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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 chronic kidney disease (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). Randomised 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 behaviours, cognitions, physiological measures, symptoms, health status and healthcare.

Results Fifty studies (19 RCTs, 7 quasi-experimental, 5 observational, 13 pre-post intervention, 1 mixed method 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 (ie, changes in general CKD knowledge, perceived self-management and motivation) were 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.

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 behavioural change theory to inform their development. This work highlights the need to involve patients to co-developed and evaluate a self-management intervention based on sound theories and clinical evidence.

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 were 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, with 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 synthesise the data. To address this challenge the two reviewers used two standardised tools to independently extract data and independently coded the outcomes into categories using the revised 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 behaviour, physiological and health status.
- ► We were unable to draw conclusions regarding the most effective self-management intervention for adult patients with chronic kidney disease, keeping in mind that our aim was to review the breadth of the current literature and present the gaps that exist.

INTRODUCTION

Chronic kidney disease (CKD) is associated with adverse health outcomes, poor quality of life and high healthcare 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

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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]

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 (eg, study type, patient population) and unclear reporting strategies (ie, 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 comorbidities associated with CKD, physiological and non-physiological outcomes and application of any behavioural change theories are often lacking. Self-management interventions need to be tailored to suit diverse patient needs and preferences as well as the local healthcare context.[7] Therefore, investigating the 'who', 'what' and the 'how' of self-management interventions is crucial. We used recognised 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 summarises 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).

MATERIALS AND METHODS

We used a scoping review methodology to enable us to incorporate a broad range of studies and to summarise 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, summarised and reported the results (5) and 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 categorising 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).

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 to 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 USA) and Clinical Trials databases (Biomed Central—ISRCTN Registry, US National Institutes of Health, ClinicalTrials.gov) during October 2016 with no language restrictions (online supplementary table 1). Our search strategy for grey literature was guided by the specific database (ie,

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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 (online supplementary table 2). 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 and so on) 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 (ie, 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 summarising the data

We developed a data extraction form based on the Template for Intervention Description and Replication (TIDieR) checklist.[19] This checklist provides a template to structure accounts of an intervention (eg, 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 Organisation of Care (EPOC) data collection form[20] to ensure we were comprehensive in extracting relevant study characteristics as outlined by Cochrane EPOC group. Study characteristics (eg, study design, country of origin, publication year), population characteristics (eg, CKD stage, comorbidities) and self-management intervention characteristics (eg, topics, format, target audience, providers, location, dose, duration and so on) were documented. For the study outcomes, the two reviewers (BK and MD) independently coded each outcome into categories identified by Grey *et al* (eg, behaviours, cognitions, physiological measures, symptoms, health status, healthcare 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 were categorised and reported descriptively (ie, 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 (eg, 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.

The most common study designs were randomised 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 USA (20%), UK (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 summarises the characteristics of the self-management interventions. Five studies reported the same self-management intervention;[21–25] therefore, 45 interventions were summarised. The most common intervention topic was diet/nutrition (64%) and the least common topics were symptom management and lifestyle (13% and 11%, respectively). The most frequent modes of delivering the intervention were face to face (80%), multiple (ie, 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

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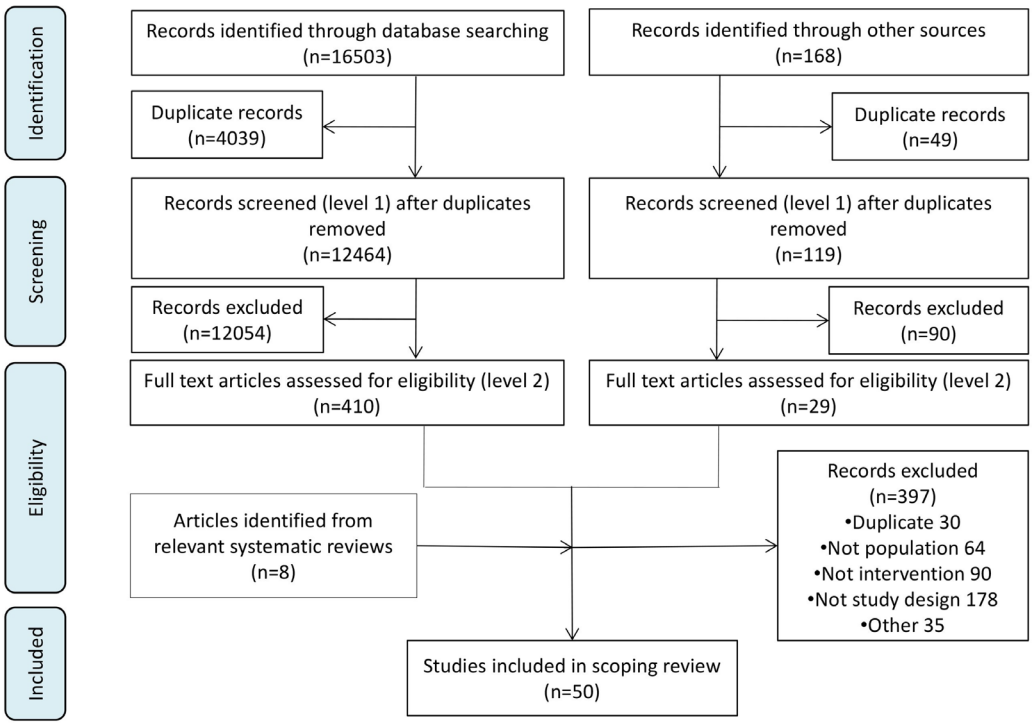

Figure 1 Prisma flow diagram.

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 behaviour change, social cognitive theory and chronic care model.[26–30] Less than 1% of the studies involved patients in the design of the intervention, where patients were interviewed regarding intervention content.[26 31–33]

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 (ie, laboratory tests, body composition and so on). The least common outcomes reported by studies were health status and healthcare (each 10%) and symptoms (ie, fatigue) (4%). Table 4 summarises the details of the quantitative studies. We categorised the overall study results descriptively as improved, unchanged or worse. Many studies had more than one outcome measure (eg, 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 behaviours, 8 were individual outcomes, 5 were health status, 4 were healthcare, 4 were intervention specific and 1 was symptom management.

Description of qualitative study outcomes and results

Table 5 summaries the findings from six qualitative studies that explored patient perspectives, one of these being a mixed methods study. All studies used semistructured 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 (eg, intervention topics, delivery mode and providers of the intervention), it was difficult to summarise findings into meaningful categories. Overall, patients highlighted that interventions needed to be individualised and tailored to their specific situations and preferences (eg, awareness of having CKD, stage of CKD, knowledge of the disease, access to resources and so on).

DISCUSSION

To our knowledge, this is the first scoping review involving patients as research partners to identify and summarise self-management interventions for adults with CKD. The scoping review methodology enabled us to systematically summarise 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 (ie, some improved and/or some worsened and/or some did not

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Table 1 Characteristics of the studies included in scoping review

Characteristic	Studies (n=50)
Study design	
Randomised controlled trial	19
Pre-post test	13
Quasi-experimental (controlled/non-random)	7
Observational	5
Qualitative	5
Mixed methods	1
Origin of study	
USA	10
UK	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

change). We found that self-management interventions for CKD is an emerging area with most studies published within the last 5 years which 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 has not been theoretically driven and they have been predominately designed by healthcare professionals without input from patients.[13 14] Person-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.[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

Table 2 Overall characteristics of self-management interventions

Variable	Intervention count (n=45)
Intervention topics	
Diet/nutrition	29
General CKD knowledge	18
Other (ie, 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 (ie, group, one-on-one)	36
Multiple modes	32
Print	29
Distance (ie, telephone, email)	13
Digital (ie, DVD, PowerPoint, audio recording)	8
Electronic (ie, 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

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Table 2 Continued

Variable	Intervention count (n=45)
Dutch	2
Cantonese	1
French	1
Greek	1
Italian	1
Japanese	1
Swedish	1
Vietnamese	1
Intervention development	
Use of framework or theory	9
Codesigned 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".
CKD, chronic kidney disease.

obtain patient perspectives, along with incorporating a behaviour 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[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 (ie, 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 comorbidities.[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 healthcare cost-effectiveness, healthcare utilisation and access, each measuring different end-points with mixed results. Future self-management interventions should include the essential principles to self-management (eg, accessing relevant health information, adhering to multiple treatment

Table 3 Summary of quantitative study outcomes*

Common outcomes	Description	Number of studies	Number of studies in which outcome improved
Physiological 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
Behaviours	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
Healthcare	Measurements of cost effectiveness, healthcare utilisation and access	5	4
Health status	Measurements of morbidity and mortality (ie, time to dialysis, survival, all-cause mortality)	5	5
Symptoms	Changes in overall symptoms (ie, 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 and 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 *et al* (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 min) *Duration*—one session *Comparator:* standard care	Health status: ▶ Duration between session and dialysis initiation—*patient in E group survived 4.6 months longer w/o requiring RRT*	
Gillis *et al* (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 modelling strategies—*decreased over time in E group* Individual outcomes: ▶ Top rated interventions by patients—*counselling, self-monitoring, protein counter*	
Devins *et al* (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 personalised for each patient ▶ Supportive (10 min max) phone calls Q3 weeks *Duration*—18 months or initiation of RRT *Comparator:* standard care	Health status: ▶ Time to dialysis—*E group had 3 month delay in dialysis compared with C group*	
Devins *et al* (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 predialysis and after dialysis initiation—*significantly longer in the E group (2.25 years and 8 months, respectively)*	
Campbell *et al* (2008)[38]	RCT	CKD 4–5	47 (E=24, C=23) Age: 68.5–72.6	▶ Diet/nutrition ▶ Other (ie, self-management principles)	Dietician	▶ Face to face ▶ Telephone	'Individual nutritional counselling': ▶ 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 V.1.3 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 *et al* (2011)[26]	RCT	CKD 1–4+HTN	81 (E=40, C=41) Age: 62.8–65.4	▶ Comorbidities (ie, 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*	

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Table 4 Continued

Study and year (Reference)	Design	Target population	Study size Age (years)	Intervention topic(s)	Provider(s)	Delivery format	Description of intervention	Study outcomes	Study results
Chen *et al* (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 hospitalisations in 1 year of follow-up—*less in E group*	
Flesher *et al* (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 sessions over 4 weeks) plus one shopping tour led by a dietician ▶ CKD cookbook ▶ 12-week exercise programme (3 × 1 hour sessions/week) led by a certified exercise physiologist and 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* Behaviours: ▶ SM score—*some changes in some components in both groups*	
Joboshi *et al* (2012)[41]	RCT	CKD	31 (E=19, C=12) Age: 69.8	▶ Other	Nurse	▶ Face to face ▶ Telephone ▶ Email	'EASE (encourage autonomous self-enrichment) programme': ▶ 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 Behaviours: ▶ Medication adherence ▶ Adherence to BP and weight measurements ▶ Limiting salt intake ▶ Alcohol consumption ▶ Smoking Physiological measures: ▶ BP	
Williams *et al* (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 × 3 months ▶ 20 min DVD ▶ Q2 week motivational interviewing follow-up via phone × 12 weeks to support BP management and optimise medication SM *Duration:* 12 weeks *Comparator*: standard care	Physiological measures: ▶ BP—*no difference between groups* Behaviours: ▶ Medication adherence—no difference between groups	

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Table 4 Continued

Study and year (Reference)	Design	Target population	Study size Age (years)	Intervention topic(s)	Provider(s)	Delivery format	Description of intervention	Study outcomes	Study results
Williams *et al* (2012)[43]	RCT	CKD 2–4+DM+ cardiovascular disease	78 (E=40, C=38) Age: 74.31	▶ Medication ▶ Comorbidities ▶ Other (ie, 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 min) via interpreter (Greek, Italian, Vietnamese) ▶ Q2 week motivational interviewing follow-up via phone × 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* Healthcare: ▶ Health care utilization—*no difference between groups* Physiological measures: ▶ Routine clinical lab surrogate measures—*no difference* Behaviours: ▶ Medication adherence—*no difference* Individual outcomes: ▶ General well-being—*no difference*	
de Brito-Ashurst *et al* (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 and 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 8 mm Hg in E group* ▶ 24 hours urinary salt excretion—*decrease in E group* ▶ eGFR—*no difference between groups*	
Paes-Barreto *et al* (2013)[45]	RCT	CKD 3–5	89 (E=43, C=46) Age: 63.4	▶ Diet/nutrition	Dietician	▶ Print ▶ Face to face ▶ Telephone	'Nutrition education programme': ▶ Standard dietary counselling AND ▶ Education folder with recipes to replace salt with sodium free seasoning blends ▶ Individual 15–20 min 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	Behaviours: ▶ 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 *et al* (2014)[46]	RCT	CKD 3	436 (E=215, C=221) Age: 72.1	▶ General CKD knowledge ▶ Comorbidities ▶ Other (ie, 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 and 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*	

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Table 4 Continued

Study and year (Reference)	Design	Target population	Study size Age (years)	Intervention topic(s)	Provider(s)	Delivery format	Description of intervention	Study outcomes	Study results
McManus *et al* (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 12 months—*no difference* Healthcare: ▶ Prescription of antihypertensive 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 *et al* (2014)[48]	RCT	CKD3+HTN+ African-American	15 Age: 58.7	▶ Other (ie, meditation)	Principle investigator, patient	▶ Face to face ▶ Audio recording	'Mindfulness meditation (MM)' ▶ 14 min of prerecorded guided MM using MP3 player and headphones *Duration*: one session *Comparator*: BP education	Physiological measures: ▶ BP—*decrease in SBP/ DBP/ HR/ MAP* ▶ Muscle sympathetic nerve activity—*decreased*	
Howden *et al* (2015)[49]	RCT	CKD 3–4 and >1 uncontrolled cardiovascular 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 hypoglycaemia ▶ Exercise prescription individualised on patient's comorbid conditions ▶ Goal=150 min/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 *Duration:* 12 months *Comparator:* standard care	Physiological measures: ▶ METS—*improved* ▶ 6 min walk distance—*improved* ▶ BMI—*improved*	
Leehey *et al* (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 programme': ▶ Dietary counselling=baseline nutritional counselling with nine follow-up phone calls (both groups) AND ▶ Supervised exercise programme 3× week (60 min cardio plus 25–30 min resistance training) ▶ Followed by home exercise phase: 3×/week × 60 min with weekly follow-up phone calls and patient encouraged to meet trainer Q1 month *Duration:* 12 months *Comparator:* diet counselling 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*	

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Table 4 Continued

Study and year (Reference)	Design	Target population	Study size Age (years)	Intervention topic(s)	Provider(s)	Delivery format	Description of intervention	Study outcomes	Study results
Montoya *et al* (2016)[30]	RCT	CKD 4	30 (E=16, C=14) Age: 67.9–68.3	▶ General CKD knowledge ▶ Diet/nutrition ▶ Medication ▶ Modalities ▶ Other (ie, 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) ▶ Three visits done in conjunction with nephrologist's examinations (first half=apt, second half=education) ▶ three visits=education only ▶ Interactive discussion at each visit ▶ Slide presentation (30–45 min) *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									
Robinson *et al* (1988)[51]	Obs	CKD	25 Age: NR	▶ General CKD knowledge ▶ Diet/nutrition ▶ Medication ▶ Other (ie, 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 *et al* (1998)[52]	QE	CKD 4–5	56 (E=28, C=28) Age: 54–58	▶ General CKD knowledge ▶ Diet/nutrition ▶ Physical activity ▶ Modalities ▶ Other (ie, psychosocial—impact of CKD on economy, family and social life)	Nurse, physician, social worker, dietician, physiotherapist	▶ 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:* four sessions *Comparator:* standard care	Individual outcomes: ▶ Functional and emotional well-being—*better in E group**	
Cupisiti *et al* (2002)[53]	PP	CKD 3b-5	20 Age: NR	▶ Diet/nutrition	NR	▶ Print	'Vegetarian diet': ▶ Alternate between animal based conventional low protein diet and a vegetable-based low-protein diet ▶ Booklets explaining general guidelines and 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* ▶ Haematocrit—*no change* ▶ Urinary protein excretion—*decreased* ▶ Urinary urea excretion—decreased ▶ Body weight—*no change*	

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Table 4 Continued

Study and year (Reference)	Design	Target population	Study size Age (years)	Intervention topic(s)	Provider(s)	Delivery format	Description of intervention	Study outcomes	Study results
Gutiérrez Vilaplana *et al* (2007)[57]	PP	CKD	24 Age: 64.5	▶ General CKD knowledge ▶ Diet/nutrition ▶ Modalities ▶ Other	Nurse, patient volunteers	▶ Print ▶ Face to face ▶ PowerPoint slides	'Education Intervention' ▶ Eight 2-hour classes ▶ Didactic and discussion *Duration*: 6 months *Comparator*: none	Cognitions: ▶ Improvement in knowledge of CKD Behaviours: ▶ Modified lifestyle, diet Intervention specific: ▶ Reduction of stress, fear ▶ Improvement in therapeutic relationships with healthcare providers, companions and multi- disciplinary team.	
Pagels *et al* (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 *et al* (2008)[56]	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*	
Gutiérrez-Vilaplana *et al* (2009)[54]	PP	CKD 4–5	41 Age: 60.56	▶ General CKD knowledge ▶ Diet/nutrition ▶ Physical activity ▶ Modalities ▶ Other (ie, psychosocial—impact of CKD family, finances, social life)	Nurse, physician, technician, three 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 *et al* (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 predialysis education (MPE)': ▶ Individual lectures, content-based on CKD stage ▶ Dietary counselling 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* Healthcare: ▶ Hospitalisation—*2.8% E group versus 16.4% in C group*	

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Table 4 Continued

Study and year (Reference)	Design	Target population	Study size Age (years)	Intervention topic(s)	Provider(s)	Delivery format	Description of intervention	Study outcomes	Study results
Wierdsma *et al* (2011)[59]	QE	CKD	54 (E=28, C=26) Age: 55–59	▶ Medication	Nurse practitioner	▶ Face to face ▶ Print	'Motivational interviewing': ▶ Counselling by nurse practitioner (in addition to care by nephrologist) using motivational interviewing ▶ Using the 'Long-Term Medication Behaviour Self-Efficacy Scale (LTMBSES)'—areas with score<5 were identified and then up to five 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 *et al* (2012)[60]	Obs	CKD	19 Age: 58	▶ General CKD knowledge ▶ Diet/nutrition ▶ Medication ▶ Symptom management ▶ Physical activity ▶ Modalities ▶ Other	Nurse, physiotherapist, dietician, pharmacist, psychologist, coordinators, nephrologist, patient mentors	▶ Face to face	'Escuela ERCA': ▶ 7 1.5 hour multidisciplinary 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	
Choi *et al* (2012)[61]	QE	CKD 1–5	61 (E=31, C=30) Age: 53.93–58.33	▶ General CKD knowledge ▶ Diet/nutrition ▶ Modalities ▶ Other (ie, understanding and compliance with SM)	Physician, nurse, dietician	▶ Face to face ▶ PowerPoint slides	'Face-to-face SM programme': ▶ 90 min lecture with slides (3–5 people/group) ▶ 20 min individual consult ▶ 1 week later individual reinforcement education and consultation *Duration:* two sessions *Comparator:* general maintenance	Cognitions: ▶ Knowledge of CKD scale—*increase>in E group* Behaviours: ▶ Self-care practice scale for patients with CKD—*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* ▶ Haemoglobin—*no change* ▶ GFR—*no change*	
Kao *et al* (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 and exercise programmes ▶ Follow-up phone calls ▶ 1x/month for patients in maintenance phase ▶ 2×/month for patients in action/prep stages ▶ 4×/month for patients at precontemplation/contemplation stages ▶ Goal: workout 3–5×/week × 30 min for 3 months *Duration*: 4 months *Comparator:* standard care	Behaviours: ▶ Exercise behaviour—*improved in E group* Cognitions: ▶ Depression—*score decreased (ie, improved) in E group* Symptom management: ▶ Fatigue—*score decreased in E group*	

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Table 4 Continued

Study and year (Reference)	Design	Target population	Study size Age (years)	Intervention topic(s)	Provider(s)	Delivery format	Description of intervention	Study outcomes	Study results
Diamantidis *et al* (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 prioritisation 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 min ▶ 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 *et al* (2013)[31]	PP	CKD 3–4 (diabetic nephropathy)	30 Age: 67	▶ Diet/nutrition ▶ Medications ▶ Physical activity ▶ Comorbidities ▶ Other (ie, stress management, identify supporters (family) & how they can contribute, goal setting)	Nurse	▶ Print ▶ Face to face ▶ Telephone ▶ Email	'SM skills programme': ▶ Textbook ▶ Daily journal ▶ Four 1 hour face-to-face sessions Q2 weeks at outpatient clinic or in home ▶ Two 30 min phone or email sessions Q1 month ▶ Then Q1 month phone calls *Duration:* 6 months *Comparator*: none	Individual outcomes: ▶ QOL—*self-efficacy and SM behaviours improved* Physiological measures: ▶ Renal function—*no change* ▶ Haemoglobin A1c—*decreased postintervention*	
Lin *et al* (2013)[63]	PP	CKD 1-3a	37 Age 67.42	▶ Other (ie, self-regulation/ selfmanagement topics)	Nurse	▶ Print ▶ Face to face ▶ Video	'SM programme': ▶ Self-monitoring workbook ▶ 5 week SM programme ▶ Weekly 90 min face- to-face group sessions (6–8 patients) ▶ CKD SM video about self-regulation *Duration:* 5 weeks *Comparator*: none	Cognitions: ▶ CKD self-efficacy—*increased* Behaviours: ▶ CKD SM— *no change* Physiological measures: ▶ Creatinine—*marginally significant decrease* ▶ GFR—*remained stable*	
Murali *et al* (2013)[28]	PP	CKD 4	12 Age: 68	▶ Diet/nutrition	Online tool	▶ Website	'Dietary assessment and evaluation tool': ▶ Self-administered ▶ Obtains 24 hours 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—*three worsened, three improved, six 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 *et al* (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* Behaviours: ▶ SM—*limited effectiveness*	

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Table 4 Continued

Study and year (Reference)	Design	Target population	Study size Age (years)	Intervention topic(s)	Provider(s)	Delivery format	Description of intervention	Study outcomes	Study results
Thomas and Bryar (2013)[33]	MM	Diabetic nephropathy (DM+microalbuminuria)	176 (E=116, C=60) Age: NR	▶ General CKD knowledge ▶ Comorbidities ▶ Lifestyle	NR	▶ Print ▶ DVD	'SM package': ▶ Written materials ▶ 20 min 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* ▶ Haemoglobin A1c—*no change* ▶ BMI—*no change*	
Walker *et al* (2013)[64]	PP	CKD with high risk of Progression+DM2+HTN + albuminuria	52 Age: 57.5	▶ Diet/nutrition ▶ Medication ▶ Symptom management ▶ Physical activity ▶ Other (ie, compliance)	Nurse, nurse practitioner	▶ Print ▶ Face to face	'Nurse practitioner intervention in primary care setting': ▶ SM booklet ▶ Initial assessment of lifestyle behaviours, SM practice, health/medication knowledge ▶ Individual education ▶ Individualised patient management plan given at end of 12 weeks ▶ Q2 week 30 min long assessments and review × 12 weeks *Duration:* 12 weeks *Comparator:* none	Behaviours: ▶ SM (Partners in Health (PIH) instrument)—*had change in certain domains*	
Wright Nunes *et al* (2013)[65]	QE	CKD 1–5	556 (E=155, Cohort=401) Age: 57	▶ General CKD knowledge ▶ Diet/nutrition ▶ Medication ▶ Physical activity ▶ Lifestyle ▶ Comorbidities ▶ Other (ie, compliance)	Nephrology fellows	▶ Print ▶ Face to face	'Physician-delivered education too' ▶ 1-page intervention worksheet delivered during clinic visits—take 1–2 min to administer *Duration*: one session *Comparator*: 'historical group'—who developed sheet	Cognitions: ▶ Kidney specific knowledge—*associated with increase in knowledge* Intervention specific: ▶ Feasibility of intervention—*physicians found it useful and efficient but had concern regarding some of the talking points*	
Walker *et al* (2014)[24]	PP	CKD with high risk of Progression+DM2+HTN + albuminuria	52 Age: 57.5	▶ See Walker *et al*[64]	Nurse, nurse practitioner	▶ See Walker *et al*[64]	▶ See Walker *et al*[64]	Physiological measures: ▶ Albuminuria—*improved* ▶ GFR—*no change* ▶ 5 year absolute cardiovascular risk—*improved* ▶ BP—*improved* ▶ Total cholesterol—*improved* ▶ Haemoglobin A1c—*improved* Cognitions: ▶ Knowledge of medications/ conditions *improved* Behaviours: ▶ Medication adherence, adherence to healthy lifestyle *improved*	
Enworom *et al* (2015)[66]	QE	CKD 1–4	49 (E=25, C=24) Age: 73	▶ General CKD knowledge ▶ Symptoms management ▶ Modalities ▶ Comorbidities ▶ Other (ie, advanced care planning)	Nurse practitioner, physician assistants, clinical nurse specialist	▶ Face to face	'Kidney Disease Education (KDE)' ▶ six education classes on one on one or group basis *Duration*: unclear *Comparator*: no KDE	Physiological measures: ▶ GFR decline—*slower in E group* ▶ Haemoglobin—*E group maintained more stable level compared with non-KDE group who lost 1 g/L from baseline* Cognitions: ▶ Kidney disease knowledge (KiKS survey)—*no change*	

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Table 4 Continued

Study and year (Reference)	Design	Target population	Study size Age (years)	Intervention topic(s)	Provider(s)	Delivery format	Description of intervention	Study outcomes	Study results
Vann *et al* (2015)[29]	PP	CKD 3b-4	9 Age: mean NR	▶ General CKD knowledge ▶ Diet/nutrition ▶ Symptom management ▶ Modalities ▶ Comorbidities ▶ Other (ie, self-care management strategies and behaviours)	Nurse practitioner	▶ Print ▶ Website ▶ Face to face ▶ White board	'CKD Education Programme' ▶ CKD education sessions ▶ Assessment of readiness to change ▶ CKD toolkit individualised 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 six visits *Comparator*: none	Cognitions: ▶ CKD-related knowledge—*improved* Behaviours: ▶ Self reported behaviour change—*improved*	🟢 🟢
Cupisiti *et al* (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* Healthcare: ▶ 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 die*	🟢 🟢 🟢
Ong *et al* (2016)[68]	PP	CKD 4–5	45 Age: 59.4	▶ Medications ▶ Symptom management ▶ Comorbidities ▶ Other (ie, tracking lab results)	Mobile application	▶ Smart phone application	'Smartphone based SM system' ▶ Application generated personalised patient messages based on prebuilt algorithms *Duration*: 6 months *Comparator*: none	Physiological measures: ▶ BP—*change in home BP readings* Intervention specific: ▶ Medications— *127 medication discrepancies identified*	🟢 🔵
Penaloza-Ramos *et al* (2016)[25]	Obs	HTN (BP>130/80)+CKD stage three or CVA/TIA or DM or MI or angina or CABG	NR Age: NA	▶ See McManus *et al*[47]	General practitioner, patient	▶ See McManus *et al*[47]	▶ See McManus *et al*[47]	Healthcare: ▶ Cost effective—*yes*	🟢

🔵 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).

BMI, body mass index; BP, blood pressure; C, control; CALD, culturally and linguistically diverse; CHD, coronary heart disease; CHEERS, Controlling Hypertension: Education and Empowerment Renal Study; CKD, chronic kidney disease; CVA, cerebrovascular accident; DBP, diastolic blood pressure; DM, diabetes mellitus; E, experimental; eGFR, estimated glomerular filtration rate; ESA, erthropoiesis stimulating agents; ESRD, early stage renal disease; HTN, hypertension; MM, mixed methods; NR, not reported; Obs, observational; PP, pre-post intervention; QE, quasi-experimental; QOL, quality of life; RCT, randomised controlled trial; RRT, renal replacement therapy; SBP, systolic blood pressure; SM, self-management; TIA, transient ischaemic attack.

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Table 5 Summary of qualitative studies

Study (Reference)	Target population	Number of participants	Aim/Intervention	Methods	Summary of findings
Blickem *et al*[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 *et al* [46]	Interviews and focus groups: no analytic methodology discussed	▶ Mixed reception from participants ▶ Formulation of 'health' in everyday life (ie, participants unaware of having CKD or its significance—confused about relevance of PLANS) ▶ Trajectories and tipping points (ie, engagement in PLANS depended on participants' stage of life—either could influence trying new things or disrupt routines) ▶ Trust in networks (ie, unwillingness to seek support, intrusive, others saw improved awareness/access to local resources; tailored support)
Heiden *et al* [69]	CKD predialysis, 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 three components—diet/fluid education; diet registry and phosphate binder decision support tool.	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
Jansen *et al*[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: – Group included predialysis 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

Continued

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Table 5 Continued

Study (Reference)	Target population	Number of participants	Aim/Intervention	Methods	Summary of findings
Thomas *et al*[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.' (p. 275) Intervention: see table 4 Thomas *et al*[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 behaviour—stop smoking, monitoring DM
Williams *et al*[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 *et al*[43]	Interviews: Ritchie and Spencer thematic approach	▶ Attitudes towards taking medications (ie, appreciate importance of taking; medication burden; concern with the number of medications, effectiveness and side effects of medications ▶ Having to take medications (ie, behaviours 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 (ie, lack of knowledge regarding medication; strong faith in physician's advice; multiple medications too overwhelming; cost)
Williams *et al*[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 coexisting diabetes, CKD and hypertension.' (p. 472) Intervention: see table 4 Williams *et al*[42]	Interviews: Ritchie and Spencer thematic approach	▶ Importance of health (ie, determined the degree of health behaviour; altered medications or use of complementary medicine to control health) ▶ Perceived seriousness of disease (ie, thinking about mortality; comorbidities complicate care; acute illness with chronic conditions) ▶ Perceived threat of disease (ie, want to learn about disease control earlier; symptom management; looking for reasons to explain why ill)

CKD, chronic kidney disease; DM, diabetes mellitus.

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protocols, changing health behaviours, shared decision making with healthcare providers),[7 75] along with evaluation of the cost-effectiveness and resource utilisation.

The majority of studies did not identify a single primary outcome but rather multiple outcomes. We found that physiological outcomes (ie, 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 (ie, symptoms, mobility, social and role function in the family or community) that could possibly maximise 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*[12] 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 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 synthesising the data given its heterogeneous nature. To address this challenge, the two reviewers used two standardised tools TIDieR[19] and the EPOC tool[20] to independently extract data and independently coded the outcomes into categories using the revised Self-and Family Management Framework .[6] Also, we were unable to assess the self-management outcomes in terms of sustained changes in behaviour, 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 that 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 codevelop and evaluate a self-management intervention based on a sound behavioural theory involving our national patient partners, specialists, primary care providers and decision makers.

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