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Factors associated with self-care in people with advanced chronic kidney disease and their experience of care in Catalonia: an application of Leventhal's self-regulatory model

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Abstract

Background Although evidence has demonstrated the influence of perceptions of chronic kidney disease on health outcomes in patients, there are still gaps in our knowledge regarding how such perceptions manifest themselves in specific populations with advanced chronic kidney disease (ACKD). This study aims to investigate the cognitive and emotional processes of people with ACKD in relation to their illness, as well as to examine their coping strategies and experiences of care in the context of outpatient care in the southern metropolitan area of Barcelona (Spain).

Methods This is a qualitative study in which the lived experiences and perceptions of ACKD are explored based on the postulates of the Self-Regulation Model (SRM). Eleven people with ACKD were selected from primary care centres and outpatient nephrology clinics at the referral hospital. A thematic analysis of the data was carried out, identifying dominant themes related to the mental structures and coping strategies for ACKD in accordance with the concepts described in the SRM.

Findings The SRM facilitated the exploration and understanding of psychosocial factors related to ACKD, as reported by patients, as well as the diverse coping strategies they adopted. Health information about ACKD, exacerbations, and/or disease progression can trigger cognitive representations such as the perception of weakness, complex therapeutic regimens, lifestyle modifications, and loss of autonomy, along with emotional representations such as sadness and fear. These mental constructs can act as mediators that influence coping responses, facilitating adaptive strategies but also potentially acting as barriers to effective self-care in ACKD. Coping efforts were primarily directed at preventing clinical decompensation and slowing disease progression. All aspects of this process were situated within

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a healthcare institutional context characterized by limited access to health information, poor coordination between healthcare professionals, and fragmented continuity of care.

Conclusion and implications for Practice The Leventhal's self-regulatory model facilitated the understanding of the psychosocial factors associated with ACKD, as reported by patients, as well as the various coping strategies they employed. Findings highlight how individuals manage ACKD based on cognitive and emotional structures, supporting future SRM applications. Educational interventions should strengthen identity, promote coping strategies while addressing barriers, and explore emotional impacts. Additionally, healthcare strategies should enhance professional awareness, improving both health education and care continuity.

Keywords Chronic kidney disease, Advanced chronic kidney disease, Primary health care, Self-regulation model, Qualitative research

Background

Chronic kidney disease (CKD) is a global health problem, with an estimated prevalence of 9.1% in the adult population; CKD was the 12th leading cause of death in 2017 [1]. Although it represents less than 5% of all cases of CKD and advanced chronic kidney disease (ACKD), which corresponds to stages 4 and 5 of CKD [2], ACKD is associated with greater frailty, a lower quality of life [3–5], a high risk of severe complications and a need for renal replacement therapy (RRT).

The impact of the symptoms experienced by people with ACKD is comparable to that experienced by those with advanced cancer [6, 7]. Although these symptoms have been documented, their management remains suboptimal, highlighting the need to incorporate people's preferences and values to improve the quality of care [8–11], as recognised by scientific consensus [12]. For effective symptom management, it is crucial that people with ACKD and their caregivers understand the disease and the self-care strategies to be adopted and are involved in the organisation, prioritisation and evaluation of care [13].

However, low health literacy in people with ACKD [14, 15], together with additional barriers such as lower coping skills and a greater disease burden [16], complicates the process. While knowledge about the disease and its treatment is essential, it does not always effectively predict self-care behaviours [17]. Factors such as perceptions, expectations, beliefs and emotions play crucial roles in coping with the disease, highlighting the need for interventions adapted to consider these conditioning factors [18]. A deeper understanding of the factors associated with self-care behaviours in people with ACKD is highly important for improving health-related quality of life.

Leventhal's self-regulation model (SRM) provides a robust conceptual framework for exploring how cognitive and emotional representations of illness influence coping strategies, defined in this study as self-care behaviours. The model includes aspects such as identity, perceived causes, the time course, consequences, and the control and coherence of the disease [19]. Its applicability has been validated in different chronic disease populations [20], including CKD patients, revealing how perceptions of a disease mediate the relationship between disease activity and key outcomes such as quality of life, adherence to treatment and mortality [21–27].

Although there is evidence to support the influence of disease perceptions on health outcomes in people with CKD [24, 25], there are still significant gaps in knowledge, especially in specific populations. These limitations highlight the need for studies that focus on exploring how illness perceptions and coping strategies manifest themselves in this population group. This study aims to investigate the cognitive and emotional processes related to ACKD in older people, with particular emphasis on their coping strategies and care experiences in an outpatient setting. Conducted in the southern metropolitan area of Barcelona, this work seeks to provide a deeper and more contextualised understanding of how beliefs, perceptions and emotions influence self-care practices in this population. The relevance of this study lies in the potential impact of self-care on improving both quality of life and health outcomes for people with ACKD. Furthermore, its findings could lay the foundations for the design of more personalised and effective interventions tailored to the specific needs and characteristics of this population profile.

Methodology

General description

The study was conducted in an outpatient setting from 1 November 2022 to 30 April 2023. This is part of a mixed-methods exploratory study designed as a basis for the development of interventions aimed at improving the management of people with ACKD in primary care in the southern metropolitan area of Barcelona. The study was approved by the local primary care (Ethical Committee for Research on Medications of the IDIAP Jordi Gol - 22/092-P) and hospital (Research Ethics Committee of the Bellvitge University Hospital - PR292/22) ethics committees. This is a qualitative study in which the

lived experiences and perceptions of ACKD are explored, based on the postulates of the SRM [28]. COREQ recommendations were followed [29].

Study participants

The project was presented to the management of the Primary Care Centres and the Nephrology Service at Bellvitge University Hospital, which belongs to the Southern Metropolitan Area of the Catalan Health Institute. Professions in these fields were subsequently consulted to identify and recruit suitable participants who met the established selection criteria within their respective target populations.

The selected participants were patients from the primary care centres and outpatient nephrology clinics at the Bellvitge University Hospital suffering from stage 4 and 5 advanced chronic kidney disease (ACKD), including both patients receiving renal replacement therapy and patients receiving conservative treatment.

Purposive sampling was used to select participants. It was aimed at identifying individuals who shared specific characteristics and who could provide rich, relevant and diverse data in relation to the research question. The homogeneity criteria included patients with stage 4 and 5 ACKD (undergoing renal replacement therapy or conservative treatment) and advanced age (over 60 years of age), while the heterogeneity criteria included sex, the type of treatment received and the origin of patients (primary care centres or nephrology outpatient clinics). The criteria for heterogeneity regarding the participants' setting of origin (primary care or hospital care) were applied based on the premise that the type of management provided in outpatient nephrology clinics differs from that in primary care. This difference may influence the participants' experiences and, consequently, their cognitive and emotional representations as well as their coping strategies.

After selecting the participants and obtaining their consent to take part in the study, members of the research team contacted them to explain in detail the objectives and procedures of the study. Face-to-face visits were then arranged for interviews, which were carried out in the nephrology clinics or in the patients' homes, depending on their preferences.

Data collection

Data collection was carried out through individual in-depth interviews conducted by a researcher (EPO, ILG, MBS, RSC or ESA), which were recorded and subsequently transcribed. The interviews were developed for this study and were conducted in either Catalan or Spanish, depending on the interviewee's preference at the time. They were transcribed in their original language, and selected quotes were subsequently translated into the manuscript by a certified translation company. Maximum discursive variability was sought until the information was saturated. A list of topics to be covered [30] (Appendix 1) was used to explore beliefs about identity, aetiology, duration, evolution, consequences, personal control, control through treatment, illness coherence and emotional representations, in accordance with the SRM [28]. Coping strategies were also explored through self-care actions—those aimed at maintaining or improving physical, mental, and social well-being—in relation to ACKD, initially undertaken by the patients themselves and, when necessary, by caregivers or family members. In addition, the therapeutic relationship with healthcare professionals was examined over time, including perceptions of clinical recommendations, the degree of acceptance or disagreement with proposed interventions, and views on the barriers to and benefits of implementing such interventions, in order to better understand the broader care context. Field notes were used during and after the interviews. The average interview duration was 26,45 minutes. The data were anonymised by assigning them a numerical code.

Data analysis

Initially, to obtain a condensed view of the information, raw data was transformed into useful data by fragmenting texts and establishing units of semantic meaning [30]. The units of significance were then related and compared by creating topics and subtopics based on the conceptual framework of the SRM [18]. All transcript data were coded on a line-by-line basis. Initial coding and analysis were carried out by two researchers (ILG and EPO), who developed a codebook, subtopics and topics inductively and deductively based on the team's discussion of the information. The codebook was refined as necessary throughout the coding process, and the transcripts were recoded accordingly. A third researcher (VMF) was consulted in the analysis process when there were discrepancies in the interpretation of the data.

A thematic analysis of the data [30, 31] was conducted in search of patterns by performing an aggregate analysis of coded extracts and identifying dominant themes and subthemes around mental structures and coping strategies in ACKD based on the theoretical framework of the SRM [28] and elements of the experience of care [32, 33]. A combination of deductive (SRM-driven) and inductive (data-driven) approaches was used to identify and organise themes while also allowing for the identification of themes that fell outside the framework to ensure that the data were analysed comprehensively. This form of analysis helped to provide more detailed information on the elements of the model in question [30]. The transcripts were returned to the participants for correction, and no comments were made.

All transcripts were entered into the qualitative analysis software Atlas.ti Web to assist with data management and analysis. Finally, the process was verified with the researcher VMF, an expert in qualitative methodology, to ensure the rigour and credibility criteria.

Results

Characteristics of the participants

The study included 11 people with ACKD, of whom 8 were women and 3 were men. The interviews were conducted at the participants' homes (7) or at the nephrology department of the referral hospital (4). The average age of the participants was 81.4 years, with a range between 71 and 96 years.

In relation to the ACKD stage, 3 participants were in stage G4, and 8 were in stage G5. In terms of treatment, 3 participants were on noninitiated renal replacement therapy (RRT), 3 were on active RRT (including one transplant recipient), and 5 were on conservative renal therapy (CRT) (Table 1). Four themes and thirteen sub-themes were identified, some of which emerged inductively, whereas most were predefined according to the SRM. The themes were cognitive representations of ACKD, emotional representations of ACKD, coping strategies and experience of care (Table 2).

Subsequently, a synthesis of the most significant findings was carried out, organised according to Leventhal's 1992 model [34].

Themes and sub-themes

Cognitive representations of ACKD

Identity Participants associated the identity of ACKD with different symptoms, linking their diagnosis (disease label), with the occurrence of some very specific symptoms such as passing blood in the urine: "*And all of a sudden I started to urinate blood" (E03, male, 72 years old, RRT not started*

G5, hospital), or changes in urinary frequency: *"That I urinated very little" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital).* Most related the symptoms to the loss of renal function, primarily mentioning problems such as difficulty passing through urine and fluid retention: "*My ankles get swollen" (E06, female, 91 years old, CRT, G5, primary care)*, or *"the fluid builds up, I don't urinate, I don't get rid of it, and it makes my lungs and heart fill up" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital).*

ACKD was identified as a limiting disease, perceived mainly through fatigue: *"It limits you a bit, because of course you can't do anything. I get tired now. So, I can't travel ..." (E05, female, 81 years old, RTT not started, G5, hospital)* and *"Tiredness means ... at the moment I feel tired" (E04, female, 75 years old, CRT, G5, primary care).* However, some participants did not present any obvious symptoms related to the disease: "*No symptoms. I didn't feel anything, I didn't feel any pain and I didn't realise I had it" (E03, male, 72 years old, RRT not started, G5, hospital).* This lack of symptoms or difficulty associated with the disease delayed the detection of its progression in some cases: *"I hadn't detected it, I was living a normal life, I did not think it would be so bad or that it could become as serious as it has" (E11, male, 75 years old, RRT transplanted, G5, hospital).*

Furthermore, although they acknowledged their diagnosis, they revealed a limited understanding of the disease: *"I don't know, I don't understand much because as I don't know ... it's something that means you don't urinate well, you have discomfort. If you don't urinate, you must have dialysis" (E06, female, 91 years old, CRT, G5, primary care).* This lack of understanding was attributed to poor information received from health professionals: *"The truth is that I don't know much because they haven't given me names" (E06, female, 91 years old, CRT, G5, primary care).* Their recollection of when they were informed of their illness was confused because of the time that had elapsed or the lack of clear explanations: "*Years ago, but I don't remember" (E09, female, 89 years old, CRT, G4, primary care)*. Others mentioned receiving the news in critical situations, such as hospitalisations: *"I was very weak; I had to be admitted to the hospital. I'd already been told about it, but I don't remember when.* Because *I have cysts, and cysts don't hurt" (E06, female, 91 years old, CRT, G5, primary care).*

Causes Some participants alluded to the causes of their previous lifestyle, including eating habits; alcohol con-

Table 1 Characteristics of participants

Participants	Age	Gender	Treatment	Stage	Setting
E01	76	M	RRT not started	G5	Hospital*
E02	81	F	RRT	G5	Hospital*
E03	72	M	RRT not started	G5	Hospital*
E04	75	F	CRT	G5	Primary care
E05	81	F	RRT not started	G5	Hospital*
E06	91	F	CRT	G5	Primary care
E07	71	F	RRT (peritoneal dialysis)	G5	Hospital*
E08	89	F	CRT	G4	Primary care
E09	89	F	CRT	G4	Primary care
E10	96	F	CRT	G4	Primary care
E11	75	M	RRT (transplanted)	G5	Hospital*

*Hospital outpatient clinic

Table 2 Themes, sub-themes, codes and representative quotes

Theme	Sub-theme	Codes	Representative quote
Cognitive representations of ACKD	Identity	Urinary problems	*"And all of a sudden I started to urinate blood" (E03, male, 72 years old, RRT not started, G5, hospital)* *"That I urinated very little" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital)* *"I don't know, I don't understand much because as I don't know..it's something that means you don't urinate well, you have discomfort. If you don't urinate, you must have dialysis" (E06, female, 91 years old, CRT, G5, primary care)*
		Fluid retention	*"My ankles get swollen" (E06, female, 91 years old, CRT, G5, primary care)*, or *"the fluid builds up, I don't urinate, I don't get rid of it, and it makes my lungs and heart fill up" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital)*
		Limiting disease	*"It limits you a bit, because of course you can't do anything. I get tired now. So, I can't travel.." (E05, female, 81 years old, RTT not started, G5, hospital)*
		Fatigue	*"Tiredness means.. at the moment I feel tired" (E04, female, 75 years old, CRT, G5, primary care)*
		Asymptomatic	"*No symptoms. I didn't feel anything, I didn't feel any pain, I didn't realise" (E03, male, 72 years old, RRT not started, G5, hospital)* *"I hadn't detected it, I was living a normal life, I did not think it would be so bad or that it could become as serious as it has" (E11, male, 75 years old, RRT transplanted, G5, hospital)*
		Lack of diagnosis moment	*"The truth is that I don't know much because they haven't given me names" (E06, female, 91 years old, CRT, G5, primary care)* *"Years ago, but I don't remember" (E09, female, 89 years old, CRT, G4, primary care)* *"I was very weak; I had to be admitted to hospital. I'd already been told about it, but I don't remember when.* Because *I have cysts, and cysts don't hurt" (E06, female, 91 years old, CRT, G5, primary care)*
	Causes	Toxic habits Lifestyle	***"****I had a lot of meetings, a lot of meals, I drank too much" (E11, male, 75 years old, RRT transplanted, G5, hospital)* ***"****The only thing I had a bit of trouble with was smoking" (E03, male, 72 years old, RRT not started, G5, hospital)*
		Comorbidities	*"From, let's say, the sugar, which I've had since I was little" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital)*
		Medication damages kidney	*"They always tell me it was the radio therapy and the chemo that affected my kidneys" (E05, female, 81 years old, RTT not started, G5, hospital)*
		Unknown cause of disease	*"I don't know. I don't know why it happened" (E10, female, 96 years old, CRT, G4, primary care)* *"They haven't told me" (E06, female, 91 years old, CRT, G5, primary care)*
	Consequences	Need for caregiver support	*"I don't walk anymore because I just can't now" (E04, female, 75 years old, CRT, G5, primary care)* *"I was used to looking after myself, doing my own thing, and now I can't" (E09, female, 89 years old, CRT, G4, primary care)* *"Nowadays I hardly do anything, she (the carer) does everything" (E09, female, 89 years old, CRT, G4, primary care)* *"For me it's a change of life.. I stopped drinking, I stopped smoking, I stopped eating the way I used to" (E11, male, 75 years old, RRT transplanted, G5, hospital)* *"Lots of medication, lots" (E08, female, 89 years old, CRT, G4, primary care)*
		Limited mobility	*"[..] it took away my freedom, [..], the day I was there I couldn't be for example where my siblings were, or where my friends were, or go on holiday" (E11, male, 75 years old, RRT transplanted, G5, hospital)*
		Isolation due to hospitalization	*"17 days without seeing anyone" (E06, female, 91 years old, CRT, G5, primary care)*
		Illness Burden	*"For me it's a change of life.. I stopped drinking, I stopped smoking, I stopped eating the way I used to" (E11, male, 75 years old, RRT transplanted, G5, hospital)* *"Lots of medication, lots" (E08, female, 89 years old, CRT, G4, primary care)*
		Staying home for treatment	*"I have to depend on being at home to do this to myself " (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital)*
		Multiple hospital admissions	*"[..] my lungs filled with water, and every time they filled with water, I had to run (referring to going to emergency)" (E08, female, 89 years old, CRT, G4, primary care)*
		No consideration of burden	*"The kidneys for me, don't affect me much.. it hasn't caused any pain or fever" (E03, male, 72 years old, RRT not started, G5, hospital).*

Table 2 (continued)

Theme	Sub-theme	Codes	Representative quote
	Timeline	Concern about progression	*"Get used to it, and if it doesn't get any worse, then well, you just carry on" (E05, female, 81 years old, RTT not started, G5, hospital)* *"It's sure to get worse. Will [the disease] get better? I don't think I'll get better" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital)* *"I [..] wanted to have a transplant. Because from the first day I went on dialysis and I knew that this, that this was not.. this was not for me, no way. And I had faith that even though I knew I was chronically ill, even though I knew that I would get a transplant" (E11, male, 75 years old, RRT transplanted, G5, hospital).*
		No expectation of improvement	*"Forever" (E10, female, 96 years old, CRT, G4, primary care)* *"There's no solution" (E06, female, 91 years old, CRT, G5, primary care)*
	Personal control	Dietary habits	*"Well, diet is very important, isn't it? If the things in your diet are harmful to you, then don't eat them and that's it" (E02, female, 81 years old, RRT, G5, hospital)*
		Fluid restriction	*"The only thing would be the liquid, which is what I'm restricted to, water" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital)*
		Weight control	*"Weight, yes, I weight myself every day, and depending on the weight they increase the furosemide" (E10, female, 96 years old, CRT, G4, primary care)*
		Self-empowerment	*"I do believe that everyone [..] can achieve goals that they themselves believe are impossible to achieve. So, I'm sure that wanting to be cured, wanting to follow the treatments more strictly [..] does have an effect. In a word, patients can do a lot for themselves" (E11, male, 75 years old, RRT transplanted, G5, hospital).*
		Self-doubt	*"I don't think so, I don't think it has any effect" (E03, male, 72 years old, RRT not started, G5, hospital)*
	Control through treatment	Medication stabilizes	*"If I take my medication there's always a little improvement" (E09, female, 89 years old, CRT, G4, primary care)* *"Since I've been on dialysis of course I feel better, [..], my legs don't swell, [..], as I have no fluid, no pain, no discomfort or anything, it's as if I were normal" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital).*
	Coherence	Long-term condition	*"I've had it for so many years" (E01, male 76 years old, RRT not started, G5, hospital; E04, female, 75 years old, CRT, G5, primary care).*
		Emerging limitations	*"Up to now, no. Now it's starting, because of course, I get tired, [..] and that's limiting" (E05, female, 81 years old, RTT not started, G5, hospital)*
		Illness security	*"I've always lived a quiet life" (E05, female, 81 years old, RTT not started, G5, hospital)* *"Well, not for sure. I know that I could die any day" (E06, female, 91 years old, CRT, G5, primary care)*
		Chronic struggle	"*Look, it's the hardest thing I must deal with" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital*)
		Burden treatment	*"Dialysis is a burden for me, it didn't offer me quality of life. It felt like being conscripted" "I have more freedom. I can go on days out, [..], you come back to reality". "I'm sure I feel more confident, before I even thought if I died it wouldn't be a problem. We have to think that human beings need quality of life, [..], the transplant has made things better, [..] the quality of life I can have now is much better than when I was on dialysis"* (*E11, male, 75 years old, RRT transplanted, G5, hospital*)
Emotional representations of ACKD	Emotions associated with ACKD	Sadness	*"I feel sadness, more than anything else" (E06, female, 91 years old, CRT, G5, primary care)* *"I feel like crying, for no reason, I feel like crying" (E08, female, 89 years old, CRT, G4, primary care)*
		Frustration	*"I have to depend on others" (E09, female, 89 years old, CRT, G4, primary care)* *"I resent what has happened to me" (E02, female, 81 years old, RRT, G5, hospital)* *"I feel frustrated because I didn't expect, [..], being an athlete, to end up in a situation that I didn't bring on myself. The only thing, the only problem is tobacco, it's the only thing, because otherwise I've lived a normal life, I've had a varied diet. I feel frustrated because of that" (E03, male, 72 years old, RRT not started, G5, hospital).*
	Emotions associated with the evolution of ACKD	Fear	*"I didn't want to because it was scary" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital)*

Table 2 (continued)

Theme	Sub-theme	Codes	Representative quote
		Concern	*"I couldn't sleep. And one of the things that worries me is going back to hospital, [..], I'm more worried about having to go back to hospital than about the operation. I had a very bad time. The experience was horrendous. And I was afraid" (E11, male, 75 years old, RRT transplanted, G5, hospital).* *"It means that if they're going to give me dialysis right now, I'll be worthless, and that will be the end for me. Because I must stay like this without seeing my home, and if I can't be there, I can't do anything. For me, that's going to be my undoing. That's it. That's, that's what's going to happen" (E02, female, 81 years old, RRT, G5, hospital)*
Coping strategies	Adaptive coping	Resignation	*"Yes, bite the bullet, that's the expression" "I can't, and I don't and that's it" (E11, male, 75 years old, RRT transplanted, G5, hospital)* *"to fight for my life" (E01, male, 76 years old, G4)* *"Yes, I have to do it, I have no choice" (E09, female, 89 years old, CRT, G4, primary care) "Obedience, I suppose" (E04, female, 75 years old, CRT, G5, primary care)*
		Acceptance	*"I have a secretary who doesn't let me do anything, she takes care of everything" and "Because when she's the one who takes care of everything and manages everything, well, I don't have to worry" (E09, female, 89 years old, CRT, G4, primary care) "* *"If she can sort it out for me, whatever. If there's a change. No, I don't change pills, but maybe how I must take them" (E06, female, 91 years old, CRT, G5, primary care)* *"Well, to get better, not to get worse" or "I want to slow it down as much as I can" (E02, female, 81 years old, RRT, G5, hospital)* *"Well, I'm just a kind of errand boy. I understand they're good, I take them without complaining. I have it all organised" (E11, male, 75 years old, RRT transplanted, G5, hospital).*
	Barriers to self-care	Difficulty with dietary compliance	*"What I find most difficult is eating without adding salt" (E01, male 76 years old, RRT not started, G5, hospital)* *"Water is what I've found most difficult, in fact, [..], I find it difficult because I drink a lot of water" (E06, female, 91 years old, CRT, G5, primary care)* *"Healthy eating didn't do it for me; because I was thinking about the time I have left. Listen, now I eat more of less whatever I fancy, what can I say.. It's not worth it" (E04, female, 75 years old, CRT, G5, primary care)*
		Difficulty with medication management	*"Sure, he tells me this in the morning, [..], or at midday or in the evening. So, I have them here" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital)* *"I have them here, the ones they've sent me, the ones I have to take every hour. So, I take them. The ones for midday, the ones for the evening (referring to a pill dispenser) (E06, female, 91 years old, CRT, G5, primary care)* *"I can't tell you exactly because I don't know exactly what they are" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital)* *"But of course, is this one for the one kidneys? I don't know which one is for the kidneys" (E06, female, 91 years old, CRT, G5, primary care)* *"A lot of medication, lots. 15 or 16 pills. I have a whole load of pills to take" (E08, female, 89 years old, CRT, G4, primary care)* *"It's because there are so many things. Look, one treatment for one thing, another treatment for another one, [..], I don't even know what I'm taking or what I'm not taking" (E06, female, 91 years old, CRT, G5, primary care)* *"I don't do that anymore, [..], I don't follow it, I can't, I can't control it" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital).*
Experience of care	Continuity of care	Lack of follow-up	"*I see the doctor once a year. I think" (E05, female, 81 years old, RTT not started, G5, hospital)* and *"I want to request an appointment for a check-up at least once a year (referring to primary care), but there's no follow up" (E05, female, 81 years old, RTT not started, G5, hospital)* "*Before, they used to weigh you, they even checked your sugar levels, and now you don't even get to sit down" (E02, female, 81 years old, RRT, G5, hospital)*
		Lack of professionals	*"Because there are no people there now. If we're without doctors, we're without nurses" (E02, female, 81 years old, RRT, G5, hospital)*
		Fragmentation of care	*"Doctors on the one hand, nurses on the other, assistants on another, [..] they don't talk to each other" (E11, male, 75 years old, RRT transplanted, G5, hospital.* *"I think it could be organised much better, the visits, the cancellations when one thing takes precedence over another" (E11, male, 75 years old, RRT transplanted, G5, hospital.*
	Accessibility of care	Home healthcare support	*"The nurse comes [..], here she tests me (referring to her home), whenever she comes, she always checks with me to see how the fluid is going (E06, female, 91 years old, CRT, G5, primary care)*

Table 2 (continued)

Theme	Sub-theme	Codes	Representative quote
		Telephone follow-up	*"It's so difficult to talk to them, because they don't pass things on. Sometimes they don't pass the requests on to the doctor." (E06, female, 91 years old, CRT, G5, primary care)* *"it's only telephone support now" (E04, female, 75 years old, CRT, G5, primary care)*
		Professional burden	*"Very often I don't bother because I feel bad for them, because I know they have a lot of work" (E08, female, 89 years old, CRT, G4, primary care)*
		Low health literacy	*"They haven't explained anything at all. Nothing. I already know that what I have is a chronic disease" (E08, female, 89 years old, CRT, G4, primary care)* *"It came as a shock to me to think that we were already at this stage (referring to the severity of ACKD)" (E02, female, 81 years old, RRT, G5, hospital)*

sumption, *e.g., "I had many meetings, many meals, I drank too much" (E11, male, 75 years old, RRT transplanted, G5, hospital);* and smoking, *e.g., "The only thing I had trouble with smoking" (E03, male, 72 years old, RRT not started, G5, hospital),* as possible factors influencing the development of the disease. The belief that ACKD is attributable to previous harmful medical treatments, such as radiotherapy and chemotherapy, was also reported: *"They always tell me it was the radio therapy and the chemo that affected my kidneys"* (*E05, female, 81 years old, RTT not started, G5, hospital*) or previous health conditions, such as diabetes: *"from, let's say, the sugar, which I've had since I was little" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital).* Many of the participants also reported uncertainty *"I don't know. "I don't know why it happened" (E10, female, 96 years old, CRT, G4, primary care)* due to the lack of information on the subject *"They haven't told me" (E06, female, 91 years old, CRT, G5, primary care).*

Consequences One of the main consequences mentioned was deterioration in quality of life, making daily activities difficult: *"I don't walk anymore* [35] *because I just can't now" (E04, female, 75 years old, CRT, G5, primary care)*, or being able to get around independently: "*I was used to looking after myself, doing my own thing, and now I can't" (E09, female, 89 years old, CRT, G4, primary care).* Several participants highlighted their loss of independence, needing carers: *"Currently I hardly do anything, she (the carer) does everything" (E09, female, 89 years old, CRT, G4, primary care).* Frequent hospitalisations due to decompensations *"[…] my lungs filling with water, and every time they filled with water, I had to run (referring to going to emergency)" (E08, female, 89 years old, CRT, G4, primary care)* also led to isolation: "*17 days without seeing anyone" (E06, female, 91 years old, CRT, G5, primary care)*, while dialysis, whether in hospital or at home, affected her freedom: *[…] it took away my freedom, […], the day I was there I couldn't be for example where my siblings were, or where my friends were, or go on holiday" (E11, male, 75 years old, RRT transplanted, G5, hospital)* or *"I have to depend on being at home to do this to myself" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital).* Furthermore, changes in lifestyle habits, such as increased self-care, changes in diet and the use of medication, were recurring themes in the testimonies: *"For me it's a change of life …. I stopped drinking, I stopped smoking, I stopped eating the way I used to" (E11, male, 75 years old, RRT transplanted, G5, hospital)* or *"Lots of medication, lots" (E08, female, 89 years old, CRT, G4, primary care).* However, one participant did not perceive a significant impact on his daily life, as he did not associate symptoms with ACKD: *"The kidneys for me, don't affect me much … it hasn't caused any pain or fever" (E03, male, 72 years old, RRT not started, G5, hospital).*

Timeline The belief that the disease is a permanent condition featured strongly, with expressions such as 'forever' *(E10, female, 96 years old, CRT, G4, primary care)* and that one must get used to living with it "*get used to it, and if it doesn't get any worse, well, you just carry on" (E05, female, 81 years old, RTT not started, G5, hospital).* Expressions such as *"there's no solution" (E06, female, 91 years old, CRT, G5, primary care)* or *"It's sure to get worse. Will [the disease] get better? I don't think I'll get better" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, hospital)* indicated participants' perception of the limited effectiveness of available treatments and reflected their lack of expectation in terms of an improvement in their condition. However, one participant expressed a more hopeful attitude, hoping to find a solution to his situation and obtain a transplant: *"I […] wanted to have a transplant. Because from the first day I went on dialysis and I knew that this, that this was not … this was not for me, no way. In addition, I had faith that even though I knew I was chronically ill, even though I knew that I would get a transplant" (E11, male, 75 years old, RRT transplanted, G5, hospital).*

Personal control Some participants expressed the belief that self-care could help improve or stabilise the disease. Among the actions they highlighted was maintaining a proper diet: *"Well, diet is very important, isn't it? If the things in your diet are harmful to you, then don't eat them and that's it" (E02, female, 81 years old, RRT, G5, hospital)*; controlling fluid intake: "*The only thing would be the liquid, I'm restricted to water" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, Hospital)*; and control of

body weight: "*Weight, yes, I weight myself every day, and depending on the weight they increase the furosemide" (E10, female, 96 years old, CRT, G4, primary care).* Moreover, the influence of the emotional state being aware of self-care was emphasised: *"I do believe that everyone […] can achieve goals that they themselves believe are impossible to achieve. So, I'm sure that wanting to be cured, wanting to follow the treatments more strictly […] does have an effect. In other words, patients can do a lot for themselves" (E11, male, 75 years old, RRT transplanted, G5, hospital).* However, some participants expressed doubts as to whether these actions had an impact on controlling the disease: *"I don't think so, I don't think it has any effect" (E03, male, 72 years old, RRT not started, G5, Hospital).*

Control through treatment Regarding pharmacological treatment for the management of ACKD, several participants underlined the importance of adherence to treatment: "*If I take my medication, there's always a little improvement" (E09, female, 89 years old, CRT, G4, primary care).* In addition, there was a reported belief that the procedures helped to improve symptoms: *"Since I've been on dialysis of course I feel better, […], my legs don't swell, […], as I have no fluid, no pain, no discomfort or anything, it's as if I were normal" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, Hospital).*

Coherence Some participants who were receiving CRT did not consider ACKD to be a significant burden in their daily lives. They said they felt "more or less" safe because they had been living with the disease for so long: *"I've had it for so many years" (E01, male 76 years old, RRT not started, G5, hospital; E04, female, 75 years old, CRT, G5, primary care).* However, one participant began to feel the burden of the disease as symptoms such as fatigue appeared: *"Up to now, no. Now it's starting, because of course, I get tired, […] and that's limiting"*, although she said, *"I've always lived a quiet life" (E05, female, 81 years old, RTT not started, G5, hospital).* Another participant revealed insecurity: "*Well, not for sure. I know I could die any day" (E06, female, 91 years old, G5).* On the other hand, people on RRT experienced dialysis as a heavy burden. E07, a 71-year-old female, RRT (peritoneal dyalisis), G5, Hospital; said, "*Look, it's the hardest thing I must deal with, "*referring to the management of peritoneal dialysis treatment at home. *E11, male, 75 years old, RRT transplanted, G5, hospital,* commented: *"Dialysis is a burden for me; it didn't offer me quality of life. It felt like being conscripted",* and he stressed how, after the transplant, he regained his autonomy: *"I have more freedom. I can go on days out, […], you come back to reality".* He also said he felt more confident after the transplant: *"I'm sure I feel more confident, before I even thought if I died it wouldn't be a problem. We have to think that human beings need quality of life, […], the transplant has made things better, […] the quality of life I can have now is much better than when I was on dialysis".*

Emotional representations

Emotions associated with ACKD The dominant emotion in the interviews was sadness: "*I feel sadness, more than anything else" (E06, female, 91 years old, CRT, G5, primary care)* because *"I have to depend on others" (E09, female, 89 years old, CRT, G4, primary care)* for everyday things and emotional lability *"I feel like crying, for no reason, I feel like crying" (E08, female, 89 years old, CRT, G4, primary care).* Some participants revealed that they felt frustrated at being ill *"I resent what has happened to me" (E02, female, 81 years old, RRT, G5, hospital) or "I feel frustrated because I didn't expect, […], being an athlete, to end up in a situation that I didn't bring on myself. The only thing, the only problem is tobacco; it's the only thing, because otherwise I've lived a normal life, I've had a varied diet. I feel frustrated because of that" (E03, male, 72 years old, RRT not started G5, Hospital).*

Emotions associated with the evolution of ACKD Emotions related to concern about the progression of ACKD were identified. The most frequently expressed was the fear of needing to start dialysis treatments "*I didn't want to because it was scary" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, Hospital)* or having to stay in the hospital for a period *"I couldn't sleep". In addition, one of the things that worries me is going back to the hospital, […], I'm more worried about having to go back to the hospital than about the operation. I had a very bad time. The experience was horrendous. And I was afraid" (E11, male, 75 years old, RRT transplanted, G5, hospital).* One participant expressed concern about the anticipation of dialysis as a future treatment in the face of the progression of the disease. She saw it as symbolic of a death sentence directly related to the loss of autonomy*: "It means that if they're going to give me dialysis right now, I'll be worthless, and that will be the end for me. Because I must stay like this without seeing my home, if I can't be there, I can't do anything. For me, that's going to be my undoing. That's it. That's, that's what's going to happen" (E02, female, 81 years old, G5).*

Coping strategies

Adaptive coping Our study identified different self-care coping strategies adopted by people with ACKD. Some participants reported managing their daily care with the help of informal carers. One 89-year-old female mentioned having "a secretary" who took care of everything, which allowed her to forget about the details of her treatment and reduce the burden associated with the disease: *"I*

have a secretary who doesn't let me do anything, she takes care of everything" and "When she's the one who takes care of everything and manages everything, well, I don't have to worry" (E09, female, 89 years old, CRT, G4, primary care). There was also evidence of reliance on primary care nurse case managers for therapeutic decision-making *"If she can sort it out for me, whatever. If there's a change. No, I don't change pills, but maybe how I must take them" (E06, female, 91 years old, CRT, G5, primary care)*. One participant expressed signs of resignation in the face of the disease *"Yes, bite the bullet, that's the expression"* and adaptation *"I can't, and I don't and that's it" (E11, male, 75 years old, RRT transplanted, G5, hospital)* and to the reality of his new situation. For some people, the motivation *"to fight for my life" (E01, male 76 years old, RRT not started, G5, hospital)* and the desire to prevent the progression of the disease *"well, to get better, not to get worse"* or *"I want to slow it down as much as I can" (E02, female, 81 years old, RRT, G5, hospital)* acted as incentives to follow the recommendations of the professionals. Others said they had to resign themselves to comply with the treatment, *"Yes, I have to do it, I have no choice" (E09, female, 89 years old, CRT, G4, primary care)* or *"Obedience, I suppose" (E04, female, 75 years old, CRT, G5, primary care)* and *"Well, I'm just a kind of errand boy. I understand they're good, I take them without complaining. I have it all organised" (E11, male, 75 years old, RRT transplanted, G5, hospital).*

Barriers to self-care Some participants reported difficulties following dietary advice such as *"what I find most difficult is eating without adding salt" (E01, male 76 years old, RRT not started, G5, hospital)* or water restrictions such as *"water is what I've found most difficult, in fact, […], I find it difficult because I drink a lot of water" (E06, female, 91 years old, CRT, G5, primary care).* Reluctance to carry out rigorous self-management of the recommendations was mentioned *as follows: "Healthy eating didn't do it for me; because I was thinking about the time I have left. Listen, now I eat more of less whatever I fancy, what can I say … It's not worth it" (E04, female, 75 years old, CRT, G5, primary care).* In relation to medication management, although good organisation and compliance with medication was generally reported, "*Sure, he tells me this in the morning, […], or at midday or in the evening. Therefore, I have them here" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, Hospital)* or "*I have them here, the ones they've sent me, the ones I have to take every hour. So, I take them. The ones for midday, the ones for the evening (referring to a pill dispenser) (E06, female, 91 years old, CRT, G5, primary care)*. Difficulties in remembering names and purposes were mentioned *"I can't tell you exactly, because I don't know exactly what they are" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, Hospital)* or *"but of course, is this one for the one kidney? I don't know which one is for the kidneys" (E06, female, 91 years old, CRT, G5, primary care).* Polypharmacy was also reported as a barrier *"Lots of medication, lots. 15 or 16 pills. I have a whole load of pills to take" (E08, female, 89 years old, CRT, G4, primary care)* and difficulties in managing more than one recommendation: *"It's because there are so many things. Look, one treatment for one thing, another treatment for another one, […], I don't even know what I'm taking or what I'm not taking" (E06, female, 91 years old, CRT, G5, primary care).* One participant mentioned the difficulty she had in understanding and carrying out the procedures related to home dialysis on her own, *"I don't do that anymore, […], I don't follow it, I can't, I can't control it" (E07, female, 71 years old, RRT (peritoneal dialysis), G5, Hospital).*

Experience of care

Continuity of care In general, participants perceived a lack of adequate follow-up and considered the number of medical visits in primary care to be insufficient. One participant stated, *"I see the doctor once a year, I think" (E05, female, 81 years old, RTT not started, G5, hospital)*, whereas another said, *"I want to request an appointment for a check-up at least once a year (referring to primary care), but there's no follow-up" (E05, female, 81 years old, RTT not started, G5, hospital)*. A decrease in the quality of care received was also noted: *"Before, they used to weigh you, they even checked your sugar levels, and now you don't even get to sit down" (E02, female, 81 years old, RRT, G5, hospital)*, which was attributed to staff shortages at the centres: *"Because there are no people there now. If we're without doctors, we're without nurses" (E02, female, 81 years old, RRT, G5, hospital)*. Additionally, participants mentioned the fragmentation of care and the lack of communication between professionals: *"Doctors on the one hand, nurses on the other hand, assistants on another … they don't talk to each other" (E11, male, 75 years old, RRT transplanted, G5, hospital)*. There was also a call to improve the organization of the health system, particularly regarding visits: *"I think it could be organised much better—the visits, the cancellations when one thing takes precedence over another" (E11, male, 75 years old, RRT transplanted, G5, hospital).*

Accessibility of care For people requiring home care, the follow-up for ACKD was led by nurses and/or primary care nurse case managers *"the nurse comes […], here she tests me (referring to her home), whenever she comes, she always checks with me to see how the fluid is going (E06, female, 91 years old, CRT, G5, primary care).*

However, several participants described experiencing difficulties accessing primary care doctors: *"It's so*

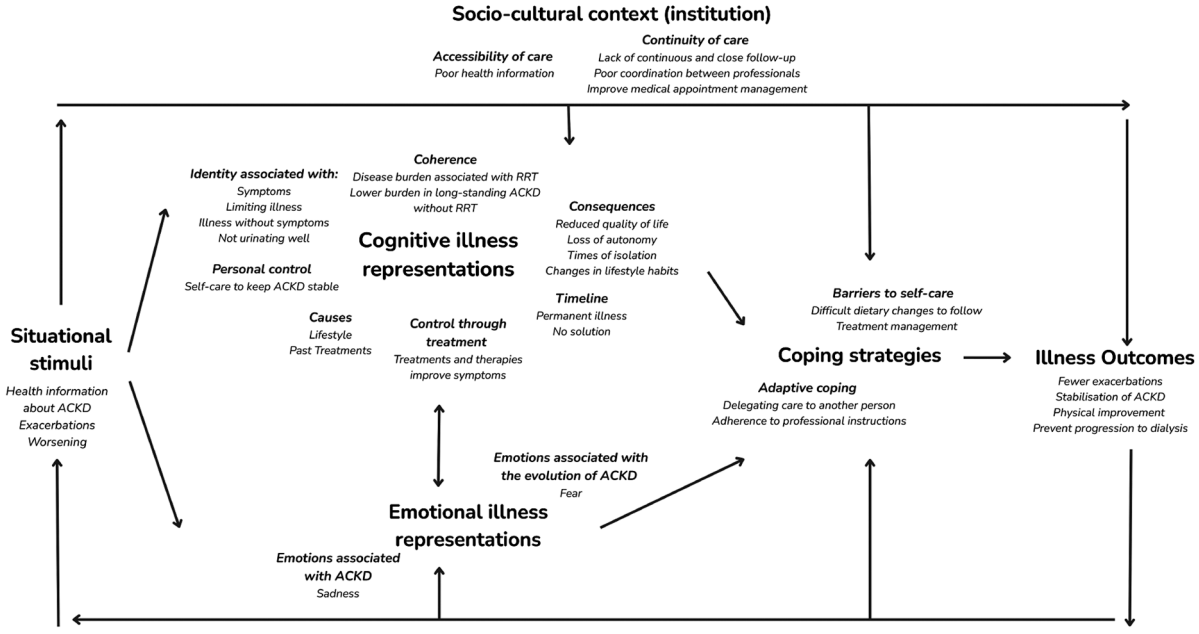

Fig. 1 Findings according to the Self-Regulatory Model in the context of ACKD. Own elaboration

difficult to talk to them, because they don't pass things on. Sometimes they don't pass the requests on to the doctor." (E06, female, 91 years old, CRT, G5, primary care). Telephone support was highlighted as the main means of communication: *"it's only telephone support now" (E04, female, 75 years old, CRT, G5, primary care).* One person said that their perception of the workload among healthcare professionals made it difficult for them to express their own needs: *"very often, I don't bother because I feel bad for them because I know they have a lot of work" (E08, female, 89 years old, CRT, G4, primary care).* It was common to report a lack of information about the disease at the initial diagnosis stage*: "They haven't explained anything at all. Nothing. I already know that what I have is a chronic disease" (E08, female, 89 years old, CRT, G4, primary care)*, and the desire for it to be treated quickly *"it came as a shock to me to think that we were already at this stage (referring to the severity of ACKD)" (E02, female, 81 years old, RRT, G5, hospital).*

Synthesis of the findings according to the self-regulatory model

This model facilitated the exploration and understanding of the psychosocial factors related to ACKD as reported by patients, as well as the various coping strategies they adopted. Given that the model posits a causal relationship between mental representations and coping strategies, the following observations were made. Health information provided about ACKD, disease-related exacerbations, and/or disease progression could act as situational stimuli and activate cognitive and emotional representations related to ACKD. According to the model's postulates, it can be interpreted that, in response to situational stimuli, individuals with CKD develop cognitive representations, such as an illness identity linked to signs, symptoms, and complex treatment regimens, lifestyle changes, and loss of autonomy, alongside related emotional representations such as sadness and fear. These mental constructs serve as mediators influencing coping strategies, leading to adaptive responses but also potentially to barriers in self-care for ACKD. The coping strategies were primarily aimed at preventing decompensations and slowing disease progression. All elements of this process were framed within an institutional context characterised by insufficient health information, lack of coordination among healthcare professionals, and discontinuity of care (Fig. 1).

Discussion

This study aimed to explore in depth the cognitive and emotional processes, coping strategies and experiences of care, all of which are factors that influence self-care in people with ACKD, using the SRM as a theoretical framework. Although the SRM has previously been used to study the coping strategies of people with ACKD [17, 22, 24–27, 36–41], we have not seen it being applied to the study of self-care behaviours in older people with ACKD treated in an outpatient setting.

Most of the sample consisted of women, owing to the fact that in the setting where our study was conducted, individuals who reach advanced stages at older ages are predominantly female [42]. Our focus was on a

population of older people with ACKD, the majority of whom were not on RRT and were receiving care in primary care and hospital outpatient settings. To this end, we investigated the dimensions proposed by the model to unravel the aspects that make up the mental representations of ACKD and condition coping strategies in this study, which are interpreted as self-care strategies.

In exploring the experience of care, we wanted to assess the institutional context (sociocultural context of the SRM) in which the study participants found themselves, understanding this as a factor that can influence self-care, in addition to the mental (cognitive and emotional) factors proposed by the model. We did this by exploring aspects of the experience of care in terms of the relationship with their ACKD referral professionals and the perceptions of their clinical recommendations.

The study participants described ACKD in terms of specific symptoms, such as the perception of tiredness as a limiting aspect of the disease. This finding is in line with the literature showing that fatigue is common in patients with ACKD and has a negative effect on their quality of life [43–45]. However, some study participants did not associate obvious symptoms with their illness. This could be explained by the fact that disease representations vary according to the stage of ACKD [46]. Moreover, no substantial differences in symptom burden were observed between individuals at different stages of the disease. This may be attributed to the fact that symptoms in ACKD are not solely determined by declining kidney function, but rather by a complex profile of comorbidities [47, 48].

In this context, we observed a tendency for patients undergoing renal replacement therapy (RRT) to perceive their disease as more burdensome compared to those receiving conservative renal therapy (CRT). This may be attributed to the type of treatment and the severity associated with each stage, which appear to significantly influence how patients interpret and experience their condition. Furthermore, although they were generally familiar with the diagnostic label of their disease, they acknowledged that they did not fully understand what it means to have ACKD. The explanation for this can be found in the literature, which indicates that 90% of people with ACKD are unaware of their diagnosis [49]. These findings could be explained by the difficulty in associating specific symptoms with the disease, especially in the absence of any pain, or by a lack of knowledge about the most common symptoms associated with their condition [26]. In our study, those participants who showed a more limited understanding of their illness also demonstrated less competence in self-managing it. This could be explained by the fact that people with less personal control and greater perceived consequences have worse clinical outcomes [24]. Furthermore, according to the SRM, the lack of full information about the nature of the disease may influence people's ability to self-regulate their health and the absence of symptoms conditions coping strategies in the face of the disease [28]. Some participants displayed uncertainty or a lack of information about the causes of ACKD, a barrier also documented in previous studies that highlights how a lack of accurate information can negatively influence the understanding and management of ACKD [50]. In fact, approximately 25% of people suffering from CKD have low health literacy [16, 51]. Low health literacy has been associated with increased mortality in people with ACKD, adverse outcomes and progression, as well as a lower glomerular filtration rate and greater incidence of associated cardiovascular disease [52, 53]. Although they were specifically asked about the recommendations received from professionals, participants did not report having a thorough knowledge of the dietary, pharmacological and physical activity recommendations contained in the guidelines for the management of ACKD [54].

Another cognitive representation worth commenting on is that of the perceived consequences of ACKD. The factors most reported by participants were dependency and isolation associated with therapies, visits to A&E and hospital admissions. This could be because the study included elderly participants without RRT who are more likely to suffer from comorbidities associated with ACKD, in line with other populations studied in Spain [55]. No relevant differences were found in the perceived consequences in patients on RRT or CRT, in line with the findings of a previous systematic review, which revealed that quality of life was similar between the two groups [56]. Furthermore, evidence supports how ACKD affects daily life, leading to physical limitations, dependence, and feelings of isolation [3, 5, 57].

Another cognitive representation studied was controllability. To explore this, we examined the degree to which the control participants had over their illness through self-care initiatives and prescribed treatments. We found that patients who reported greater controllability had previously shown greater understanding of ACKD. The literature indicates that those with greater health literacy and specific knowledge about their ACKD tend to take a more active role in their care, which improves both health outcomes and quality of life [58].

We investigated the coherence of the disease through the perception of burden and the perceived sense of security in living with the disease. Our findings highlight how the understanding and management of ACKD varies significantly depending on the stage of the disease and the treatment received. In this small qualitative sample, those who reported a greater illness burden tended to be experiencing more pronounced symptomatology and were undergoing RRT, whereas those who perceived a lower burden were generally not yet on RRT or were receiving

CRT. Although patients with ACKD treated conservatively are equally symptomatic, this could be explained by the burdens associated with RRT, such as dialysis (multiple visits to nephrology centres, infections, and vascular access problems) [56]. These observations should be interpreted with caution, given the limited sample size and the exploratory nature of the study. The participants with a long history of living with ACKD developed familiarity with the disease, which reinforced their perception of control and reduced their level of perceived threat, and they felt more confident. However, the appearance of new symptoms such as fatigue or the start of treatments such as dialysis reduced the perception of safety, highlighting the impact of functional and emotional limitations on quality of life. This finding is consistent with the SRM, which suggests that representations of the disease are constructed and adjusted on the basis of experience. Renal transplantation was considered a treatment that brought about a marked improvements in quality of life, a sense of safety and autonomy.

In terms of emotional representations of ACKD, the themes that emerged were related to feelings about the disease itself and its impact. Our study revealed that sadness, fear and frustration were the dominant emotions among participants, especially in relation to treatment dependence and loss of autonomy. These findings are consistent with previous research, which stresses that patients with ACKD experience a high level of emotional distress, which is influenced by the chronic nature of the disease and its impact on quality of life [5, 23, 24, 57, 59].

In relation to the coping strategies of people with ACKD, participants used different techniques that enabled them to better manage their condition and reduce the perceived burden of the disease. A key strategy was the delegation of treatment-related tasks to informal carers, such as family members, or to health professionals. Intrinsic motivation, such as the desire to prevent disease progression and to improve quality of life, was also highlighted as a driver for following professional recommendations. However, resignation was also observed as a strategy of acceptance of the limitations related to ACKD.

All of these strategies represented in our study are common in people with CKD and depend on personal and contextual factors [60, 61].

However, despite these strategies, participants faced barriers that made self-care difficult. Dietary restrictions, particularly the reduction of salt and fluids, were mentioned as significant challenges. In addition, polypharmacy emerged as a major barrier, not only because of the number of drugs prescribed but also because of the difficulty in remembering the specific names and purposes of each drug. The technical complexity of home dialysis was also a significant barrier, highlighting the need for greater educational and technical support to ensure adherence to and the effectiveness of the treatment.

In relation to sociocultural and socioeconomic factors, we acknowledge that in this study such aspects were explored solely at the level of the healthcare institutions with which individuals with ACKD were affiliated, without a deeper examination of broader contextual dimensions. However, we identified social aspects that were closely associated with participants' advanced age, such as the substantial presence of both formal and informal caregivers.

This circumstance may have contributed to limited health literacy regarding ACKD, as many participants had a poor understanding of their diagnosis and treatment, which may have reduced their perceived sense of control over the condition. Nevertheless, in response to this, some participants delegated self-care tasks to their caregivers, which helped mitigate some of the barriers associated with the complexity of ACKD treatment, as previously discussed. These findings suggest that socioeconomic conditions may shape the cognitive representations of ACKD, as well as the coping strategies adopted by patients. Restricted access to information or understanding of the disease could lead to diminished perceptions of control and coherence, while the presence of social support might compensate by facilitating practical coping and treatment adherence.

We looked at the experience of care to study the institutional context in which the participants found themselves when dealing with this disease. When exploring the relationship with professionals and perceptions of their recommendations, we found that there is a generalised perception of insufficient medical follow-up of people with ACKD in primary care, especially those who have outpatient follow-up in hospital nephrology services. The infrequency of appointments, noted by several participants, suggests that the primary health care system may not provide the continuity of care necessary for the effective management of ACKD. However, nurses were perceived as a frequent resource for the follow-up of people with ACKD in home care because of the continuity of comprehensive care. Their ability to conduct assessments, coordinate care, and provide education and support at home contributes significantly to improved health outcomes and patient satisfaction [62, 63]. Finally, accessibility to primary care physicians was a significant barrier, not least because of the perceived overburdening of healthcare professionals [64]. Furthermore, the difficulty in obtaining face-to-face appointments and the dependence on telephone support frustrated some participants. This situation could be related to the impact of the COVID-19 pandemic, which may have perpetuated remote care patterns.

Limitations

This study has several limitations. First, the selection of participants with ACKD was carried out through recommendations from professionals in the field, who identified individuals willing to participate in a study about their experiences with the disease. This method of recruitment may have conditioned the sample towards more socially active or engaged individuals, leaving outpatients less involved in the management of their disease or in healthcare. Second, although the analysis was conducted via an initially deductive thematic approach based on the dimensions of the SRM and then complemented inductively, there is a risk that some significant psychosocial experiences of patients with ACKD in the community setting were not picked up if they did not fit within this theoretical framework. These limitations suggest the need to explore complementary approaches and to use more diverse samples in future studies to gain a more comprehensive understanding of the experiences of this patient group.

Implications for practice

The application of the Self-Regulation Model to patients with ACKD yields clinically relevant implications for professionals in primary care and nephrology. This study contributes to the growing evidence on how older people with ACKD manage the disease based on their previous cognitive and emotional structures. Furthermore, it could serve as a basis for future applications of SRM in the community context. For example, it could guide the design of educational interventions aimed at strengthening identity, promoting coping strategies that consider the barriers identified in this study, or addressing and exploring in greater depth the emotional state associated with the impact of the disease itself. Primary care professionals should consider exploring aspects of identity more deeply to improve levels of understanding and self-management of the disease. Secondly, our study revealed that sadness, fear and frustration were the dominant emotions among the participants, especially in relation to the consequences of the disease and treatments. These emotions are considered risk factors for depression and could interfere with treatment adherence and self-care; thus, primary care professionals should look for the presence of these emotions when addressing adherence and self-care in ACKD. Finally, the most common coping strategies were the modification of eating habits and the rigorous use of medication; however, everyday tasks were the most challenging, so delegating these strategies to carers was a common strategy. Due to his experiences with the disease, the principal motivation for adherence to recommendations was to avoid disease progression and acute complications. Professionals should address these strategies more specifically, considering not only the patients but also adapting the recommendations to the primary carers to achieve greater success in the self-management of ACKD and to avoid possible complications.

Conclusions

The Leventhal's self-regulatory model facilitated the understanding of the psychosocial factors associated with ACKD, as reported by patients, as well as the various coping strategies they employed. This study revealed several findings in older people with ACKD in outpatient care related to the mental representations proposed by the self-regulation model. The key representations found were cognitive, i.e., identity limited to symptoms, consequences related to the social dimension, the burden associated with treatments; emotional representations, i.e., negative emotions associated with the impact of the disease; coping strategies, i.e., lifestyle modifications that were recognised as major challenges; and seeking support from caregivers and experience of care, i.e., a lack of information regarding the disease and a lack of continuity of care.

Abbreviations

RRT	Renal replacement therapy
CRT	Conservative renal therapy
SRM	Self-regulation Model
CKD	Chronic kidney disease
ACKD	Advanced Chronic Kidney Disease

Supplementary information

The online version contains supplementary material available at https://doi.org/10.1186/s12882-025-04338-2.

Supplementary Material 1

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Authors contributions

BSG, ILG, and EPO participated in the project design and literature review. ILG, EPO, VMF, MBS, RSC and ESA participated in the preinterviews, expert consultation, recruitment, informed consent, interviews, and data collation. LBA, BSG, ELG, EPO, OCP and ILG participated in the comprehensive manuscript review and preparation.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

This study was performed in accordance with the principles of the Declaration of Helsinki. The study was approved by the Ethics Committees at the primary care and hospital reference centers: Ethical Committee for Research on Medications of the IDIAP Jordi GoI (22/092-P). Research Ethics Committee of the Bellvitge University Hospital (PR292/22). All the participants were informed of the research objectives, interview topics, and data usage, explained the confidentiality criteria, were anonymous, and were right to withdraw from the study. Each participant was provided with an informed consent form, giving them the choice to participate. By signing this form, they voluntarily confirmed their participation and agreed to the anonymous use of their data for communications and scientific publications. The participants were informed of their rights regarding access, rectification, erasure, objection, processing restrictions, and data portability. These rights could be exercised by contacting the study's principal investigator. The participants also had the right to lodge a complaint with the Catalan Data Protection Authority if they felt that their rights were violated by any actions of the Department of Health. The study personnel processed and utilised the data while maintaining strict confidentiality, adhering to the guidelines outlined in Organic Law 3/2018, dated December 5, regarding personal data protection and digital rights guarantees, and the subsequent Regulation (EU) 2016/679 General Data Protection Regulation.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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