions: • Depression – *score decreased (i.e. improved) in E group*	
								Symptom management: • Fatigue - *score decreased in E group*	
Diamantidis 2013 (62)	PP	CKD 3-5	108 Age: 64	• Diet/nutrition • Medication	Online tool	• Website	"Disease-specific safety information": • Safe kidney care website – patient/family member and provider portals • Education modules displayed in circular distribution to avoid prioritization of topics *Duration:* Not applicable	Intervention specific: • First entry into website - *<30% of participants entered within 365 days (total follow up period)* • Average dwell time on the website – *7 minutes* • Modules were ranked by frequency of selection - *The three most*	

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CKD self-management interventions

							Comparator: None	*frequently visited pages were "Renal function calculator", "Pills to avoid", and "Foods to avoid"*	
Kazawa 2013 (31)	PP	CKD 3-4 (diabetic nephropathy)	30 Age: 67	• Diet/nutrition • Medications • Physical activity • Comorbidities • Other (i.e. stress management, identify supporters (family) & how they can contribute, goal setting)	Nurse	• Print • Face to face • Telephone • Email	"SM skills program": • Textbook • Daily journal • Four 1-hour face-to-face sessions Q2 weeks at outpatient clinic or in home • Two 30 minute phone or email sessions Q1 month • Then Q1 month phone calls *Duration:* 6 months *Comparator*: None	Individual outcomes: • QOL – *self-efficacy and SM behaviors improved*	
								Physiological measures: • Renal function – *no change* • Hemoglobin A1c – *decreased post intervention*	
Lin 2013 (63)	PP	CKD 1-3a	37 Age 67.42	• Other (i.e. self-regulation/ self-management topics)	Nurse	• Print • Face to face • Video	"SM program": • Self-monitoring workbook • 5 week SM program • Weekly 90 minute face- to-face group sessions (6-8 patients) • CKD SM video about self-regulation *Duration:* 5 weeks *Comparator*: None	Cognitions: • CKD self-efficacy – *increased*	
								Behaviors: • CKD SM – *no change*	
								Physiological measures: • Creatinine – *marginally significant decrease* • GFR – *remained stable*	
Murali 2013 (28)	PP	CKD 4	12 Age: 68	• Diet/nutrition	Online tool	• Website	"Dietary assessment and evaluation tool": • Self -administered • Obtains 24 hour food history • Then evaluates diet based on KDOQI GL • Then share general tips for success	Cognitions: • Change in patients' self-efficacy to adhere to KDOQI GL after single exposure to the tool – *3 worsened, 3 improved, 6 no change*	

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CKD self-management interventions

							• A report is generated for the nephrologist to guide discussion with patients *Duration:* single exposure *Comparator:* None	Intervention specific: • Tool acceptability – *well accepted* • Congruence of patient and provider attitudes – *incongruence in 4/10 cases where provider states used report but patient doesn't verify*	
Nauta 2013 (32)	PP	CKD	22 Age: 55.2-59.8	• Diet/nutrition • Physical activity • Lifestyle	Online tool	• Print • Website	"Lifestyle management tool": • 33-page quick start guide provided • Patients had access to site for 4 months – patient choice to frequency of visits to website • *Duration*: 4 months • *Comparator*: None	Cognitions: • Self-efficacy – *limited effectiveness* Behaviors: • SM – *limited effectiveness*	
Thomas 2013 (33)	MM	Diabetic nephropathy (DM + micro-albuminuria)	176 (E = 116, C = 60) Age: NR	• General CKD knowledge • Comorbidities • Lifestyle	NR	• Print • DVD	"SM package": • Written materials • 20 minute DVD • Self-monitoring diary • Fridge magnet with key messages • BP monitor if needed *Duration*: One session *Comparator*: standard care	Physiological measures: • BP – *no statistically sig difference* • Hemoglobin A1c– *no change* • BMI – *no change*	
Walker 2013 (64)	PP	CKD with high risk of progression + DM2 + HTN + albuminuria	52 Age: 57.5	• Diet/nutrition • Medication • Symptom management • Physical activity • Other (i.e. compliance)	Nurse, nurse practitioner	• Print • Face to face	"Nurse practitioner intervention in primary care setting": • SM booklet • Initial assessment of lifestyle behaviors, SM practice, health/medication knowledge • Individual education • Individualized patient management plan given at end of 12 weeks • Q2 week 30 minute long assessments & review x 12 weeks *Duration:* 12 weeks *Comparator:* None	Behaviors: • SM (Partners in Health (PIH) instrument) – *had change in certain domains*	
Wright Nunes 2013 (65)	QE	CKD 1-5	556 (E = 155, Cohort = 401)	• General CKD knowledge • Diet/nutrition • Medication	Nephrology fellows	• Print • Face to face	"Physician-delivered education too'" • 1-page intervention worksheet delivered during clinic visits – take 1-2 minutes to administer	Cognitions: • Kidney specific knowledge – *associated with increase in knowledge*	

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			Age: 57	• Physical activity • Lifestyle • Comorbidities • Other (i.e. compliance)			*Duration*: one session *Comparator*: "historical group" – who developed sheet	Intervention specific: • Feasibility of intervention – *physicians found it useful and efficient but had concern regarding some of the talking points*	
Walker 2014 (24)	PP	CKD with high risk of progression + DM2 + HTN + albuminuria	52 Age: 57.5	• See Walker (65)	Nurse, nurse practitioner	• See Walker (65)	• See Walker (65)	Physiological measures: • Albuminuria – *improved* • GFR – *no change* • 5 year absolute cardiovascular risk – *improved* • BP – *improved* • Total cholesterol – *improved* • Hemoglobin A1c – *improved*	
								Cognitions: • Knowledge of medications/ conditions – *improved*	
								Behaviors: • Medication adherence, adherence to healthy lifestyle – *improved*	
Enworom 2015 (66)	QE	CKD 1-4	49 (E = 25, C = 24) Age: 73	• General CKD knowledge • Symptoms management • Modalities • Comorbidities • Other (i.e. advanced care planning)	Nurse practitioner, physician assistants, clinical nurse specialist	• Face to face	"Kidney Disease Education (KDE)" • 6 education classes on one on one or group basis *Duration*: unclear *Comparator*: no KDE	Physiological measures: • GFR decline – *slower in E group* • Hemoglobin – *E group maintained more stable level compared to non-KDE group who lost 1g/dL from baseline*	
								Cognitions: • Kidney disease knowledge (KiKS survey) – *no change*	
Vann 2015 (29)	PP	CKD 3b-4	9 Age: mean NR	• General CKD knowledge • Diet/nutrition • Symptom management • Modalities • Comorbidities • Other (i.e. self-	Nurse practitioner	• Print • Website • Face to face • White board	"CKD Education Program" • CKD education sessions • Assessment of readiness to change • CKD toolkit individualized for each participant • Collaborative goal setting between nurse practitioner and patient • Information booklet with websites	Cognitions: • CKD related knowledge – *improved*	

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				care management strategies and behaviors)			listed • Patients met with nurse practitioner for 60 min *Duration*: over 6 visits *Comparator*: none	Behaviors: • Self reported behavior change - *improved*	
Cupisiti 2016 (67)	Obs	CKD 3b-5	823 (E = 305, C = 518) Age: 69-74	• Diet/nutrition	Dietician	• Face to face	"Nutritional Treatment" • Renal dietician assessed dietary habits using 3 day dietary recall & performed an intervention tailored to the needs/clinical features of the patient • Progressed from "normal" diet → low protein diet → very low protein diet depending on needs *Duration*: at least 6 months *Comparator*: standard care	Physiological measures: • Phosphaturia – *lower in E group*	
								Health care: • Furosemide use – *lower in E group* • Calcium free phosphate bind use – *lower in E group* • ESA use – *lower in E group* • Active vitamin D preparation use – *lower in E group*	
								Individual outcomes: • Dietary satisfaction questionnaire – *majority of E group patients were satisfied with their diet*	
Ong 2016 (68)	PP	CKD 4-5	45 Age: 59.4	• Medications • Symptom management • Comorbidities • Other (i.e. tracking lab results)	Mobile application	• Smart phone application	"Smartphone based SM system" • Application generated personalized patient messages based on pre-built algorithms *Duration*: 6 months *Comparator*: none	Physiological measures: • BP – *change in home BP readings*	
								Intervention specific: • Medications – *127 medication discrepancies identified*	
Penaloza-Ramos 2016 (25)	Obs	HTN (BP>130/80) + CKD stage 3 or CVA/TIA or DM or MI or angina, or CABG	NR Age: NA	• See McManus (48)	General practitioner, patient	• See McManus (48)	• See McManus (48)	Health care: • Cost effective – *yes*	

Abbreviations: BP – blood pressure; E – experimental; C – control; CHD – coronary heart disease; CHEERS – Controlling Hypertension: Education and Empowerment Renal Study; DM – diabetes mellitus; HTN – hypertension; NR – not reported; RRT – renal replacement therapy; TIA – transient ischemic attack; QOL – quality of life; RCT = randomized controlled trial; QE = quasi-experimental; PP = pre-post intervention; Obs = observational; MM = mixed methods; SM – self-management

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Key:

Not applicable

Outcome improved post intervention

Outcome worsened post intervention

Outcome unchanged post intervention

Outcome had mixed results (some improved and/or some worsened and/or some did not change)

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Description of qualitative study outcomes and results

Table 5 summarizes the findings from six qualitative studies that explored patient perspectives, one of these being a mixed methods study. All studies used semi-structured interviews and one also used a questionnaire. The aims of all these studies were to examine patient perspectives' regarding the self-management interventions they were involved in. Due to the variety of interventions (e.g. intervention topics, delivery mode and providers of the intervention) it was difficult to summarize findings into meaningful categories. Overall, patients highlighted that interventions needed to be individualized and tailored to their specific situations and preferences (e.g. awareness of having CKD, stage of CKD, knowledge of the disease, access to resources, etc.).

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Table 5 Summary of qualitative studies

Study (Reference)	Target population	Number of participants	Aim/Intervention	Methods	Summary of findings
Blickem (21)	CKD Stage 3	20	"To explore the experience of patient-led assessment for network support (PLANS) from the perspectives of participants and telephone support workers." (p.1) Intervention: see Table 4 Blakeman (47)	Interviews and focus groups: No analytic methodology discussed	• Mixed reception from participants • Formulation of "health" in everyday life (i.e. participants unaware of having CKD or its significance - confused about relevance of PLANS) • Trajectories and tipping points (i.e. engagement in PLANS depended on participants' stage of life – either could influence trying new things or disrupt routines) • Trust in networks (i.e. unwillingness to seek support, intrusive, others saw improved awareness/access to local resources; tailored support)
Heiden (69)	CKD pre-dialysis, dialysis, transplant	5	To identify participant's perspective regarding a "web application prototype to help make decisions regarding diet restrictions and phosphate binder dosage." (p.544) Intervention: Website tool for patients that included 3 components – diet/fluid	Interviews: no analytic methodology discussed	• Benefits: o Education tool increased insight and understanding o Assisted in tracking and choosing best food alternative o Decision support for binder dosage • Limitations: o Targeted users familiar with using computers o Users had different information needs o One-way communication o Need self-care resources in place to carry out recommendations

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			education; diet registry; and phosphate binder decision support tool.		
Jansen (70)	CKD Stages 4 – 5	7	Feasibility of "a psychosocial intervention to assist ESRD patients and their partners in integrating renal disease and treatment into daily activities, primary work and thereby increasing autonomy." (p.280) Intervention: Group teaching and handbook regarding coping strategies and goals based on self-regulation, social learning and self-determination theories.	Interviews: no analytic methodology discussed	• Benefits: o Group included pre-dialysis and dialysis patients o Leaders addressed individual needs, situations and questions • Limitations: o Patient preferences for information differed by stages of CKD o Patient schedules need to be considered when intervention offered o Consider offering intervention shortly after diagnosis of CKD
Thomas (33)	Type 1 or 2 DM with microalbuminuria	5 (3 face-to-face interviews)	To evaluate "whether patients understood the content of the pack and whether they could make any recommendations."	Questionnaire and interview: no analytic methodology discussed	• Mixed responses • DVD – content distressing and took effort to use • Written material useful, but need to elaborate on seriousness of disease • Package helped change behavior – stop smoking, monitoring DM

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			(p.275) Intervention: See Table 4 Thomas (30)		
Williams (22)	CKD Stages 2 – 4 with diabetes and cardiovascular disease	26	"Examine the perceptions of a group of CALD participants with comorbid diabetes, chronic kidney disease and cardiovascular disease … using an intervention to influence their medication self-efficacy." (p. 1271) Intervention: see Table 4 Williams (44)	Interviews: Ritchie and Spencer thematic approach	• Attitudes towards taking medications (i.e. appreciate importance of taking; medication burden; concern with the number of medications, effectiveness and side effects of medications • Having to take medications (i.e. behaviors and family support to assist taking medications; forgetting and non-adherent; motivation to take to prevent becoming worse) • Impediments to chronic illness medication self-efficacy (i.e. lack of knowledge regarding medication; strong faith in physician's advice; multiple medications too overwhelming; cost)
Williams (23)	CKD Stages 2 – 4, with coexisting diabetes and hypertension	39	Individual perceptions of a "telephone call using a motivational interviewing approach to improve medication adherence in participants with co-existing diabetes, CKD and hypertension."	Interviews: Ritchie and Spencer thematic approach	• Importance of health (i.e. determined the degree of health behavior; altered medications or use of alternative medicine to control health) • Perceived seriousness of disease (i.e. thinking about mortality; comorbidities complicate care; acute illness with chronic conditions) • Perceived threat of disease (i.e. want to learn about disease control earlier; symptom management; looking for reasons to explain why ill)

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			(p.472) Intervention: see Table 4 Williams (43)		

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DISCUSSION

To our knowledge, this is the first scoping review involving patients as research partners to identify and summarize self-management interventions for adults with CKD. The scoping review methodology enabled us to systematically summarize a broad range of self-management interventions, and describe their features. We identified 50 studies that investigated self-management interventions for adults with CKD, with considerable variation in interventions, outcomes assessed and results obtained (i.e. some improved and/or some worsened and/or some did not change). We found that self-management interventions for CKD is an emerging area with most studies published within the last five years, and may be related to the growing recognition of the importance of incorporating patients and their families in managing their disease to improve outcomes (7).

Our findings are similar to prior reviews reporting that the design of self-management interventions for CKD have not been theoretically driven and have been predominately designed by healthcare professionals without input from patients (13, 14). Person-centered care is changing how healthcare professionals deliver care to patients, but more importantly how patients and their families are actively involved in self-managing their chronic conditions (71). Engaging patients by having them co-design self-management interventions will ensure that patient preferences based on their values, culture, and psychosocial needs will be addressed in the self-management intervention (12-14). Through our current national partnership with patients, researchers and clinicians we have the opportunity to obtain patient perspectives, along with incorporating a behavior change theory to inform the future design of a self-management intervention for CKD.

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Only 28% of studies that we identified included patients with CKD plus other comorbidities, despite the common presence of comorbidities in this patient population. Less than one-quarter of included studies provided information on how to manage comorbid conditions such as tracking lab results and symptom management. This highlights the need to consider "whole person care", where the self-management intervention needs to encompass the physical, mental and emotional needs of the patient (72, 73) that are important to them, as well as meeting the individuals desires by collaboration between relevant providers (71).

Forty-five different self-management interventions were identified, with one or more topics presented in a variety of formats and by a variety of providers. Symptom management and lifestyle topics were not included in many of the interventions. Based on prior work (3), non-dialysis patients with CKD have indicated that these were important topics for them in managing their CKD with an aim to slow the progression of CKD, and will be important to consider in the development of future interventions. Face to face was the most common delivery format while electronic (internet or mobile application) was least common, with many studies reporting multiple formats (i.e. face to face and printed materials). With the expansion of electronic platforms for supporting patients and providers in the uptake of evidence-based care, there is the potential to use an electronic format to support patients in self-managing their CKD and other co-morbidities (74). It is worth noting that there was variability in duration and frequency of face to face encounters, from a single session to multiple sessions over weeks to months. While varied options for in-person delivery is good if it meets the needs of the patients and their families, it may not be feasible on a larger scale due to the resources required. Only five studies looked at self-management health care cost-effectiveness, health care utilization and access, each measuring different end-points with mixed results. Future self-management interventions should

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include the essential principles to self-management (e.g. accessing relevant health information, adhering to multiple treatment protocols, changing health behaviors, shared decision making with healthcare providers) (7, 75), along with evaluation of the cost-effectiveness and resource utilization.

The majority of studies did not identify a single primary outcome but rather multiple outcomes. We found that physiological outcomes (i.e. blood pressure) were the most commonly reported and symptoms were the least mentioned. These findings demonstrate the lack of patient driven outcomes that may be important to them. For example, a patient's individual health goals across a variety of dimensions (i.e. symptoms, mobility, social and role function in the family or community) that could possibly maximize their quality of life. Work by Tong et al. (2015) highlights this concept, where patients with CKD are more interested in treatment choices that influence non-traditional clinical outcomes such as impact on family and lifestyle (72). A holistic approach should be considered where mental and psychosocial outcomes are investigated, rather than just physiological endpoints.

Our findings from the qualitative studies looking at patient perspectives are inconclusive because of the limited number of studies and the heterogeneity of the interventions. Havas et al. (2016) similarly reported a lack of research related to patient perspectives on self-management in CKD (12). There is also a lack of qualitative studies overall, which could provide valuable information regarding attitudes and challenges of self-management interventions from the perspective of both providers and patients.

Strengths of our study include the comprehensive nature of our search, inclusion of all study designs and consideration of self-management features that have not been investigated previously. We also engaged patient partners in determining the research question, advising us

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on search terms, grey literature sources and reviewing the results to ensure we captured and reported the data meaningfully. One of the main limitations was the challenge in synthesizing the data given its heterogeneous nature. To address this challenge the two reviewers used two standardized tools TIDieR (19) and the EPOC tool (20) to independently extract data, and independently coded the outcomes into categories using the Self-and Family Management Framework (6). Also, we were unable to assess the self-management outcomes in terms of sustained changes in behavior, physiological, and health status. A final limitation was our inability to draw conclusions regarding the most effective self-management intervention for adult patients with CKD, keeping in mind our aim was to review the breadth of the current literature and present the gaps that exist.

Overall, we found considerable variation in self-management interventions for adults with CKD with respect to their content and delivery, as well as the outcomes assessed and results obtained. Major gaps in the literature include the lack of patient engagement in the design of the self-management intervention, along with the lack of a behavioral change theory to inform their design. Our future research will incorporate intervention frameworks to co-develop and evaluate a self-management intervention based on a sound behavioral theory involving our national patient partners, specialists, primary care providers, and decision makers.

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CONFLICT OF INTEREST STATEMENT

All authors certify that our manuscript has not been published in whole or in part elsewhere, nor is it currently being considered for publication elsewhere. All authors declare that they have no relevant conflicts of interest.

AUTHORS' CONTRIBUTIONS

MD, BK, HB, SS, PR, GH, AT, AG, BW, CL, CL, LH, MN, MJ, ME, NF, SB, SS and HRB contributed to the research idea and study design. MD and BK acquired the data. MD, BK and BRH completed data analysis and interpretation. MD, BK, HB, SS, PR, GH, AT, AG, BW, CL, CL, LH, MN, MJ, ME, NF, SB, SS and HRB contributed important intellectual content during manuscript drafting and revisions. All authors read and approved the final manuscript. BRH and PR provided mentorship.

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DATA SHARING STATEMENT

The following data will be available, study protocol and analysis plan to anyone who wishes to access the data and will be available immediately following publication from the corresponding author.

TABLES

Table 1 Characteristics of studies

Table 2 Overall characteristics of self-management interventions

Table 3 Summary of quantitative outcomes

Table 4 summary of quantitative studies

Table 5 Summary of qualitative studies

FIGURES

Figure 1 Prisma flow diagram

SUPPLEMENTARY MATERIAL

Table S1. Search strategies used to search traditional databases

Table S2. Search strategies used to search Canadian Agency for Drugs and Technology (CADTH) databases

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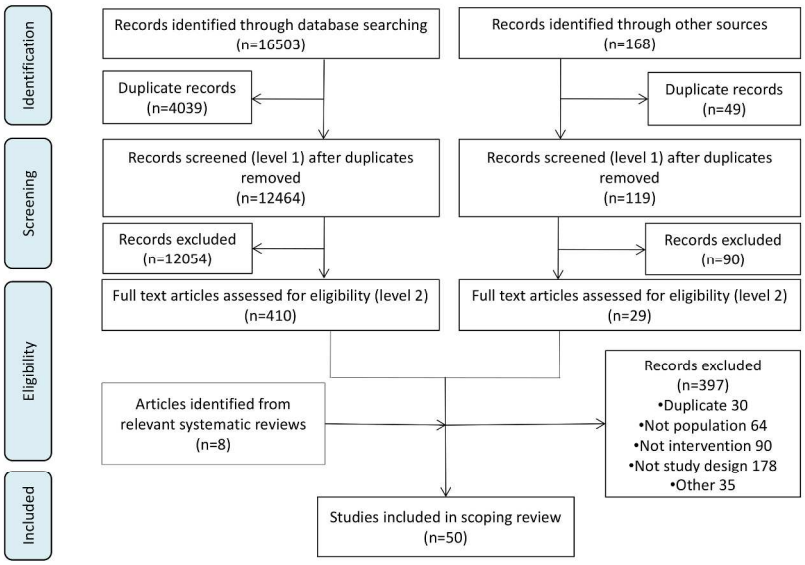
Figure 1. PRISMA Flow Diagram



270x203mm (300 x 300 DPI)

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Table S1. Search strategies used to search traditional databases

MEDLINE search via OVID Dates: Inception (1946) to present (October 26, 2016) October 26, 2016 at 1:36 pm		
#	**Searches**	**Results**
1	exp Renal Insufficiency, Chronic/	96206
2	(chronic kidney failure or chronic renal failure or kidney failure, chronic or renal failure, chronic or failure, chronic kidney or failure, chronic renal or chronic kidney disease* or chronic kidney insufficienc* or chronic renal disease* or chronic renal insufficienc* or disease*, chronic kidney or disease*, chronic renal or kidney disease*, chronic or kidney insufficienc*, chronic or renal disease*, chronic or renal insufficienc*, chronic or Predialysis or CKD).tw	64304
3	1 or 2	124633
4	exp Self Care/	46548
5	(care, self or self care or self-care or self-management or disease management or patient-centred care or patient centred care or patient-centered or patient centered or self monitor* or self-monitor* or self-efficacy or self efficacy or self-regulat* or self regulat* or patient orient* monitor* or patient-orient* monitor* or health educat* or health promot* or patient educat*).tw	138032
6	exp Adaptation, Psychological/ or exp Behavior Therapy/ or exp Health Behavior/ or exp Peer Group/ or exp Social Support/ or exp Self-Help Groups/ or exp Patient Education as Topic/	427541
7	(psychosocial intervention* or psycho-educational intervention* or behavioral intervention* or health behavior* or support or peer support*).tw	795044
8	4 or 5 or 6 or 7	1261025
9	3 and 8	6959
10	(dialysis or hemodialysis or haemodialysis).ti.	69512
11	9 not 10	4872

EMBASE search via OVID Dates: Inception (1974) to present (October 25, 2016) October 26, 2016 at 1:55 pm		
#	**Searches**	**Results**
1	exp chronic kidney disease/ or exp chronic kidney failure/	114971
2	(chronic kidney failure or chronic renal failure or kidney failure, chronic or renal failure, chronic or failure, chronic kidney or failure, chronic renal or chronic kidney disease* or chronic kidney insufficienc* or chronic renal disease* or chronic renal insufficienc* or disease*, chronic kidney or disease*, chronic renal or kidney disease*, chronic or kidney insufficienc*, chronic or renal disease*, chronic or renal insufficienc*, chronic or Predialysis or CKD).tw	91596
3	1 or 2	133908
4	exp self care/	66210
5	(care, self or self care or or self-care or self-management or disease management or patient-centred care or patient centred care or patient-centered or patient centered or self monitor* or self-monitor* or self-efficacy or self efficacy or self-regulat* or self regulat* or patient orient* monitor* or patient-orient* monitor* or health educat* or health promot* or patient educat*).tw	167301
6	exp wellbeing/ or exp adaptive behavior/ or exp psychoeducation/ or exp social adaptation/ or exp coping behavior/ or exp behavior therapy/ or exp health behavior/ or exp patient education/ or peer group/ or support group/ or self-help/	719350
7	(psychosocial intervention* or psycho-educational intervention* or behavioral intervention* or health behavior* or support or peer support*).tw	959549
8	4 or 5 or 6 or 7	1692732
9	3 and 8	8746
10	(dialysis or hemodialysis or haemodialysis).ti.	87234
11	9 not 10	7258

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PsycINFO search via OVID Dates: Inception (1806) to October Week 3 2016 October 26, 2016 at 2:23 PM		
#	**Searches**	**Results**
1	exp Kidney Diseases/	1802
2	(chronic kidney failure or chronic renal failure or kidney failure, chronic or renal failure, chronic or failure, chronic kidney or failure, chronic renal or chronic kidney disease* or chronic kidney insufficienc* or chronic renal disease* or chronic renal insufficienc* or disease*, chronic kidney or disease*, chronic renal or kidney disease*, chronic or kidney insufficienc*, chronic or renal disease*, chronic or renal insufficienc*, chronic or Predialysis or CKD).tw	995
3	1 or 2	2206
4	exp Self-Management/ or exp Self-Care Skills/ or exp Self-Efficacy/	26573
5	(care, self or self care or or self-care or self-management or disease management or patient-centred care or patient centred care or patient-centered or patient centered or self monitor* or self-monitor* or self-efficacy or self efficacy or self-regulat* or self regulat* or patient orient* monitor* or patient-orient* monitor* or health educat* or health promot* or patient educat*).tw	95899
6	exp emotional adjustment/ or exp coping behavior/ or exp well being/ or exp social adjustment/ or exp health behavior/ or exp behavior therapy/ or exp psychoeducation/ or exp client education/ or exp support groups/	148066
7	(psychosocial intervention* or psycho-educational intervention* or behavioral intervention* or health behavior* or support or peer support*).tw	405092
8	4 or 5 or 6 or 7	582953
9	3 and 8	506
10	(dialysis or hemodialysis or haemodialysis).ti.	1281
11	9 not 10	368

Cochrane Central Register of Controlled Trials search via OVID Dates: Inception to September 2016 October 26, 2016 at 2:36 pm		
#	**Searches**	**Results**
1	exp Renal Insufficiency, Chronic/	3857
2	(chronic kidney failure or chronic renal failure or kidney failure, chronic or renal failure, chronic or failure, chronic kidney or failure, chronic renal or chronic kidney disease* or chronic kidney insufficienc* or chronic renal disease* or chronic renal insufficienc* or disease*, chronic kidney or disease*, chronic renal or kidney disease*, chronic or kidney insufficienc*, chronic or renal disease*, chronic or renal insufficienc*, chronic or Predialysis or CKD).tw	4416
3	1 or 2	6614
4	exp Self Care/	4111
5	(care, self or self care or or self-care or self-management or disease management or patient-centred care or patient centred care or patient-centered or patient centered or self monitor* or self-monitor* or self-efficacy or self efficacy or self-regulat* or self regulat* or patient orient* monitor* or patient-orient* monitor* or health educat* or health promot* or patient educat*).tw	14913
6	exp Adaptation, Psychological/ or exp Behavior Therapy/ or exp Health Behavior/ or exp Peer Group/ or exp Social Support/ or exp Self-Help Groups/ or exp Patient Education as Topic/	32694
7	(psychosocial intervention* or psycho-educational intervention* or behavioral intervention* or health behavior* or support or peer support*).tw	40963
8	4 or 5 or 6 or 7	76837
9	3 and 8	375
10	(dialysis or hemodialysis or haemodialysis).ti.	6157
11	9 not 10	251

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Cochrane Database of Systematic Reviews search via OVID Dates: 2005 to October 19, 2016 October 26, 2016 at 2:43 pm		
#	**Searches**	**Results**
1	(chronic kidney failure or chronic renal failure or kidney failure, chronic or renal failure, chronic or failure, chronic kidney or failure, chronic renal or chronic kidney disease* or chronic kidney insufficienc* or chronic renal disease* or chronic renal insufficienc* or disease*, chronic kidney or disease*, chronic renal or kidney disease*, chronic or kidney insufficienc*, chronic or renal disease*, chronic or renal insufficienc*, chronic or Predialysis or CKD).tw	254
2	(care, self or self care or self-care or self-management or disease management or patient-centred care or patient centred care or patient-centered or patient centered or self monitor* or self-monitor* or self-efficacy or self efficacy or self-regulat* or self regulat* or patient orient* monitor* or patient-orient* monitor* or health educat* or health promot* or patient educat*).tw	1359
3	(psychosocial intervention* or psycho-educational intervention* or behavioral intervention* or health behavior* or support or peer support*).tw	9203
4	2 or 3	9230
5	1 and 4	235
6	(dialysis or hemodialysis or haemodialysis).ti.	53
7	5 not 6	209

CINAHL Plus with Full Text Dates: Inception to Present October 26, 2016 at 3:00 pm		
#	**Searches**	**Results**
S1	(MH "Renal Insuffiency, Chronic+")	18210
S2	TI (chronic kidney failure or chronic renal failure or kidney failure, chronic or renal failure, chronic or failure, chronic kidney or failure, chronic renal or chronic kidney disease* or chronic kidney insufficienc* or chronic renal disease* or chronic renal insufficienc* or disease*, chronic kidney or disease*, chronic renal or kidney disease*, chronic or kidney insufficienc*, chronic or renal disease*, chronic or renal insufficienc*, chronic or Predialysis or CKD) OR AB (chronic kidney failure or chronic renal failure or kidney failure, chronic or renal failure, chronic or failure, chronic kidney or failure, chronic renal or chronic kidney disease* or chronic kidney insufficienc* or chronic renal disease* or chronic renal insufficienc* or disease*, chronic kidney or disease*, chronic renal or kidney disease*, chronic or kidney insufficienc*, chronic or renal disease*, chronic or renal insufficienc*, chronic or Predialysis or CKD)	14082
S3	S1 OR S2	25927
S4	(MH "Self Care+")	34818
S5	TI (care, self or self care or or self-care or self-management or disease management or patient-centred care or patient centred care or patient-centered or patient centered or self monitor* or self-monitor* or self-efficacy or self efficacy or self-regulat* or self regulat* or patient orient* monitor* or patient-orient* monitor* or health educat* or health promot* or patient educat*) OR AB (care, self or self care or or self-care or self-management or disease management or patient-centred care or patient centred care or patient-centered or patient centered or self monitor* or self-monitor* or self-efficacy or self efficacy or self-regulat* or self regulat* or patient orient* monitor* or patient-orient* monitor* or health educat* or health promot* or patient educat*)	217,342
S6	(MH "Adaptation, Psychological+")	25,552
S7	(MH "Psychoeducation")	2,066
S8	(MH "Behavioral Changes")	7,345
S9	(MH "Health Behavior+")	70,654
S10	(MH "Peer Group") OR (MH "Support Groups+")	16,890
S11	(MH "Patient Education+")	62,454
S12	TI (psychosocial intervention* or psycho-educational intervention* or behavioral intervention* or health behavior* or support or peer support*) OR AB (psychosocial intervention* or psycho-educational intervention* or behavioral intervention* or health behavior* or support or peer support*)	223,599

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S13	S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12	531,208
S14	S3 AND S13	4239
S15	TI dialysis or hemodialysis or haemodialysis	12802
S16	S14 NOT S15	3363

Web of Science
Dates: 2006-2016
Limited document types to Meeting Abstract, Meeting Summary
October 23, 2016 at 3:30 pm

#	Searches	Results
1	TS=(chronic kidney failure or chronic renal failure or kidney failure, chronic or renal failure, chronic or failure, chronic kidney or failure, chronic renal or chronic kidney disease* or chronic kidney insufficienc* or chronic renal disease* or chronic renal insufficienc* or disease*, chronic kidney or disease*, chronic renal or kidney disease*, chronic or kidney insufficienc*, chronic or renal disease*, chronic or renal insufficienc*, chronic or Predialysis or CKD) NOT TI=(dialysis or hemodialysis or haemodialysis)	5704
2	TS=(care, self or self care or or self-care or self-management or disease management or patient-centred care or patient centred care or patient-centered or patient centered or self monitor* or self-monitor* or self-efficacy or self efficacy or self-regulat* or self regulat* or patient orient* monitor* or patient-orient* monitor* or health educat* or health promot* or patient educat* or psychosocial intervention* or psycho-educational intervention* or behavioral intervention* or health behavior* or support or peer support*) NOT TI=(dialysis or hemodialysis or haemodialysis)	35005
4	#2 AND #1	182

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Table S2. Search strategies used to search Canadian Agency for Drugs and Technology (CADTH) databases

Grey Literature – Google Canada **Limited to first 10 webpages in Google for each search strategy** **October 02, 2016 at 2:30 pm**	
Search Terms	
1	"Chronic kidney disease-transplant self-management"
2	"Self-management in chronic kidney disease" (Google suggestion)
3	"self-efficacy and self-management behaviors in patients with chronic kidney disease" (Google suggestion)
Total hits: 110	
Articles/abstracts/theses/trials: 58	
Other (websites, reports, documents, etc.): 52	
Grey Literature – Google Canada **Limited to first 10 webpages in Google for each search strategy** **October 21, 2016 at 1:30 pm**	
Search Terms	
1	"chronic kidney disease" and "psychological" or "psychosocial" or "psycho-educational" interventions and "Self-management in chronic kidney disease"
2	"psychological effects of dialysis" (Google suggestion) – NOT RELAVENT
3	"chronic kidney disease" and "behavioral intervention" or "health behaviors"
Total hits: 29	
Articles/abstracts/theses/trials: 18	
Other (websites, reports, documents, etc.): 11	
Grey Literature – CADTH Grey Matters **Databases: HTA agencies, Clinical trials, Databases (free), Other** **October 03, 2016 at 9:30 am**	
Search Terms	
1	"Chronic kidney disease self-management"
2	"Chronic kidney disease"
Total hits:	
HTA Agencies: 28 databases	
Clinical Trials: 4 databases	
Databases (free): 4 databases	
Other: 1 database	

***Note:** No search in CADTH Grey Matters for "psychological" or "psychosocial" or "psycho-educational interventions" or "behavioral intervention" or "health behaviors" since "chronic kidney disease" was the main concept and thus would include all concepts related to any type of intervention.

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PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	5
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	7
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	N/A
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	8
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	8
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Tables S1, S2
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	8
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	9
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	9
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	N/A
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	N/A

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PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Figure 1
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Table 1, 2, 3, 4, 5
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	N/A
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	37
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	39
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	40
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	41

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

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