

SELF-MANAGEMENT SUPPORT FOR PEOPLE WITH CHRONIC KIDNEY DISEASE: PATIENT PERSPECTIVES

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SUMMARY

Background: Self-management of chronic kidney disease (CKD) is crucial for health outcomes and people need to be effectively supported by healthcare professionals (HCPs). Some programmes designed to improve self-management have been implemented, but people with the disease are rarely consulted regarding what they desire from these programmes.

Objectives: To provide a synthesis of the literature on preferences for self-management support of people with CKD.

Design: An integrative review.

Methods: Four databases (MedLine, CINAHL, PsycARTICLES and PsycINFO) were searched using relevant search terms.

Results: The search strategy identified 1,913 records, of which 12 studies met inclusion criteria. Ten themes were identified as important areas to be addressed by self-management interventions. In addition, patient suggestions for implementation of such interventions are discussed.

Conclusion: The principles of a person-centred approach ought to frame the support provided by HCPs when supporting those with CKD to better self-manage.

KEY WORDS Chronic kidney disease • Education • Patient-centred care • Self-care • Self-management

INTRODUCTION

Chronic kidney disease (CKD) stages 1–5 affects up to 16% of adults worldwide (Jha *et al.* 2013). It is progressive and classified into stages 1–5, with stage 5 being end-stage kidney disease (ESKD) that requires renal replacement therapy (RRT). CKD takes a toll on physical and mental health, decreasing quality of life

(QoL) (Pagels *et al.* 2012). Furthermore, treatment of ESKD is a financial burden on individuals (Harwood *et al.* 2005) and health care systems (Kerr *et al.* 2012).

Self-management is the ability to manage living with chronic disease, which involves monitoring the condition, adhering to treatment and responding to maintain QoL (Barlow *et al.* 2002). In CKD, self-management involves monitoring fluid retention, managing medications and modifying diet, exercise and fluid habits (Welch *et al.* 2014). Effective self-management improves health outcomes, slows disease progression and delays RRT (e.g. Devins *et al.* 2003). However, self-management is complex and requires support (Ormandy & Hulme 2013), yet many with CKD do not recall receiving support with the daily self-management of their disease (Van Biesen *et al.* 2014). In light of this, self-management programmes (SMPs) are important, and individuals must learn skills that can be applied to self-manage their disease. SMPs for CKD have been evaluated, yet most are not theoretically driven or evidence-based, nor are they informed by patient preferences (Bonner *et al.* 2014).

Healthcare professionals (HCPs) are ideally placed to support people with CKD to self-manage, yet research suggests HCPs and patients have differing views of self-management (Griva *et al.* 2012; Sadler *et al.* 2014). HCPs often believe that, if patients know what to do, they *will* self-manage (Mirzaei *et al.* 2013;

BIO DATA

Kathryn Havas has a background in psychology, and is a current PhD candidate in the School of Nursing at the Queensland University of Technology. Her research focuses on increasing effective self-management among people with earlier stages of chronic kidney disease.



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Sadler *et al.* 2014). However, simply providing information is not sufficient for behaviour change and people may struggle to integrate this advice into their lives (Granger *et al.* 2009). HCPs may not appreciate the complexities of self-management. Some HCPs believe patients fail to prioritise self-management and this is why they are 'non-compliant' (Yen *et al.* 2011), while others believe that although self-management is 'work' it should be easy to do (Granger *et al.* 2009). In contrast, people with CKD report needing to learn to self-manage and integrate self-management into their lives (Costantini *et al.* 2008). Partnerships with HCPs and individualised support are integral to self-management (Sadler *et al.* 2014).

The goal of SMPs is to shift some responsibility for disease management from HCPs to the patient. However, differences between HCP and patient understandings of self-management indicate a mismatch between the intent behind SMPs and what patients receive. Many SMPs are prescriptive and deliver information and instructions, without taking into account patient understandings of self-management or the fact that self-management occurs in a social context (Sadler *et al.* 2014). Thomas (2014) suggests a ladder of patient-involvement, ranging from patients having no control to patients taking full control of their healthcare. Ideally, patients should share power over their healthcare with HCPs, yet research suggests HCPs employ a model in which they convey information and expect patients to follow instructions (Sadler *et al.* 2014).

The purpose of this review is to explore *what* people with CKD would like in a SMP, *how* and *when* they would like it delivered, and *by whom*. This article synthesises research in this area, which may guide future SMPs in CKD.

METHODS

An integrative review was conducted, using a systematic search strategy. Integrative reviews have great potential to inform evidence-based practice, as they allow for synthesis of findings from diverse research methodologies (Whittemore & Knaf 2005). CINAHL, MEDLINE, PsycARTICLES and PsycINFO databases were searched via EBSCOhost in May 2014 with key terms combined using Boolean operators (i.e. 'and', 'or') (see Table 1).

Initially, it was planned to include articles investigating desires for self-management support across multiple chronic diseases (chronic obstructive pulmonary disease (COPD), diabetes and heart failure (HF), in addition to CKD) and at this point, 46 articles

met inclusion criteria. The review question was further refined to include only articles addressing self-management support in people with CKD, with the former used to inform the discussion. Articles were included if they: (a) involved adults (≥ 18 years) with CKD; (b) reported patient preferences for self-management support, patient experiences of SMPs, or patient-reported successful self-management strategies and (c) were available in English. Appraisal of articles was conducted by a reviewer (KH), who read all potentially includable articles to investigate whether they met inclusion criteria. All authors agreed on the studies included. As included studies are highly heterogeneous and largely qualitative in nature, results are reported in narrative form.

RESULTS

The search retrieved 1,913 publications. A total of 12 studies met final inclusion criteria; directly or indirectly assessing desires of adults with CKD for self-management support. These studies can be seen in Table S1. Three studies were conducted in America, three in Australia, two in Canada, two in England, one in New Zealand and one in Singapore. Some studies included only participants from a distinct sub-group of people with CKD (e.g. ESKD on PD; Curtin *et al.* 2004), whereas some were open to participants with any stage of CKD (e.g. Ormandy & Hulme 2013). The purported purpose of five studies was to ascertain informational and/or educational needs of people with CKD, whereas three studies explicitly included preferences for self-management support in their stated purpose. Others claimed to focus on other topics, including stressors (Harwood *et al.* 2005), barriers and facilitators (Griva *et al.* 2012), impact of CKD treatment (Shih & Honey 2011) and motivation and confidence (Williams & Manias 2013).

The majority of studies (seven) used individual qualitative interviews only (Curtin *et al.* 2004; Harwood *et al.* 2005; Costantini *et al.* 2008; Clarkson & Robinson 2010; Shih & Honey 2011; Horigan *et al.* 2013; Williams & Manias 2013). One used focus groups only (Lopez-Vargas *et al.* 2014), one used interviews and focus groups (Griva *et al.* 2012) and one used a structured interview to create quantitative data (Lewis *et al.* 2010). Another study used interviews and a quantitative instrument, which generated both qualitative and quantitative data (Ormandy & Hulme 2013), and the final article was a review which included both qualitative and quantitative studies (Ormandy 2008).

Data analysis techniques varied, with most (five) studies using content analysis (Curtin *et al.* 2004; Harwood *et al.* 2005; Costantini *et al.* 2008; Horigan *et al.* 2013) or a mix of content

Search strings used for search of CINAHL, MEDLINE, PsycARTICLES and PsycINFO using keywords		Results
S1	topic* OR theme* OR strateg* OR subject* OR matter* OR issue* OR focus* OR question* OR knowledge OR info* OR adheren* OR complian*	7,507,548
S2	'self-management' OR 'self management' OR 'self-care' OR 'self care' OR 'patient-management' OR 'patient management' OR 'health-management' OR 'health management' OR 'disease-management' OR 'disease management'	121,695
S3	intervention OR program* OR educat* OR session OR training OR system	6,098,645
S4	'chronic kidney disease' OR CKD OR 'renal insufficiency' OR 'renal disease' OR 'end stage kidney disease' OR ESKD OR 'end stage renal disease' OR ESRD OR 'established renal failure' OR 'established kidney failure' OR diabetes OR 'heart failure' OR 'chronic obstructive pulmonary disease' OR COPD	302,405
S5	want* OR need* OR desir* OR wish* OR request* OR identif* OR important OR deem OR report OR state* OR say OR said OR tell* OR told OR feedback OR view* OR perception OR perceiv*	10,107,399
S6	S1 AND S2 AND S3 AND S4 AND S5	1,913

Table 1: Search strings used for EBSCOHOST (CINAHL, MEDLINE, PsycARTICLES and PsycINFO).

and thematic analysis (Ormandy & Hulme 2013). Three studies used thematic analysis (Griva *et al.* 2012; Williams & Manias 2013; Lopez-Vargas *et al.* 2014). In one case, it was not explicitly stated whether content or thematic analysis was used; wording suggests that it was one of the two (Clarkson & Robinson 2010). One further qualitative study used Heideggerian Hermeneutics (Shih & Honey 2011). Quantitative data were generated in two cases, and were analysed using descriptive statistics such as percentages and rankings (Lewis *et al.* 2010; Ormandy & Hulme 2013), whereas the review article used a narrative summary format (Ormandy 2008).

NATURE AND QUALITY OF THE EVIDENCE

The Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong *et al.* 2007) was used to critically appraise articles. All included studies were judged to be of average/moderate to high quality. Strengths common to multiple studies included: clear explanation of guiding framework; purposive sampling; reporting of data collection setting; and data collection to saturation. Limitations common to several studies included: not providing characteristics of interviewers/facilitators and/or their relationship with participants; not listing questions used; and not reporting length of interviews/focus groups. Further detail regarding strengths and limitations of individual studies can be seen in Table S1.

STRUCTURE OF REMAINDER OF RESULTS

From the included studies, we identified 10 self-management topics as important for people with CKD. Synthesis of included study findings in this manner provides a multi-factorial framework of CKD self-management from the patient's perspective. Table S1 displays topics identified as important to self-management in each

included article. These broad categories are discussed in terms of what successful self-managers report doing, what those who have participated in SMPs report finding helpful, and what topics patients believe deserve greater attention.

DISEASE-SPECIFIC KNOWLEDGE

Eight of the included studies identified disease-specific knowledge as an important factor in effective self-management. Many people with CKD have low levels of knowledge regarding kidneys, the disease and treatment options (Finkelstein *et al.* 2008; Griva *et al.* 2012), but wish to learn (Costantini *et al.* 2008; Ormandy & Hulme 2013), and understand that increasing their knowledge is important (Harwood *et al.* 2005; Shih & Honey 2011). One study involving people with stage 4 CKD found acquisition of disease-specific knowledge to be the most pressing desire amongst participants, with 96% of participants stating that they would want this information included in a SMP (Lewis *et al.* 2010). Knowledge desires include how kidneys work and what they do (Ormandy 2008), as well as CKD causes and renal physiology (Lopez-Vargas *et al.* 2014).

MANAGING MEDICATIONS

Knowledge about and adherence with medications are areas of importance for people with CKD, as noted in eight of the included studies. People require assistance with: integrating medication regimens into their lives, including remembering to take their medications (Costantini *et al.* 2008; Lewis *et al.* 2010; Griva *et al.* 2012; Ormandy & Hulme 2013; Williams & Manias 2013); understanding medications, including side effects (Clarkson & Robinson 2010); and understanding consequences of non-adherence (Ormandy 2008). People with CKD have concerns about medication safety, and feel frustrated when they

receive contradictory advice from different HCPs (Lopez-Vargas *et al.* 2014). Williams & Manias (2013) identify that interventions designed to increase self-efficacy and motivation to take medications as prescribed are likely to be more successful than simply setting patients clinical targets which may be perceived as unrealistic.

ENGAGING AND SUSTAINING SOCIAL SUPPORT

Self-management behaviour occurs in a social context, and seven studies discuss individuals' desire for assistance in engaging with friends, family and community groups. In CKD, family and friends provide practical and emotional support and facilitate self-management (Clarkson & Robinson 2010; Shih & Honey 2011; Griva *et al.* 2012; Williams & Manias 2013); however, some express concern about being a burden on their family (Harwood *et al.* 2005). Conversely, unsupportive family and friends are a barrier to self-management (Williams & Manias 2013). Interaction with others with CKD can also facilitate self-management in people with CKD (Griva *et al.* 2012), and those with the disease desire this interaction (Ormandy & Hulme 2013). Furthermore, successful self-managers report finding such support (e.g. support groups) essential (Ormandy 2008; Clarkson & Robinson 2010). However, people are unsure of available support and desire that SMPs include information about local, community-based resources, organisations and support groups (Lopez-Vargas *et al.* 2014).

MAINTAINING SOCIAL AND OCCUPATIONAL ROLES

Seven studies identify the importance of being able to self-manage without sacrificing roles in life. People with CKD want assistance with maintaining a 'normal' lifestyle, including sustaining relationships, hobbies, social lives and occupations (Costantini *et al.* 2008; Ormandy 2008; Ormandy & Hulme 2013; Lopez-Vargas *et al.* 2014). People also desire advice regarding how to engage in 'normal' activities like vacations (Lewis *et al.* 2010, Ormandy & Hulme 2013). Research with those on HD has found that limited social contact can be a challenge (Clarkson & Robinson 2010); however, successful PD self-managers report this form of dialysis facilitates maintenance of roles and relationships (Curtin *et al.* 2004).

MODIFYING LIFESTYLE

People with CKD must follow strict guidelines pertaining to diet and fluid consumption, and six of the included papers identified this area as an important aspect to include in SMPs. People with CKD desire clarification of sometimes confusing dietary guidelines

(Lewis *et al.* 2010; Ormandy & Hulme 2013), finding them difficult to understand (Griva *et al.* 2012). People report wanting practical dietary advice that can be implemented in daily life regarding food preparation and avoidance (Lopez-Vargas *et al.* 2014). Similarly, people with all stages of CKD report needing training in fluid self-management (Ormandy 2008; Lewis *et al.* 2010; Ormandy & Hulme 2013), and confess that they find adherence to fluid guidelines difficult (Costantini *et al.* 2008). Those in later stages of CKD express regret that they were unaware of the consequences of poor fluid and dietary control earlier (Harwood *et al.* 2005).

DEVELOPING AND SUSTAINING A POSITIVE ATTITUDE AND CARING FOR MENTAL AND PHYSICAL WELLBEING

Emotional and mental health and attitude affect self-management ability. Five of the included studies noted the importance of keeping a positive attitude, with successful CKD self-managers taking an optimistic view of their health (Harwood *et al.* 2005; Curtin *et al.* 2008) and believing that this helps them to cope and enjoy life (Lopez-Vargas *et al.* 2014). Positive belief in one's ability to self-manage is a facilitator of self-management (Curtin *et al.* 2004; Williams & Manias 2013), and this can be developed via positive reinforcement (e.g. good reports from HCPs; Williams & Manias 2013). Optimism also facilitates coping with medication regimens (Williams & Manias 2013); and those with ESKD desire help with maintaining a positive attitude (Ormandy & Hulme 2013). Recent research highlights that CKD patients often lack confidence and optimism regarding self-management abilities (Lopez-Vargas *et al.* 2014), and that SMPs should provide strategies to improve self-management confidence (Griva *et al.* 2012).

Six studies discuss the role that taking care of overall health (physical and/or mental) has in self-management behaviour. People find it important to engage in activities such as exercise, healthy eating, quitting smoking and reducing alcohol consumption in order to keep themselves as physically healthy as possible (Costantini *et al.* 2008), and report that acute illness makes self-management behaviour more difficult (Williams & Manias 2013). Participants also note the importance of taking care of their mental health, by making time for themselves (Costantini *et al.* 2008) and seeking information to allay any anxieties (Ormandy 2008) and help them to cope and adjust (Ormandy & Hulme 2013).

BUILDING AND SUSTAINING EFFECTIVE RELATIONSHIPS WITH HCPs

Six studies discuss the importance of good relationships with HCPs for people with CKD. Poor relationships and

communication with HCPs are a barrier to self-management (Harwood *et al.* 2005; Costantini *et al.* 2008; Griva *et al.* 2012; Williams & Manias 2013; Lopez-Vargas *et al.* 2014), whereas effective relationships and communication are a facilitator (Curtin *et al.* 2004). People across all stages of CKD recommend building collaborative relationships with HCPs, including not being afraid to ask questions, voice concerns, or ask for what they want based on research and/or experience (Curtin *et al.* 2004; Lopez-Vargas *et al.* 2014).

ESTABLISHING ROUTINE AND PLANNING AHEAD

Those with CKD have complex regimens, including medications, weight monitoring, and tracking fluid and food. Four of the included studies identified the importance of getting into good routines and using reminder systems (e.g. phone alarms, pill boxes) (Costantini *et al.* 2008; Williams & Manias 2013). These routines and reminders are also important in managing fatigue associated with CKD (Horigan *et al.* 2013), and successful self-managers report having such systems in place (Griva *et al.* 2012).

ACTIVELY PARTICIPATING IN HEALTHCARE

Participants in three of the included studies identify the importance of taking control and being an active participant in their healthcare. Successful CKD self-managers identify the importance of doing so, including learning to adjust their treatment based on experience and HCPs' recommendations (Curtin *et al.* 2004; Costantini *et al.* 2008; Lopez-Vargas *et al.* 2014). People with CKD recommend learning what to do and developing plans for when things go wrong through personal experience and discussion with HCPs (Costantini *et al.* 2008).

RECOGNISING AND EFFECTIVELY RESPONDING TO SYMPTOMS

Three studies note that the ability to notice symptoms, identify causes and begin treatment is essential in effective CKD self-management. A review indicated that people with CKD wish to know what causes symptoms and whether and how they can be eliminated (Ormandy 2008). Successful CKD self-managers discuss the importance of noticing symptoms and acting accordingly (Curtin *et al.* 2004; Costantini *et al.* 2008).

WHEN SHOULD SMPs BE DELIVERED?

A need for early intervention is identified in four studies. People with CKD suggest SMPs should be delivered early in the disease (Clarkson & Robinson 2010), and report disappointment that

they were not given more information soon after diagnosis (Costantini *et al.* 2008). Those with later stage CKD express regret, indicating that they would have changed their eating and fluid habits (Harwood *et al.* 2005) and better controlled their blood pressure (Williams & Manias 2013) had they realised the impact of doing so.

DISCUSSION

We identified 12 studies that directly or indirectly investigated the support that people with CKD (regardless of stage) desire to assist them to self-manage. Synthesis of this literature provides insight into important areas of training for those with CKD, and suggests a complex, multi-factorial model of self-management from the patient's perspective. People with CKD recognise self-management as a system of processes to be implemented in daily life. We have identified 10 areas that individuals find important in self-management, which contrasts with professional understandings that patients should simply follow instructions (Sadler *et al.* 2014). People with CKD desire practical assistance integrating self-management into their lives (Granger *et al.* 2009), and SMPs aim to support patients to take responsibility for disease-management. However, research suggests a mismatch between what patients' desire and what they receive. Furthermore, SMPs that have been evaluated frequently fail to take patient preferences into account, and are often not theoretically based (Bonner *et al.* 2014).

Future research should further explore CKD patient preferences for SMPs. In particular, there is almost no literature regarding how they would like SMPs to be delivered. Research involving people with other chronic diseases may provide some insight in this area. For example, people with HF report a preference for interactive, multimodal activities, such as shopping trips during which they learn to read food labels, followed by cooking classes where they learn to cook healthy food that fits with their dietary recommendations (Dickson & Riegel 2009). They also desire written, take-home materials that they can later refer to (Nahm *et al.* 2008), and people with COPD concur (Rodgers *et al.* 2007). Those with COPD have indicated their first preference for mode of delivery would be a face-to-face programme (with follow-up phone calls), and that internet would be their last preference (Carlson *et al.* 2006; Apps *et al.* 2013). Travel issues are identified by people with COPD as a potential barrier to SMP participation (Benzo *et al.* 2013), and some with HF express desire for an at-home programme (Whitty *et al.* 2012). Those with HF report learning to self-manage with experience (Dickson

& Riegel 2009), so there may be value in group-based learning. Consistent with this, patients with COPD or HF who have participated in SMPs report that group formats are useful as they provide an environment in which to interact with others with their disease and to help combat anxiety and loneliness (Rodgers *et al.* 2007; Tully *et al.* 2010; Casey *et al.* 2011; Whitty *et al.* 2012). People with HF or COPD report that SMPs they have participated in should have been longer than six (Rodgers *et al.* 2007) or eight (Benzo *et al.* 2013) weeks. Those with HF, diabetes or COPD also report that they would like the option to bring a friend or family member along to a SMP with them (Rodgers *et al.* 2007; Mirzaei *et al.* 2013).

Research involving those with COPD indicates that people who are working desire evening sessions, while those who are not working would prefer daytime sessions (Rodgers *et al.* 2007), and that they would prefer to receive self-management support from somebody other than a GP, who was going to see them multiple times and get to know them (Tully *et al.* 2010; Apps *et al.* 2013).

Future research may also further explore the model of self-management from the patient's perspective developed here (10 main important aspects discussed above), by assessing how important people with CKD deem these aspects of self-management to be, as well as whether there are further aspects that should be considered. It is important to collaborate with patients in order to gain insight into what they deem to be the most important areas for future research. This research, in conjunction with the literature discussed here and literature on behaviour changing theories, can be used to help to guide the delivery and evaluation of SMPs. Rigorous intervention studies are required, to determine the utility and efficacy of person-centred SMPs designed to promote CKD self-management. This research will provide an evidence-base for the provision of person-centred care in clinical practice.

IMPLICATIONS FOR PRACTICE

There is a divide between HCPs and patients regarding conceptualisation of chronic disease self-management (Lake & Staiger 2010). In order for individuals with CKD to effectively self-manage, they require support above and beyond information and instructions (Sadler *et al.* 2014), and need to share power over their treatment (Thomas 2014). It has been suggested that HCPs need extra training to develop skills in effective health

communication in order to build collaborative partnerships with patients, thereby acknowledging patients' roles in their health-care (Lawn *et al.* 2009). Indeed, many HCPs do not receive any formal training in delivering self-management support (Lake & Staiger 2010). The gap between patients' needs and HCPs' understandings can begin to close with knowledge of what those with CKD desire for self-management support and by having appropriately trained HCPs provide this support.

CONCLUSION

People with CKD require practical, individualised support that helps them integrate self-management into their lives. This requires person-centred care, where HCPs take into account individuals' circumstances and encourage them to share responsibility for their treatment (Thomas *et al.* 2008). Those with CKD are seldom consulted regarding the self-management support they desire or how they would like to receive this support. Findings from research involving participants with other chronic diseases provide insight into potential areas of importance for future CKD research (e.g. how they would like to receive self-management support and whether they identify additional topics as important). This research will be important in development of effective, person-centred SMPs.

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CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

KH: Conceived study, conducted literature search and identified articles for inclusion, drafted manuscript. AB: Assisted with study conception and design, approved included articles, helped to draft and revise manuscript, read and approved the final manuscript. CD: Assisted with study conception and design, approved included articles, helped to draft and revise manuscript, read and approved the final manuscript.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article at the publisher's web-site.

Table S1. Summary of included studies (n = 12).