

Engaging people with chronic kidney disease in their own care an integrative review

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Abstract *The treatment of chronic kidney disease (CKD) places a major burden on patients and their families. Interventions such as nutritional management, medication regimen, and renal replacement therapies require active patient participation. An integrative literature review was carried out to identify articles on the engagement and participation of people with CKD in their care. The Medical Subject Headings (MeSH) “Kidney Failure, Chronic”, “Self Care”, and “Patient Participation” were used to conduct a search on the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), the U.S. National Library of Medicine® (Medline/PubMed), Biblioteca Virtual em Saúde (Bireme). A total of 21 articles published between 2012 and 2016 were selected. The most commonly used data collection and analysis techniques were semi-structured interviews and phenomenological thematic analysis, respectively. The articles were categorized into the following thematic groups: illness management and treatment; involvement in the decision-making process; advanced care plan; and home peritoneal dialysis. We found that there is a lack of qualitative research in certain areas, namely kidney transplant recipients and people with initial stages of CKD. People with CKD should be encouraged to actively engage in their own care, which in turn requires the knowledge, motivation and support of health professionals.*

Key words *Chronic renal disease, Self-care, Patient participation*

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Introduction

Complex chronic diseases such as chronic kidney disease (CKD) are a global public health problem^{1,2}. Health system responses to this problem are based on care models that emphasize behavioral change, the adoption of healthy lifestyles, and adherence to treatment regimens³⁻⁴. Overloading patients and carers with guidelines pertaining to the disease is a concern that has driven considerable research in this area⁵.

CKD requires dietary restrictions, polypharmacy, and specialized care during both the initial stages and renal replacement therapy (hemodialysis, peritoneal dialysis, and kidney transplantation)⁴. As the disease develops, patients experience a decline in their overall health status, including their physical and psychosocial functions⁶.

Individual behavior has a major influence on the success of therapy and achieving care plan goals. Various factors influence adherence to treatment, including motivation, information, and social and family support. In this respect, the support provided by health professionals and healthcare services plays a critical role in improving knowledge, the adoption of adaptive coping strategies, and building self-confidence⁶⁻⁷.

Psychometric instruments designed to measure, among other things, self-efficacy, engagement, motivation, adherence, knowledge, and patient activation⁸⁻⁹ can further our understanding of the interconnections between the above factors and how they influence the provision of adequate treatment.

Qualitative research approaches allow researchers to gain valuable insight into the perceptions of people living with kidney disease to support strategies to increase patient activation.

In view of the above, the guiding question of this study was: what are the most common features of qualitative studies on the engagement and participation of patients with CKD in their own care?

Given the importance of patient-centered care¹⁰, where the effective participation of patients in decision-making about their care is a key element of high-quality care, we conducted a literature study of qualitative research addressing the engagement and participation of people with CKD in their treatment.

Methods

A integrative literature review was conducted consisting of the following stages: formulation of the guiding question; definition of inclusion and exclusion criteria for the literature search; definition of the information to be extracted from the selected studies; analysis of the selected studies; interpretation of results, and presentation of the review¹¹.

The Medical Subject Headings (MeSH) “Kidney Failure, Chronic”, “Self Care”, and “Patient Participation” were used to conduct a search on the following databases in February 2017: Cumulative Index to Nursing and Allied Health Literature (CINAHL), the U.S. National Library of Medicine® (MEDLINE/PubMed), *Biblioteca Virtual em Saúde* (BIREME). A total of 2,647 references were found, of which 28 met the inclusion criteria after reading the titles and abstracts.

The following inclusion criteria were used for the selection of articles for the final sample: primary studies using a qualitative research design published between January 2012 and December 2016 involving participants with CKD in any one of its stages; full version of the article available electronically in English, Portuguese, or Spanish; articles addressing aspects directly related to the engagement and participation of patients in their care.

In addition to articles that did not meet the above criteria, experience reports, letters to the editor, reviews, descriptions of programs, and mixed method studies with the predominance of quantitative methods were also excluded. Seven studies were shown not to meet the inclusion criteria after reading the selected articles in their entirety, resulting in a final sample of 21 articles.

The study was restricted to qualitative studies because qualitative research has the capacity to unravel the perceptions, feelings, and experiences of people with CKD in relation to their engagement and participation in their own care. According to Minayo¹², through systematic analysis, qualitative research enables the objectification of a type of knowledge whose raw material are opinions, beliefs, values, representations, relations, and human and social actions from the intersubjective perspective of actors.

A template elaborated by the authors was used to present the selected studies including the following information: article title, year and journal, method used for data analysis, proposed objective, number and sex of the participants, data collection method, and main results. A par-

tial version of the completed template was presented at an international event¹³.

Results

The years with the largest number of articles were 2014 and 2016, each with six publications. The articles reported research conducted in four continents: Europe, America, Oceania, and Asia. The country with the largest number of studies was the United States, followed by Canada. There was a predominance of journals specializing in nephrology, with the *Journal of Clinical Nursing* accounting for the largest number of articles with four publications.

Nursing was the area that most addressed patient engagement and participation in their care. The main research settings were dialysis clinics/centers and out-patient clinics that specialize in care and treatment for kidney disorders.

Qualitative data collection methods included semi-structured interviews, used by 81% of the studies, focus groups, nonparticipant observation, and motivational interviewing. The most commonly used data analysis method was phenomenological thematic analysis.

The use of software for data organization/qualitative analysis, particularly NVivo®, was reported by eight studies, illustrating that the use of these technology resources in qualitative research is widespread.

The studies explored a diverse range of topics, which were categorized into the following thematic groups related to the engagement and participation of patients in their own care: illness management and treatment; involvement in the decision-making process; advanced care plan (ACP); and home peritoneal dialysis (HPD).

Themes explored by the research included key elements of the life of people with CKD, especially those undergoing dialysis, including thirst and weight management and management of symptoms and medication regimen, including patient participation in choosing the type of vascular access used for dialysis.

Chart 1 shows the main features of the selected articles highlighting the main findings of each study.

The main findings show the complexity of CKD and the effects of the disease on different aspects of patients' lives, including eating habits, medication use, decline in physical functions and capacity, the emergence of specific symptoms such as pain, and psychosocial limitations. These

effects require patients to develop individual adaptation and coping strategies.

Discussion

In the illness management and treatment group we included articles addressing aspects directly related to disease management and dialysis, such as symptoms, medication, renal replacement therapy (RRT), physical exercise, and adherence. The research shows that thirst and hunger management is an inherent burden that generates different emotional responses in different patients. Self-management of these symptoms consists of a combination of behavioral and cognitive elements¹⁴.

Uncomfortable symptoms reported by people undergoing chronic hemodialysis include fatigue, cramps, pruritus, and depression, while key coping mechanisms include health team support and individual self-control¹⁵.

One of the studies¹⁶ explored self-management of medication from the perspective of patients on dialysis. The findings show that the use of multiple medications and the weekly routine of three dialysis sessions are barriers to adherence to prescribed medication and carers and family members play an important role in adherence to medication regimens.

According to patients, exercising while on dialysis is considered less important than dialysis itself and requires encouragement and support from the health team and dialysis service. This perception was shown to be a barrier to intradialytic exercise¹⁶.

Only one article addressed treatment adherence among patients on hemodialysis¹⁷. The findings show that the support of the family and other patients, perception of risk, and routine nature of treatment are facilitators of adherence, while barriers include forgetfulness, time spent on treatment, limited understanding of dietary control and medication, and lack of communication. These findings reinforce some key concepts that should be incorporated into care programs for people on hemodialysis: the involvement of family members and carers, effective communication, and confidence in the support provided by health professionals.

A study³⁵ of self-care in people with chronic conditions also highlighted the influence of family, health services, and healthcare professionals on chronic illness management. The findings also show the need to develop interpersonal re-

Chart 1. Summary of the selected articles (n = 21). Brasília, 2017.

Title	Country/ Year	Data collection technique	Qualitative analysis method	Main findings
Illness management and Treatment				
The management of food cravings and thirst in hemodialysis patients: A qualitative study ¹⁴	Singapore 2016	Semi-structured interview	Thematic analysis (Braun and Clarke, 2006) NVivo® 9 software (QSR International™)	Food cravings and thirst were common in patients undergoing cognitive-behavioral therapy: nonadherence, controlled intake and substitution, self-monitoring and compensation.
Symptoms among patients receiving in-center hemodialysis: A qualitative study ¹⁵	United States 2016	Semi-structured interview / group discussion	NVivo®	Most uncomfortable symptoms: muscle cramps; fatigue, pruritus, and depression. Basic coping strategies: partnership with dialysis team and “taking control of your own self-management”.
A Qualitative study to explore patient and staff perceptions of intradialytic exercise ¹⁷	Canada 2016	Semi-structured interview	Coding using a broad-based coding scheme	Three main themes emerged: support, the role of the dialysis nurse, and norms within the unit.
Managing treatment for end-stage renal disease--a qualitative study exploring cultural perspectives on facilitators and barriers to treatment adherence ¹⁸	Singapore 2013	Semi-structured interview and focus group	Thematic analysis Nvivo®	Two themes analyzed: facilitators and barriers to treatment adherence.
Knowledge deficit of patients with stage 1-4 CKD: a focus group study ¹⁹	Australia 2016	Focus group	Thematic analysis using Hyper RESEARCH®	Six themes emerged: medical attentiveness; learning self-management; contextualizing comorbidities; prognostic uncertainty; motivation and coping mechanisms; and knowledge gaps.
Exploring motivation and confidence in taking prescribed medicines in coexisting diseases: a qualitative study ²⁰	Australia 2015	Motivational interview	Thematic analysis in the health beliefs model	Motivation and confidence were frustrated by complex prescribed medication and clinical conditions. Development of health risk coping strategies.
Dry weight from the haemodialysis patient perspective ²¹	Switzerland 2015	Semi-structured and open interviews	Manifest content analysis, Krippendorff (2004)	Four categories related to care actions: self-care control strategies; transfer of responsibility to hemodialysis team; management of physical consequences; management of social and psychological concerns.
Clinical conditions and health care demand behavior of chronic renal patients ²²	Brazil 2014	Semi-structured interview	Collective subject discourse. Software <i>Qualiquantisoft</i> ®	Delays in treatment and nonacceptance of the disease and treatment were factors that affected disease control.

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Chart 1. Summary of the selected articles (n = 21). Brasília, 2017.

Title	Country/ Year	Data collection technique	Qualitative analysis method	Main findings
The delicate balance of keeping it all together: Using social capital to manage multiple medications for patients on dialysis ¹⁶	United States 2016	Semi-structured interview	Thematic and structural analysis (Creswell J., 2009)	Patients engaged in various coping strategies, including reliance on activating social capital and/or family social support, to manage their medications and health; most respondents thought medication management services would be beneficial, but not necessarily for themselves.
A qualitative study of treatment burden among haemodialysis recipients ²³	United Kingdom 2014	Semi-structured interview	Interpretative phenomenological analysis (Osborn and Smith, 1998)	Patients have a range of beliefs about their illness and treatment consistent with the self-regulatory model of illness: identity, cause, consequences, timeline and cure.
The experience and self-management of fatigue in patients on hemodialysis ²⁴	United States 2013	In-depth interview	Manifest and latent content analysis (Hsieh & Shannon, 2005)	Four themes: the nature of fatigue, management of fatigue, consequences of fatigue, and factors associated with fatigue.
Perceptions of patient participation amongst elderly patients with end-stage renal disease in a dialysis unit ²⁵	Norway 2012	Semi-structured interview	Critical discourse analysis (Fairclough - three-dimensional conception of discourse)	Two discourses were identified: the health care team's power and dominance and the patients struggling for shared decision making
The experience of empowerment in the patient-staff encounter: the patient's perspective ²⁶	Switzerland 2012	Semi-structured interview	Inductive content analysis (Krippendorff 2004)	Comprehensive theme: creation of trust and learning through encounter. Sub-themes representing empowerment/non empowerment
Involvement in the Decision-making Process				
Development of a decision aid to inform patients' and families' renal replacement therapy selection decisions ²⁷	United States 2012	Focus group	Thematic analysis	Three themes emerged: difficulties in identifying type of treatment; complexity of information; and desire to have clear and understandable quantitative data and scientific studies.
Are you sure about your vascular access? Exploring factors influencing vascular access decisions with chronic hemodialysis patients and their nurses ²⁸	Canada 2016	Semi-structured interview	Content analysis (Bradley, Curry & Devers, 2007)	Patients' decisions regarding vascular access were influenced by observations, experiences, and dialogue in the dialysis unit.
Patients' experiences of involvement in choice of dialyses mode ²⁹	Denmark 2015	Semi-structured interview	Systematic text condensation (Malterud 2012)	Three main themes: patients are a significant part of the decision; health care professionals contribute to the experience of being involved; patients keep putting off the final choice.

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Chart 1. Summary of the selected articles (n = 21). Brasília, 2017.

Title	Country/ Year	Data collection technique	Qualitative analysis method	Main findings
Dialysis modality decision-making for older adults with chronic kidney disease ³⁰	Canada 2014	Semi-structured interview	Thematic analysis NVivo®	The following factors influence dialysis modality decision-making among older adults: older adults are often in a precarious state with limitations on modality options, personal factors, gender differences, and support needs.
Advanced Care Plan				
Advance care planning: The patient perspective ³¹	United States 2016	Semi-structured interview	Thematic analysis	Themes identified included a precipitating health care crisis, the experience of decision-making for others, and availability of advance directive information.
Advance care planning: a qualitative study of dialysis patients and families ³²	United States 2015	Semi-structured interview and nonparticipant observation.	Thematic analysis Dedoose®	Three themes emerged: prior experiences with ACP, factors that may affect perspectives on ACP, and recommendations for discussing ACP.
Home Peritoneal Dialysis				
Patients' experiences of peritoneal dialysis at home: a phenomenological approach ³³	Brazil 2012	Semi-structured interview	Thematic analysis Paul Ricoeur Hermeneutic phenomenology	Three themes emerged: facing up to the world of kidney failure and dialysis; experiencing body changes, and sources of support.
Patient and family perspectives on peritoneal dialysis at home: findings from an ethnographic study ³⁴	Kingdom 2014	Semi-structured interview and observation of the home dialysis process	Thematic analysis (Wolcott's, 1994) NVivo®	Four themes emerged: initiation, limitation, uncertainty, and freedom.

relationships with more trust and commitment between patients, family members/carers, and health professionals in order to promote autonomy and co-responsibility for care.

With respect to involvement in the decision-making process, one article suggests that in order to promote involvement in choosing the type of RRT it is necessary to simplify concepts and technical knowledge so that patients are able to make an informed decision regarding the treatment that best suits their needs²⁷. Another study²⁰ investigating decision-making regarding the type of vascular access for hemodialysis showed that people with a catheter preferred this method because, based on their prior experiences, they were afraid of making the incision necessary for forming an arteriovenous fistula,

and because they believe that this type of access is easier to manage. This perception goes against clinical recommendations for the early formation of a fistula.

According to patients, empowerment is influenced by trust, participation in decision-making, and the learning process, while lack of communication and indifference on the part of health professionals represent nonempowerment²⁶.

Structural barriers to patient empowerment should be identified so that finding mechanisms to overcome them becomes an explicit part of the process. Attention should be paid to the structural forces that affect the conditions of health and the individual's self-care skills³⁶. Supporting patients to make informed decisions regarding available care through facilitating patient engage-

ment and empowerment is the responsibility of health services.

Advanced care plans were addressed by two articles^{31,32}. In one study, patients were interviewed about their experiences with ACP and offered recommendations, including discussion of the ACP among the health team based on patients' perceptions. The second analyzed the experiences of three people who participated in the preparation of their own ACPs, highlighting implementation barriers such as beliefs and lack of family support.

Elements identified as personal barriers to the implementation of ACPs should be contextualized in a particular way by health teams that promote this care approach. The uniqueness and subjectivity of each particular situation requires a personalized approach to handling these elements, which in turn demands specific skills from the health team. In this sense, understanding the patients' vision and experiences with ACP can contribute to the improvement of this emerging approach.

In this respect, discussing this matter and the maturation of bioethical issues involved in the implementation of ACPs by health teams would appear to be an interesting first step towards developing these practices.

Finally, two studies explored peoples' experiences of home peritoneal dialysis^{33,34}, both of which revealed a common theme: coping with dependence on dialysis in the face of end-stage renal disease. However, the studies show that home dialysis meant that patients gained new knowledge and learned new practices and took on greater responsibility, leading to better self-care and self-monitoring on the one hand and anguish and feeling of dependence on family members and health professionals on the other.

By revealing patients' perceptions of this treatment, these studies help to raise the awareness of health professionals regarding the need to focus on social and emotional aspects during all stages of peritoneal dialysis. In addition to the burden of the techniques and procedures associated with this type of intervention, the factors outlined above coupled with inadequate self-care can ultimately lead to the failure of treatment.

With regard to the research method, the qualitative design made it possible to turn the experiences of people living with CKD into scientific knowledge, considering various approaches to the management of the disease. The use of this type of methodology should therefore be stim-

ulated in nephrology research, extending its application to other contexts and groups, such as those in the early stages of CKD. In this respect, we identified only one qualitative study with people with stage 1 to 4 CKD¹⁹, which highlighted the knowledge needs of patients and their sense of uncertainty about the future.

It is important to recognize that the complexities of CKD stretch beyond pathophysiology and multiprofessional treatment, involving intersubjective dimensions such as motivation and confidence, requiring health professionals to take a partnership approach to support individuals in achieving self-management.

Final considerations

The perspective of people with kidney disease is an important reference point for health service management, developing standard operational protocols, recommendations, and expert consensus. The qualitative approach adopted in this study showed itself to be effective for capturing the subjective meanings of individual and group representations of the engagement of people with CKD in their care, even in the face of cultural barriers such as low health literacy.

Qualitative research allows us to gain a more in-depth understanding of a given reality from a unique angle, furthering possibilities and strategies for promoting patient engagement and participation in their care in partnership with health services and professionals, thus enabling them to assume co-responsibility for their health and that of their peers.

Apart from outlining which qualitative research methods were used and how, this study identified research gaps and highlighted the settings in which people with kidney disease are involved or can be involved in their own care.

We also identified some areas that have yet to be explored using qualitative methods, namely kidney transplant recipients and people with initial stages of CKD with comorbidities besides diabetes or high blood pressure.

Despite the complexity of CKD treatment and the importance of engaging patients and their families in the care process, it is evident that participation is limited in practice. It is therefore necessary to overcome the barriers that prevent patient engagement in their own care, which requires the knowledge, motivation, and support of healthcare professionals

Collaborations

OAE Almeida: project conception and data analysis and interpretation. WS Santos and TMSB Rehem: data analysis and drafting and critical revision of this article. M Medeiros: critical revision of this article.

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