

BMJ Open Patients' and healthcare professionals' beliefs, perceptions and needs towards chronic kidney disease self-management in China: a qualitative study

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To cite: Shen H, van der Kleij RMJJ, van der Boog PJM, et al. Patients' and healthcare professionals' beliefs, perceptions and needs towards chronic kidney disease self-management in China: a qualitative study. *BMJ Open* 2021;**11**:e044059. doi:10.1136/bmjopen-2020-044059

► Prepublication history and additional material for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2020-044059>).

Received 21 August 2020
Revised 19 November 2020
Accepted 19 February 2021



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ABSTRACT

Objectives To support the adaptation and translation of an evidence-based chronic kidney disease (CKD) self-management intervention to the Chinese context, we examined the beliefs, perceptions and needs of Chinese patients with CKD and healthcare professionals (HCPs) towards CKD self-management.

Design A basic interpretive, cross-sectional qualitative study comprising semistructured interviews and observations.

Setting One major tertiary referral hospital in Henan province, China.

Participants 11 adults with a diagnosis of CKD with CKD stages G1–G5 and 10 HCPs who worked in the Department of Nephrology.

Results Four themes emerged: (1) CKD illness perceptions, (2) understanding of and motivation towards CKD self-management, (3) current CKD practice and (4) barriers, (anticipated) facilitators and needs towards CKD self-management. Most patients and HCPs solely mentioned medical management of CKD, and self-management was largely unknown or misinterpreted as adherence to medical treatment. Also, the majority of patients only mentioned performing disease-specific acts of control and not, for instance, behaviour for coping with emotional problems. A paternalistic patient–HCP relationship was often present. Finally, the barriers, facilitators and needs towards CKD self-management were frequently related to knowledge and environmental context and resources.

Conclusions The limited understanding of CKD self-management, as observed, underlines the need for educational efforts on the use and benefits of self-management before intervention implementation. Also, specific characteristics and needs within the Chinese context need to guide the development or tailoring of CKD self-management interventions. Emphasis should be placed on role management and emotional coping skills, while self-management components should be tailored by addressing the existing paternalistic patient–HCP relationship. The use of electronic health innovations can be an essential facilitator for implementation.

Strengths and limitations of this study

- This is the first study to describe the beliefs, perceptions and needs towards self-management of chronic kidney disease (CKD) of patients and healthcare professionals in China.
- The triangulation of data sources and framework method analysis optimised the internal validity and reliability of our results.
- As our findings were not quantified, the relative importance of influencing factors (eg, paternalistic patient–healthcare professional relationships) for CKD self-management could not be determined.
- The healthcare professionals who provided CKD care in the institution were predominantly female, and this group may not be representative of all healthcare professionals in nephrology practice.

INTRODUCTION

Chronic kidney disease (CKD) is a severe public health problem.^{1 2} Globally, 697.5 million individuals have been affected by CKD.³ The burden of CKD is high in China, with an estimated prevalence of 10.8% (119.5 million adults).⁴ CKD is characterised by a gradual and irreversible loss of renal function and is categorised in five stages (CKD stages G1–G5) based on the estimated glomerular filtration rate (eGFR).⁵ Patients with CKD often report significant impairment in health-related quality of life⁶ and experience adverse health outcomes.⁷ Also, CKD imposes a substantial economic burden due to its considerable health-related and societal cost.⁸

Disease self-management (hereafter referred to as self-management) is vital to reducing disease burden and to controlling the healthcare expenditures for patients with chronic disease.^{9 10} As previously noted,¹¹ self-management is composed of three main tasks: medical, emotional and role



management. Hence, self-management is not limited to medical management but also aims to optimise the uptake of new meaningful behaviours or life roles, and it promotes adequate coping disease consequences.¹¹ Appropriate self-management has the potential to optimise one's ability to perform the cognitive, behavioural and emotional behaviour necessary to maintaining a satisfactory health-related quality of life.¹² Also, for patients with CKD, self-management interventions may improve self-management behaviours^{13–15} and disease-specific knowledge,¹³ health-related quality of life¹⁶ and health outcomes,^{16 17} while it may also slow disease progression.^{9 18–20} Despite these reported successes, many existing self-management interventions are prescriptive and deliver information without taking into account the patients' understanding of self-management^{21 22} or the fact that self-management occurs in a social context.²³ Patients' needs for self-management support are not always known or met,²⁴ and there is very little knowledge on how people with CKD would like to receive self-management interventions.²⁵

Research on CKD self-management interventions has mostly focused on high-income countries, whereas the CKD burden is highest in low-income and middle-income countries.²⁶ Hence, there is an urgent need for effective interventions that can decrease the CKD burden in countries with the fewest resources. One possible solution is to translate CKD self-management interventions that have been proven to be effective in high-resource settings to low-resource settings. However, applying a 'one-size-fits-all' approach is not sufficient as interventions cannot be simply translated as a whole to a different context. Instead, the target context should be explored along with the beliefs, perceptions and needs of the target population.²⁷ To optimise chances of successful implementation, this information should then be used to make context-specific adaptations to the intervention and implementation strategies.²⁸

To adapt and prepare an existing evidence-based CKD self-management intervention for implementation in China, we performed a qualitative study to examine the beliefs, perceptions and needs of patients with CKD and healthcare professionals (HCPs) towards CKD (self-management) in China.

METHODS

Overview

The knowledge generated from this basic interpretive,²⁹ cross-sectional qualitative study will inform the adaptation and evaluation of a tailored electronic health (eHealth) self-management intervention for patients with CKD in China based on the Dutch Medical Dashboard intervention.^{17 30} Details on the study protocol have been described elsewhere.³¹

We followed the Consolidated Criteria for Reporting Qualitative Health Research (see online supplemental appendix 1).³²

Study setting and participant selection

This study took place within the First Affiliated Hospital of Zhengzhou University in the Henan province in China. Henan accounts for 9% of the rural Chinese population. An estimated 12 million or 16.4% of all adults in rural areas of Henan suffer from CKD.³³ The Department of Nephrology of the hospital has approximately 276 beds, and more than 60 000 patients with CKD visit the outpatient clinic of this department each year.

Previous literature indicates that patients with CKD G1 or G2 report a multitude of symptoms and fairly high disease burden.^{34 35} Therefore, we anticipated that all patients with CKD (regardless of the CKD stage) have a great need for self-management interventions. Individuals eligible for inclusion were: (1) patients with a diagnosis of CKD with CKD stages G1–G5 and (2) HCPs who worked in the Department of Nephrology. Participants needed to be 18 years or older and speak Chinese. We followed the principles of 'purposive and convenience sampling'³⁶ to capture a diverse sample. Two sampling frames were used. The sampling frame for patients comprised the following variables: CKD stage, gender and age range. The sampling frame of HCPs comprised the variables: work experience, profession, gender and age. Also, we used snowball sampling³⁷ to identify additional participants, in which current participants were asked if they knew any other individual who could participate in the study. For instance, participant AW knew another patient via WeChat who was severely ill and therefore did not visit the hospital often. This patient had not heard about the study. We asked participant AW to contact this patient and provide information on study participation. The patient then agreed to participate in our study. Study invitation strategies included: provision of flyers and face-to-face verbal invitations for both patients and HCPs and an online invitation for HCPs. All participants provided written informed consent to participation. Also, patients and HCPs received a reimbursement (20 RMB of telephone credit) for their time spent on the study.

Data collection

One researcher (HS, Msc, female) conducted semistructured face-to-face interviews and observations (see online supplemental appendix 2) between January 2019 and April 2019. The interviewer had no prior contact with participants. The semistructured interview guide and observation forms were developed based on the FRESH AIR (Free Respiratory Evaluation and Smoke-exposure reduction by primary Health cAre Integrated gRoups) study,³⁸ examples of similar studies³⁹ and research team discussions (see online supplemental appendix 3). Also, the interview guide was theory driven as concepts of the Health Belief Model and the Theory of Planned Behavior were used to develop the topic list. A pilot interview was conducted with both a patient and an HCP to evaluate its content, length and understandability.

The interviewer was trained and had ample experience with qualitative research. To ensure confidentiality

and privacy, face-to-face interviews were performed in a private room in the department. Also, the passive participant observations⁴⁰ were conducted during patient outpatient clinic follow-up or during routine care visits. The behaviour by and conversation between patient and HCP were both observed. The observations were used to triangulate the interview data and to identify potential differences and similarities between what was said to happen when considering self-management behaviours (interviews) and what actually occurred in practice (observations). The sample size for the interviews and observations was not predetermined. Instead, the sample size was determined based on when data saturation was achieved, being the point at which no new or relevant information could be identified through the iterative, preliminary analysis of the data.⁴¹ All interviews were audiotaped digitally. After each interview, the interviewer made field notes detailing the interview setting, atmosphere and participants' non-verbal behaviours. Additionally, we collected demographic and clinical characteristics of the participants from the patient medical records.

Data analysis

A Framework Method⁴² was used to guide our qualitative analysis.

Stages A and B: transcribing and familiarisation

All audio-taped interviews were anonymised and transcribed verbatim. Also, observation forms were digitalised and transported to Microsoft Excel 2010. Names and identifiers were removed to protect participant confidentiality. One researcher performed transcription and another researcher checked transcripts to ensure content accuracy. Before coding, each transcription was read as full text by the researchers in order to become familiar with the data set.

Stage C: development of an analytical framework and coding

Atlas.ti for Windows V.7.5.18 (Scientific Software Development, Berlin) was used for data analysis. We built initial coding trees based on the theoretical framework developed in our study protocol and the Theoretical Domains Framework (TDF).⁴³ Three transcripts were coded using the initial tree. New codes that emerged were added to the tree. After discussion among the research team, a final coding tree was agreed on. Then, one researcher coded all transcripts and observation forms using the final coding tree. The assigned codes were verified by a second researcher (WW).

Stage D: charting data into the framework matrix

Data were further reduced by formulating within-cases and cross-cases.⁴⁴ Next, data were charted into matrices per research question using Microsoft Excel 2010 and reviewed by all authors. The matrix comprised one row per participant and one column per code.

Stage E: interpreting the data

Themes were generated from codes derived from the data set by reviewing the matrix and making connections within and between participants and codes. Emergent themes were then organised into major themes and subthemes. All themes were discussed among the research team and modified if needed. Also, the results of participant observation were triangulated with face-to-face interview analysis.

Establishing rigour in the data collection and analysis process

Rigour in data collection and analysis, by ensuring credibility, confirmability, dependability, transferability and authenticity, was achieved in the following ways.⁴⁵ Two team members most closely involved in the fieldwork (HS and WW) met frequently to discuss the constancy of the data collection process and (preliminary) analysis. At regular intervals, meetings were held with members of the wider research team with extensive qualitative (RMJJvdK) and clinical (PJMvdB) experience to discuss codes and categories emerging from the analysis. Also, the framework approach to data analysis allowed data to be compared through the formulation of narratives (in-depth focus) and within-case and cross-case comparisons (comparative focus). Additionally, during data analysis, the two fieldwork researchers kept a research diary and made reflective notes.

Reflexivity

The research group was multidisciplinary as it included researchers, clinicians, nurses and academics from both China and the Netherlands. The diverse disciplinary backgrounds, research experiences and positions of the members of this group stimulated the collection and analysis of rich data, as each member held different perspectives, which were shared and debated during research meetings. As the management of CKD is very different in the Netherlands compared with China, all members reflected on their own experiences with CKD (self-) management and how these might have affected the performance of their research tasks. Moreover, during research meetings, all members reflected on the professional lens through which they observed the phenomenon of interest and how this might have impacted their research tasks.

Patient and public involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

RESULTS

Participant and interview characteristics

A total of 21 face-to-face interviews and 26 observations were conducted (tables 1 and 2). Out of 15 approached patients, 11 patients (73%) agreed to participate in the interview study. Out of 11 approached HCPs, 10 (91%)

Table 1 Characteristics of patients in face-to-face interview

Characteristics	Value (N=11)
Age, years*	38.9±9.6 (18–53)
Age category (years), n (%)	
18–28	1 (9)
29–39	4 (36)
40–50	4 (36)
51–61	2 (19)
Sex, n (%)	
Male	5 (46)
Female	6 (54)
Marital status, n (%)	
Never married	1 (9)
Married	9 (82)
Divorced	1 (9)
Highest level of education completed, n (%)	
≤Primary school	3 (27%)
Middle school	3 (27%)
≥High school graduate	5 (46%)
Employment status, n (%)	
Employed (full time and part time)	2 (18)
Not employed	7 (64)
Farming	0 (0)
Student	1 (9)
Retired	1 (9)
Time since CKD diagnosis (years), n (%)	
<1	5 (46)
1–5	3 (27)
>5	3 (27)
Current CKD stage, n (%)	
CKD stages G1–G3	5 (46)
CKD stages G4–G5	6 (54)
Body weight, kg*	56.8±13.2 (35–79)
Serum albumin, g/L*	35.1±3.9 (29.9–41.9)
Haemoglobin, g/L*	105.8±28.5 (53.1–158)
Serum creatinine, ummol/L*	523.6±519.3 (62–1380)
eGFR, mL/min/1.73 m ² †	13.7 (3.6–92.7)

Complete data available with the exception of the following variables, with data of body weight available for nine patients (82%), serum creatinine for eight patients (73%) and eGFR for nine patients (82%).

*Mean±SD (range).

†Median (IQR).

CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate.

HCPs agreed. Reasons for refusal to participate included a lack of time due to patients' extended waiting time for a physician consultation or intravenous infusion or lack of interest in the research presented. Reasons reported by

Table 2 Characteristics of healthcare professionals

Characteristics	Value (N=10)
Age, years*	33±6.1 (25–46)
Age category (years), n (%)	
21–30	4 (40)
31–40	5 (50)
41–50	1 (10)
Female sex, n (%)	9 (90)
Job occupation, n (%)	
Nurse	7 (70)
Nephrologist	3 (30)
Marital status, n (%)	
Never married	2 (20)
Married	8 (80)
Highest level of education completed, n (%)	
Bachelor's degree	5 (50)
Master's degree	3 (30)
Doctoral degree	2 (20)
Years of work experience in medical practice, n (%)	
<5	2 (20)
5–10	3 (30)
>10	5 (50)
Years of work experience in nephrology practice	
<5	3 (30)
5–10	3 (30)
>10	4 (40)

*Mean±SD (range).

HCPs included a lack of time due to work obligations (see online supplemental appendix 4 for interview characteristics). No significant differences were observed between the final sample and those who refused to participate.

Themes

Four major themes emerged for both patients and HCPs. These themes and respective subthemes are described in the following sections with reference to the relevant quotes (see [tables 3 and 4](#), online supplemental appendix 5).

Theme 1: CKD illness perceptions

CKD diagnosis and anticipated consequences of illness (patient generated)

More than half of patients mentioned that they had a 'late' CKD diagnosis and attributed this to their limited awareness and recognition of CKD symptoms ([table 3, Q1](#)). Patients with CKD mentioned initial difficulties in understanding and accepting their CKD diagnosis ([table 3, Q2](#)), as they felt fearful and uncertain about the permanence of CKD, its influence on their future health ([table 3, Q3](#)) and the anticipated social and financial burden ([table 3, Q4](#)).

Table 3 Representative quotations on CKD illness perceptions, understanding of and motivation towards CKD self-management

Themes and subthemes	Representative quotation
CKD illness perceptions	
Anticipated concerns on diagnosis	<p>Q1. <i>[I had] swollen eyes and legs, [I thought] I was just not acclimatized at that time. I have never heard of this disease.</i> (Patient 7, 29–39 years, CKD G4–G5)</p> <p>Q2. <i>I have not even had a cold before. Why do I get this CKD?</i> (Patient 3, 40–50 years, CKD G4–G5)</p> <p>Q3. <i>The first is that it is really difficult to accept that I am sick. [CKD is] unlike getting cold or fever. I have a feeling that whether I would be useless in the rest of my life.</i> (Patient 5, 29–39 years, CKD G1–G3)</p> <p>Q4. <i>I only have a part-time job. If I have dialysis four times a day, I need to work part-time for [a few] hours, which is equivalent to cutting off the source of the financial resources of my family.</i> (Patient 9, 51–61 years, CKD G4–G5)</p>
Physical consequences	<p>Q5. <i>Patients are very weak, and the symptoms of fatigue are more prominent.</i> (HCP6, 29–39 years)</p> <p>Q6. <i>[I had] retching and vomiting. Also, I smell the urea when I breathe out. It is really uncomfortable.</i> (Patient 10, 40–50 years, CKD G4–G5)</p>
Psychosocial consequences	<p>Q7. <i>I have my own space and social connections with job. Now, I can only stay at home and do not have any contact with the world outside. I am abandoned by the world.</i> (Patient 8, 40–50 years, CKD G1–G3)</p> <p>Q8. <i>The biggest impact [of CKD] is being unable to work. I can not make money to support my family.</i> (Patient 5, 29–39 years, CKD G1–G3)</p> <p>Q9. <i>I need to count on my husband to earn money and pay for my costs... If my husband does not need to take care of me, he can make money.</i> (Patient 10, 40–50 years, CKD G4–G5)</p>
Lifestyle consequences	<p>Q10. <i>The first [influence] is [that I need] to take medicines at home every day and stay at home.</i> (Patient 8, 40–50 years, CKD G1–G3)</p> <p>Q11. <i>Because I need to conduct dialysis several times every day, I can not go anywhere.</i> (Patient 7, 29–39 years, CKD G4–G5)</p>
Understanding of and motivation towards CKD SM	
Understanding of CKD SM	
Patients' responses towards the understanding of CKD SM	<p>Q12. <i>The doctor has prescribed a way how to do it. I should try my best to do it. I should do what the doctor says and pay attention to what precautions doctors mentioned.</i> (Patient 7, 29–39 years, CKD G4–G5)</p> <p>Q13. <i>Doctors said that I can not exercise too much, eat spicy [food], and should eat less salt.</i> (Patient 2, 18–28 years, CKD G1–G3)</p> <p>Q14. <i>I hear from nurses that I need to take care of self-protection, paying attention to the sanitation of environment of dialysis.</i> (Patient 1, 40–50 years, CKD G4–G5)</p>
HCPs' responses towards the understanding of CKD SM	<p>Q15. <i>After the patient is discharged from the hospital, he can manage the disease himself, for example, his adherence to taking medication, diet [restrictions], exercise, and regular follow up.</i> (HCP3, 18–28 years)</p> <p>Q16. <i>Patients [with CKD] must have the knowledge of this disease at first...what disease stage he is in now...then they can pay attention to... improving their lifestyles...</i> (HCP5, 29–39 years)</p>
Motivation towards CKD SM	<p>Q17. <i>I stayed up late. It can be a cause and risk of the CKD. So I have to avoid it...I should have restrictions according to what doctors told me, for example, eating.</i> (Patient 6, 29–39 years, CKD G4–G5)</p> <p>Q18. <i>CKD SM is very important...patients with peritoneal dialysis...are with severe symptoms... But patients with good adherence can even lead the whole family to travel abroad.</i> (HCP1, 29–39 years)</p> <p>Q19. <i>Doctors and nurses are the leading roles, such as...deciding taking medicine. I need to listen to the [medical care of] doctors and nurses.</i> (Patient 4, 29–39 years, CKD G1–G3)</p>

Continued

Table 3 Continued

Themes and subthemes	Representative quotation
	Q20. <i>I should actively cooperate with treatment, follow the taboos or precautions that the doctors recommended, and cooperate with treatment much better.</i> (Patient 5, 29–39 years, CKD G1–G3)
	Q21. <i>We as health care professionals play a role in letting patients correctly understand the CKD. Then, we can guide the patients how to adhere to treatment, which is very important.</i> (HCP4, 29–39 years)

CKD, chronic kidney disease; HCP, healthcare professional; Q, quote; SM, self-management.

Physical, psychosocial and lifestyle consequences of CKD (patient and HCP generated)

Patients frequently mentioned that they felt ‘discomfort’ and ‘weakness’ because of symptoms such as fatigue (table 3, Q5), especially those with CKD stages G4–G5 (table 3, Q6). Also, both patients and HCPs highlighted the psychosocial impact of CKD. Patients expressed frustration and depression due to their deteriorating health status and impairments in their social life (table 3, Q7). Also, patients mentioned losing their job and facing difficulties in re-entering the workforce as a consequence of CKD, making them feel anxious about their financial situation (table 3, Q8). Additionally, they felt guilt and regret about the burden their disease imposed on family members (table 3, Q9). All these impacts were also observed in the consultations (see online supplemental appendix 5).

More than half of patients mentioned that CKD treatment requirements made them feel that they were not living a ‘normal life’ (table 3, Q10). Also, patients receiving dialysis mentioned that their daily treatment schedule led to difficulties in travelling and engaging in social activities (table 3, Q11).

Theme 2: understanding of and motivation towards CKD self-management

Understanding of CKD self-management (patient and HCP generated)

Patients and HCPs both mentioned that they considered CKD self-management to be solely ‘medical management’. However, how they expressed this understanding differed significantly (table 3).

More than half of patients and HCPs described CKD self-management as ‘adherence to medical advice and treatment as prescribed’ (table 3, Q15). Patients also described CKD self-management as ‘being obedient’, literally quoting their HCPs’ medical advice (table 3, Q12–14). Also, HCPs expressed that improving patient disease knowledge as the priority of CKD self-management (table 3, Q16).

Motivation towards CKD self-management (patient and HCP generated)

Patients expressed the belief that self-management could slow down their disease progression and optimise their health status (table 3, Q17). More than half

of HCPs considered CKD self-management as a necessity to control patients’ symptoms and for improving health-related outcomes (table 3, Q18).

Patients believed that HCPs were sufficiently knowledgeable to help them manage their disease (table 3, Q19) and named their own responsibilities within CKD self-management as ‘strictly following medical advice’ (table 3, Q20). HCPs frequently expressed that their role in self-management was to inform patients about the importance of adherence to medical advice and enable this adherence by providing health education (table 3, Q21).

Theme 3: current CKD practice

Theme 3a: current self-management practice by patients (patient generated)

All concepts related to self-management practice by patients are operationalised in online supplemental appendix 6.^{46 47}

When asked about their current CKD self-management, patients mostly named concepts related to medical management, such as disease-specific controlling behaviours (DCBs). The most frequently mentioned DCBs were: adhering to medical advice on medication use (table 4, Q22), treatment and regular follow-up, self-monitoring (table 4, Q23) and symptom management (table 4, Q24). Additionally, more than half of the patients mentioned the performance of healthy behaviour, such as diet restrictions (table 4, Q25). The discussion of patients’ DCBs was frequently observed in consultations (see online supplemental appendix 5). Other aspects of self-management, such as role and emotional management, were not frequently mentioned. Some patients described a shift towards a more passive ‘patient role’ (table 4, Q26). Two patients mentioned the experience of coping with emotional problems (table 4, Q27–28).

Patients frequently named the use of problem-solving and decision-making skills when experiencing physical symptoms (table 4, Q29). Patients searched and obtained disease-related knowledge from various sources including their HCPs, the internet, hospital brochures and contact with other patients (table 4, Q30–31). These findings were consistent with observation data (see online supplemental appendix 5). Other aspects of CKD self-management skills, such as partnering with their HCPs

Table 4 Representative quotations on current CKD practice, barriers, (anticipated) facilitators and needs towards CKD self-management

Themes and subthemes	Representative quotation
Current CKD practice	
Current SM practice by patients	
Medical management	<p>Q22. <i>I took medications very regularly. Otherwise, my blood pressure will be high and I can not control it.</i> (Patient 7, 29–39 years, CKD G4–G5)</p> <p>Q23. <i>I paid attention to the [chronic kidney] disease. If I felt uncomfortable, I quickly measured my blood pressure.</i> (Patient 4, 29–39 years, CKD G1–G3)</p> <p>Q24. <i>My legs were swollen. I started to restrict water [intake]. Then, the edema slowly disappeared.</i> (Patient 8, 40–50 years, CKD G1–G3)</p> <p>Q25. <i>I eat food based on doctor's requirements every day, low salt and low fat, and high-quality protein.</i> (Patient 5, 29–39 years, CKD G1–G3)</p>
Role and emotional management	<p>Q26. <i>I took medicines on time and had a rest every day. I am a patient and just consider medicines every day.</i> (Patient 11, 51–61 years, CKD G1–G3)</p> <p>Q27. <i>I try to comfort myself. I can not leave medicines...But you are sick and you have to take them. I can focus on the present life.</i> (Patient 5, 29–39 years, CKD G1–G3)</p> <p>Q28. <i>I do not have much stress on this disease. Because it is useless, I want to live in the present life in a happy way every day.</i> (Patient 1, 40–50 years, CKD G4–G5)</p>
SM skills	<p>Q29. <i>I used the small spoon to add salt in the food. My blood pressure was as high as 145 or 156 before, now my blood pressure is around 123 after limiting salt intake.</i> (Patient 11, 51–61 years, CKD G1–G3)</p> <p>Q30. <i>When I searched the [chronic kidney] disease online, I searched the information about the cause of disease, treatment or what precautions I need to care about.</i> (Patient 5, 29–39 years, CKD G1–G3)</p> <p>Q31. <i>There is a diet list [for CKD]. Also, I searched the information by asking other patients during hospitalization.</i> (Patient 6, 29–39 years, CKD G4–G5)</p> <p>Q32. <i>If I saw that I had swollen legs or eyes... I called the doctors and they told me not to put the dialysis fluid in the abdomen for a long time.</i> (Patient 1, 40–50 years, CKD G4–G5)</p> <p>Q33. <i>I insist on exercising for more than 10 000 steps every day...if I only exercised for four or five thousand, I will go outside to reach 10 000 steps.</i> (Patient 4, 29–39 years, CKD G1–G3)</p>
Implementation of SM intervention by HCPs	<p>Q34. <i>If patients did not correctly take the medication, you can tell him [the correct way]. When he is prepared for discharge from the hospital, repeat it again.</i> (HCP1, 29–39 years)</p>
Barriers, (anticipated) facilitators and needs toward CKD SM	
Barriers	
Knowledge	<p>Q35. <i>I did not know that I can not eat red dates. I heard that eating red dates can nourish the blood. My potassium was high and I had serious edema.</i> (Patient 7, 29–39 years, CKD G4–G5)</p>
Environmental context and resources	<p>Q36. <i>There is no good way. One way is the Wechat public account we created. Another is the internet. But the information is not written by professionals, not true and disordered.</i> (HCP3, 18–28 years)</p> <p>Q37. <i>Patients want detailed information from doctors, for instance, diet and detailed medical advice on all aspects. But the doctor's ward round is tight, and they are busy every day.</i> (HCP9, 29–39 years)</p>
Social influence	<p>Q38. <i>Patients' families do not follow the strict rules such as dietary habits to assist patients to manage themselves.</i> (HCP2, 29–39 years)</p> <p>Q39. <i>Some patients want to give CKD treatment up. Then, it can be challenging to communicate with them. They would not adhere to lifestyle changes.</i> (HCP3, 18–28 years)</p>
(anticipated) Facilitators	
Knowledge	<p>Q40. <i>If the patient often read the information related to the disease...he will have a deeper understanding of our medical care. If the knowledge is increased, his SM will be improved.</i> (HCP3, 18–28 years)</p>

Continued

Table 4 Continued

Themes and subthemes	Representative quotation
Environmental context and resources	Q41. <i>We have Wechat account, which is trustworthy. It can help them when they ask whether they can eat a specific food, especially when we are too busy to tell them details.</i> (HCP4, 29–39 years)
Social influence	Q42. <i>My family members are helpful. If there is something I do not understand, he will check it from the Internet. I think this helps a lot.</i> (Patient 11, 51–61 years, CKD G1–G3) Q43. <i>I did not want to have dialysis. But after talking to doctor Xin, I know that I can live for more than ten years with dialysis. Then, I accepted it.</i> (Patient 3, 40–50 years, CKD G4–G5)
Needs	
Knowledge	Q44. <i>Patients need related knowledge like the diet [restrictions]...such as he can not eat this food or eat less.</i> (HCP4, 29–39 years)
Environmental context and resources	Q45. <i>I need clear information online...what food I can eat online is not clear and not detailed...The information is conflicting...</i> (Patient 6, 29–39 years, CKD G4–G5)

CKD, chronic kidney disease; HCP, healthcare professional; Q, quote; SM, self-management.

and action planning based on goal setting, were not frequently mentioned. Some patients mentioned that HCPs provided advice on how to cope with symptoms (table 4, Q32) or stated to have created and modified self-management action plans (table 4, Q33).

Theme 3b: implementation of self-management intervention by HCPs (HCP generated)

HCPs mentioned facilitating patients' self-management by providing health education, especially about strict adherence to medical treatment (table 4, Q34). Observations confirmed that CKD-specific health education was frequently provided by HCPs (see online supplemental appendix 5).

Theme 4: barriers, (anticipated) facilitators and needs towards CKD self-management

Identified barriers, facilitators, and needs towards CKD self-management were classified using the TDF⁴³ (details provided in table 5 and online supplemental appendix 7).

Barriers

Patients and HCPs frequently named a lack of knowledge of CKD (eg, symptoms) and difficulties in making necessary lifestyle changes as barriers to patients' self-management outcomes (table 4, Q35). Moreover, patients and HCPs frequently mentioned barriers related to the environmental context and resources, such as limited (online) education resources and HCPs' time constraints (table 4, Q36–37). Barriers for patients related to 'social influence' were named by HCPs, such as inadequate support from family members (table 4, Q38). Also, HCPs stated that they felt patients' emotional problems interfered with the patient–HCP communication, impeding patients' self-management (table 4, Q39).

(anticipated) Facilitators and needs

Patients and HCPs commonly mentioned that sufficient disease-related knowledge might support patients'

adherence to treatment and improve self-management skills (table 4, Q40). Also, patients and HCPs emphasised that access to trustworthy (online) educational resources might facilitate self-management efforts (table 4, Q41). Additionally, patients and HCPs cited adequate family-level support and effective patients–HCP communication as facilitators (table 4, Q42–43). Needs reflected the anticipated facilitators: patients and HCPs expressed the need for better access to and provision of disease-related knowledge (table 4, Q44), especially through eHealth mediums (table 4, Q45).

DISCUSSION

The beliefs, perceptions and needs of patients with CKD and HCPs regarding CKD self-management were examined. Our study revealed that almost all patients and HCPs solely mention the medical management of CKD: self-management is largely unknown or misinterpreted as adherence to medical treatment. Also, both patients and HCPs mentioned heavy psychosocial impact resulting from CKD. Furthermore, we found that a paternalistic patient–HCP relationship was often present.

Our finding that self-management is often misinterpreted as adherence to medical treatment underlines the importance of education on the core concepts and possible advantages of self-management interventions. Self-management is comprised of medical, emotional and role management,¹¹ and it aims to optimise the uptake of meaningful behaviours or life roles, promoting adequate coping with disease consequences.¹¹ Hence, if patients and HCPs do not fully understand the concept of self-management, this might influence their uptake of self-management interventions in practice.^{47 48} A recent review examined the effectivity of interventions to educate professionals on how to support patient self-management through eHealth.⁴⁹ For example, blended learning that combines e-learning and face-to-face methods is suggested to support self-management skills development for HCPs.⁴⁹ Also, improving health literacy, namely the ability

Table 5 Identified barriers, (anticipated) facilitators of CKD self-management in five domains

TDF domain	Patient	HCP	Operationalisation
Barrier			
Knowledge	x*	x	Patients' lack of general knowledge of CKD.
			Patients' lack of knowledge on lifestyle changes.
			Patients' lack of knowledge of treatment.
Environmental context and resources	x	x	Limited education resources or materials for patients' knowledge.
			Time constraints of HCPs.
Behavioural regulation	x		Patients' insufficient information on lifestyle behaviour change.
			Patients' difficulties in breaking certain habits.
Emotion		x	Patients' experienced fear, anxiety and depression.
			Patients' lack of confidence deal with heavy disease burden.
Social influence		x	Inadequate support from family members.
			Interfered patient–HCP communication.
(anticipated) Facilitator			
Knowledge	x	x	Patients' sufficient general knowledge of CKD (treatment).
			Patients' sufficient knowledge of symptom management and lifestyle changes.
Environmental context and resources	x	x	Patients' access to educational resources.
Social influence	x	x	Adequate family-level support.
			Effective patient–HCP communication.
Behavioural regulation	x		Patients' being able to adhere to the lifestyle changes prescribed.

*Domain mentioned by stakeholder.

HCP, healthcare professional; TDF, Theoretical Domains Framework.

to access, process, comprehend, use health information and to effectively communicate with HCPs about health information, has been associated with successful disease self-management of patients with CKD.⁵⁰ An intervention that focusses on education about self-management and aims to improve health literacy may improve the chances of successful uptake of self-management behaviours.

Patients almost never mentioned the psychosocial aspects of self-management, but they did mention the heavy psychosocial impact resulting from CKD. Considering this contradiction, we advise future research and developers in China to increase their focus on the psychosocial aspects of CKD and to contemplate the use of cognitive-behavioural therapy elements⁵¹ to help manage this impact. Also, patients' self-efficacy and ultimately their self-management health behaviours^{52–54} are associated with psychosocial well-being, making an increased focus on the psychosocial aspects of the disease as a prerequisite for successful disease self-management in general.

Consistent with previous literature,⁵⁵ patients with CKD stages G4–G5 in our study frequently mentioned a heavy symptom burden. However, these patients did not express a greater need for self-management interventions, as we would expect from previous research.⁵⁵ This

may be explained by the fact that patients cannot ask for things they do not know: patients' misinterpretation of self-management may have limited their ability to express their needs. Also, as patients with CKD G4 or G5 have often suffered from the disease for a long period, they may have adapted to living with their disease and therefore feel less need for self-management interventions.

Patient autonomy is a core principle of the patient–doctor interaction in Western cultures.^{56 57} However, under certain conditions, the paternalistic relationship we encountered in our study can be valuable and even essential to improving health outcomes and treatment adherence in some cultural contexts, for instance, if patients prefer a paternalistic approach over autonomy.^{58 59} We advise not to try and eliminate this paternalistic relationship but to incorporate its potentially positive aspects in self-management interventions. Also, improving patient activation has been an important factor for successful self-management and should be fostered.^{60 61} Previous literature has showed that a higher level of patient activation is associated with higher levels of self-care in patients with CKD.⁶¹ Hence, we argue that it is important to focus on and improve patient activation before implementing self-management intervention, especially considering



the current dominant patient–HCP relationship. For example, an intervention can be developed by building patients' skills in posing more and better questions to their doctors and in recognising the importance of asking questions in the decision-making process.⁶² Additionally, increasing patients' empowerment can be an effective way to facilitate shared decision making. A more individualised and specialised empowerment intervention is needed,⁶³ for instance, by providing patients with tailored education and psychosocial support including a focus on self-confidence. Such an intervention can increase patients' awareness of self-management behaviours and strengthen their ability to successfully manage their disease and life.

A barrier to adequate self-management that was frequently reported by patients is a lack of knowledge. We found that the use of eHealth was largely supported by patients and HCPs to address this barrier. As such, we advocate the development of a national, trustworthy health education resource platform to address the needs expressed by patients for access to reliable medical information. As an example, an evidence-based health information website (<http://www.thuisarts.nl>) in the Netherlands has effectively improved self-management and reduced healthcare usage.⁶⁴ However, previous literature showed that only increasing patients' knowledge was insufficient to modify their behaviour.⁶⁵ Thus, we highlight the importance of also improving both patients' motivation and their behavioural skills to facilitate their CKD self-management. As an example, serious gaming has the potential to improve patients' motivation and behaviours of self-management. China has numerous internet and mobile phone users,⁶⁶ and serious gaming is cost-effective, flexible, portable and could invoke intense and durable interest among patients and HCPs in engaging in regular self-management (implementation).⁶⁷

To our knowledge, this is the first study to describe the beliefs, perceptions and needs towards CKD self-management of patients and HCPs in China. We performed an exploratory, cross-sectional study taking a basic interpretive (generic) qualitative research approach.²⁹ We argue that this approach is most suitable for examining the individual beliefs, perceptions and needs towards CKD self-management, as it allows us to provide a low-inference description of the phenomenon of interest, allows us to combine inductive and deductive reasoning while building on the existing knowledge base on this topic mostly derived from research performed in western countries. We also considered taking a phenomenological approach. However, we were not primarily interested in the inner dimensions or essence of the concepts and processes that we investigated. Instead, we were interested in the participants' interpretation of the beliefs, perceptions and needs themselves. In other words, we wanted to know what patients believed and not necessarily how these beliefs came to be. Grounded theory was not an option, as we did not aim to build a theory from scratch explaining (the interaction

between) these concepts (like one would when applying a grounded theory approach). As we are aware of the pitfalls of generic qualitative research,^{68 69} we therefore adhere to the 'big-tent' criteria for excellent qualitative research. Tracy *et al*⁷⁰ suggest that when designing qualitative research, developers should focus on the 'ends' rather than getting stuck in methodology-bound 'means'. Also, we follow the guidance provided on how to perform and report on generic qualitative research^{68 69} to optimise the quality and the validity of the results. Moreover, the framework method for data analysis is consistent with our research design, as it is not aligned with a particular epistemological, philosophical or theoretical approach to qualitative research. Instead, it can be (adapted) for use in different approaches that aim to examine specific topics or themes.⁷¹ It is furthermore especially suitable for multidisciplinary health research that includes both patients and HCPs.⁴² The framework method can be used for both inductive and deductive coding to understand the phenomenon of interest. In our study, we expand and falsify existing knowledge on beliefs, perceptions and needs about CKD. We thus need to combine the inductive and deductive aspects of coding, making the framework method an excellent match. By using the framework approach, we clearly and systematically detail the steps performed as well as the perspective taken on the data collection and the analysis process, hence preventing 'method slurring'.⁷² Additionally, other strategies to optimise quality and the validity of the results were adopted. As our study includes the triangulation of data sources, rigour was established in the data collection and analysis process.

Nevertheless, there are also limitations. First, as our findings were not quantified, the relative importance of influencing factors (eg, paternalistic patient–HCP relationship) for CKD self-management could not be determined. Second, the HCPs who provided CKD care in the institution were predominantly female. The HCP group interviewed was not representative of all HCPs in nephrology practice. This selection bias might be caused by the fact that participants who were more positive towards self-management were more likely to participate in our study. However, the number of negative experiences and barriers identified in this study might indicate that this bias has remained limited. Due to time restrictions, participants were not asked to provide feedback on the transcripts and results. However, during the interviews, the interviewer often summarised her interpretation of participants' answers in order to receive clarifications and confirmation.

CONCLUSION

This study provides a comprehensive overview of patients' and HCPs' beliefs, perceptions and needs towards CKD self-management in China. To optimise the implementation of self-management interventions, future developers should be mindful of the limited understanding of CKD

self-management and prepare their interventions accordingly. Also, considering the heavy psychosocial impact of CKD, the focus of self-management interventions should be put on enhancing patients' role management and emotional skills. We advise developing intervention components tailored to the specific cultural context to improve CKD self-management implementation in developing countries. With this approach, selected self-management intervention elements can be implemented using eHealth mediums.

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Acknowledgements The authors would like to thank all the research participants who provided their valuable time to share their experiences. Also, we would like to acknowledge researchers Jie Chen and Shuchen Wang in the First Affiliated Hospital of Zhengzhou University for their support in organising the research. This work has not been presented at a conference/published as a conference abstract.

Contributors HS led the design of this study and is the main contributor in writing this manuscript, with contributions from all authors. HS and WW participated in data collection and analysis. RMJJvdK, PJMvdB, XS, ZL, XL and NC contributed to the design of the study and editing of this manuscript. All authors read and approved the final manuscript.

Funding This work was supported by the China Scholarship Council (CSC) (grant number 201707040096).

Competing interests None declared.

Patient consent for publication Not required.

Ethics approval This study was approved by the Ethics Committee of the First Affiliated Hospital of Zhengzhou University (reference number 2019-KY-52).

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request.

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Appendix 1. Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19(6):349-57.

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Page 7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Page 7
3. Occupation	What was their occupation at the time of the study?	Page 7
4. Gender	Was the researcher male or female?	Page 7
5. Experience and training	What experience or training did the researcher have?	Page 7
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	Page 7
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Page 6
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Page 7
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Page 6
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Page 6
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Page 6
12. Sample size	How many participants were in the study?	Page 7
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Page 9
<i>Setting</i>		

14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Page 6
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Page 7
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Page 10-11
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 7
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	No, see online supplementary appendix 4
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Page 7
20. Field notes	Were field notes made during and/or after the interview or focus group?	Page 7
21. Duration	What was the duration of the interviews or focus group?	Online supplementary appendix 4
22. Data saturation	Was data saturation discussed?	Page 7
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No, due to time constraints, Page 23
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	Page 8
25. Description of the coding tree	Did authors provide a description of the coding tree?	Page 8
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 8
27. Software	What software, if applicable, was used to manage the data?	Page 8
28. Participant checking	Did participants provide feedback on the findings?	No, due to time constraints, Page 23
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Page 12 to 15
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes, there was. Page 16 to 20
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes. they were. Page 16 to 20
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Page 12 to 15

Appendix 2. Field methods for research topics

Method	Patients		Health care professionals	
	Beliefs, perceptions toward chronic kidney disease and self-management	Needs toward chronic kidney disease self-management	Beliefs, perceptions, toward chronic kidney disease and self-management	Needs toward chronic kidney disease self-management
Face to face interview	X	X	X	X
Observation	X	X	X	X

Appendix 3. Semi-structured interview guide and observation forms

Appendix 3a. Interview guide: Patients with Chronic Kidney Disease

Duration Interview: 45-60 min

- A. Introduction, explanation, consent
- B. Demographic data:
- Identification number, sex, age, education, profession (e.g., type of work, daily routine)
 - Personal and cultural background (e.g., family situation – and size, composition, religion)
 - External health-related conditions (e.g., distance to a health care facility), disease stage
-
- C. Topic lists of belief, perception of disease
1. How do you feel when you were told that you had CKD?
(Probe: What do you think has caused this problem? Did you have any worries or concerns, the most fear?)
 2. How do you feel of having CKD?
(Probe: What do you know about CKD? What are the changes in your life/impact? How? How do you cope with these impacts)
-
- D. Topic lists of belief, perception of self-management
- Attitude toward self-management
3. Do you know self-management?
 4. How do you feel about self-management? And why?
(Probe: Do you have experience with it? What can you do? How do you think of the advantages of self-management? How do you feel about disadvantages of self-management?)
- Subjective norms in self-management interventions in CKD and normative beliefs
5. How do you think others' feelings of self-management?
(Probe: government nurses, doctors, your caregivers? Other stakeholders for approving or disapproving?)
- Perceived control in self-management interventions in CKD, barriers and facilitators
6. Do you feel that you would be able to manage the disease by yourself?
(Probe: Do you have confidence in self-management in CKD? Facilitators? Barriers?)
 7. How do you perceive your role in self-management?
(Probe: do you think you, as a patient, should be actively involved in managing your disease? Is it your role/ duty as a patient?)
-
- E. Topic lists of needs toward CKD self-management
- Current care
8. How do you manage CKD?
(Probe: What kind of support do you get of CKD care? Who, what?)

Feelings, challenges, barriers

9. How do you feel of your CKD care or the current care provided to you?
(Probe: What are good aspects of CKD care? What are the problems, challenges of CKD care? What are the problems, challenges of managing the CKD by yourself?)

Needs of CKD self-management

10. Is there anything else that should be done to support you to manage CKD?
(Probe: What for CKD management should be done in the future, when, and from whom?
What support should be done to support your self-management of CKD?)

Appendix 3b. Interview guide: Health care professional

Duration Interview: 45-60 min

- A. Introduction, explanation, consent
- B. Demographic data (Baseline data):
- Name, sex, age, profession, education (the type of work, years of work experience, type of healthcare facility)
 - Personal and cultural background (family situation – and size, composition, religion)
-
- C. Topic lists of belief, perception of disease
1. How do you feel about CKD?
(Probe: What is the impact of CKD? and how?)
 2. How do you tell patients that they have CKD?
(Probe: What will you tell patients that they have CKD? What worries and concerns of their future?)

-
- D. Topic lists of belief, perception of self-management

Attitude toward self-management interventions in CKD and behavioural beliefs

3. Do you know self-management?
4. How do you feel of self-management in patients with CKD? And why?
(Probe: Do you have any experience with it? How do you think of the advantages of self-management? How do you feel about disadvantages of self-management)

Subjective norms in self-management interventions in CKD and normative beliefs

5. How do you think others' feelings of self-management?
(Probe: government, nurses, patients, patients' caregivers? Other stakeholders for approving or disapproving?)

Perceived control in self-management interventions in CKD, barriers and facilitators

6. How do you think the possibility of self-management in patients with CKD?
(Probe: Do you have confidence in self-management in CKD? Facilitators? barriers)
7. How do you perceive your role in patients' self-management? What is your responsibility?
(Probe: Are you willing to be more involved in the patients' self-management? Can you explain in which way you want to be involved?)

-
- E. Topic lists of needs toward CKD self-management

Current care

8. Can you tell me about your ongoing care for the patients with CKD?

(Probe: What are your roles in clinical care? What types of care will you give to patients? If you follow some kinds of protocols for their care? Are there some protocol contains something related to self-management?)

Challenges and barriers

9. Do you have any barriers in the health care of CKD management?
(Probe: Do you have some challenges in patient care? Do you have some barriers to promoting patients' self-management?)

Needs of CKD self-management

10. Is there anything else that should be done to support you in the clinical care of CKD?
(Probe: Do you have some suggestions for the management? What sorts of programs or support should be done to support self-management for patients?)

Appendix 3c. Observation list

Study Setting _____Location of consultation/Clinic _____Details

outpatient clinic/ daily clinical care

.....
(please specify)Healthcare worker description

Male / female Age: _____ Education: _____

Profession: _____

Total years work experience: _____

Years of work experience in community: _____

Patient description

Male / female Age: _____ Stage: _____

Comorbidity: _____

Activity _____

Observer _____Start

_____ : _____ AM/PM

End

_____ : _____ AM/PM

Please circle the option that you observe. If you observe option 2, this would look like:option 1 option 2 / option 3If more than one option is observed, please circle every applicable option

1) Belief, perception toward disease

a) Health care professionals: 1. feelings of CKD 2. concerns of CKD**b) Patients:** 1. Feelings of CKD 2. Changes in life 3. Impacts of CKD 4. Coping with

2) Belief, perception toward self-management

a) Health care professionals: 1. Attitude 2. Subjective norms 3. Perceived control 4. Professional role

b) Patients: 1. Attitude 2. Subjective norms 3. Perceived control 4. Professional role

3) Describe: interaction between the health care professional and the patient

a) Description of the communication (e.g., adherence, future concerns, sensitive and personal issues)

b) Are there times when it has been hard for patients to follow what has been told by health care professionals? Why?

c) Whether patients can ask questions openly with your doctor?

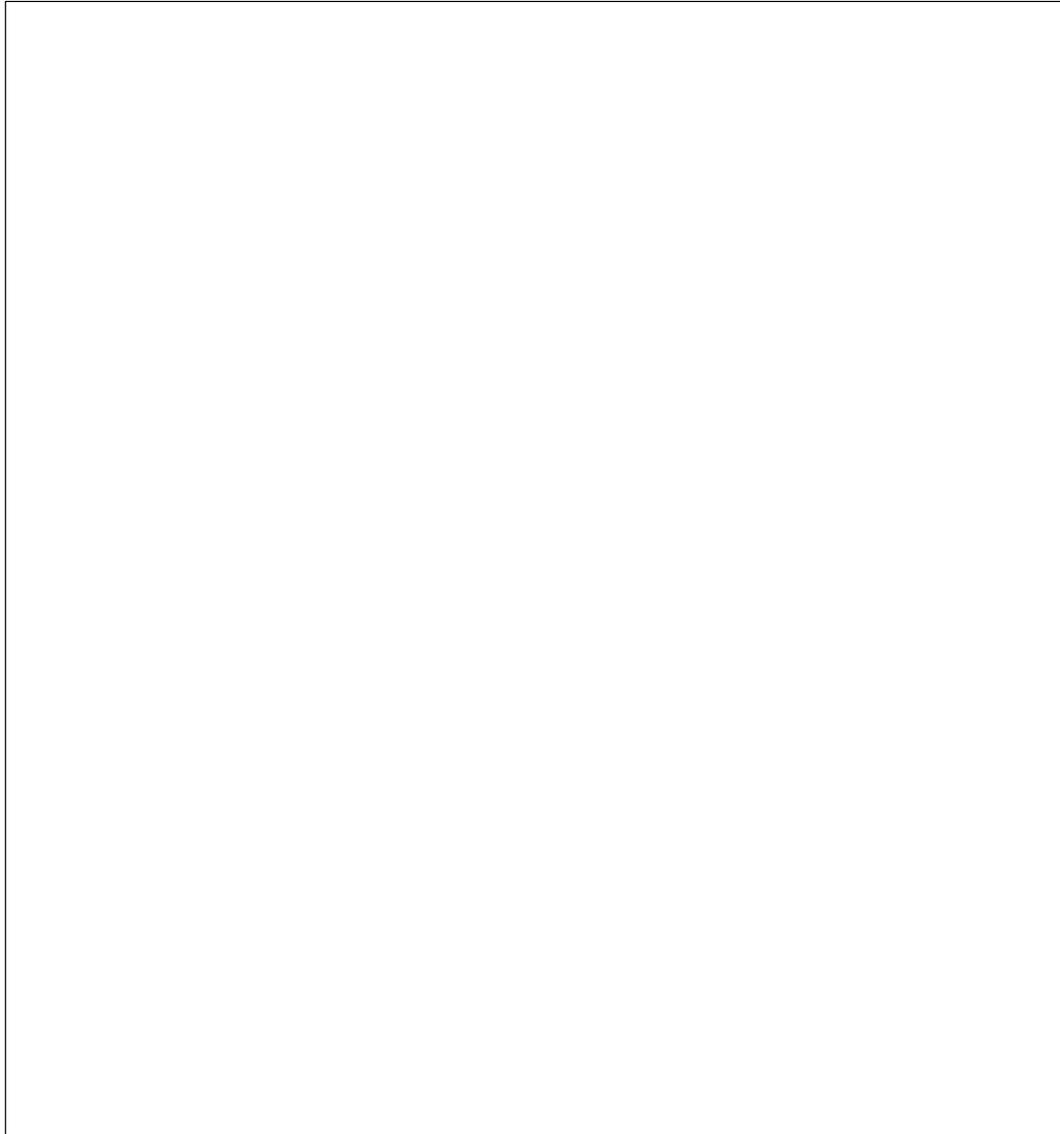
4) Needs of CKD self-management

a) Health care professionals: 1. Current care 2. Challenges and barriers 3. Needs

b) Patients: 1. Ongoing care 2. Challenges, barriers, feelings 3. Needs

c) Caregivers: 1. Current involvement 2. Challenges and barriers 3. Needs

Additional remarks and observations



Appendix 4. Description of interview characteristics

	Value
Interviews	
Patient face-to-face interviews	
No. of patients participating/invited	11/15
Reasons for non participation	Lack of time due to patients' extended waiting time for a physician consultation or intravenous infusion or lack of interest in the research presented
Duration of patient interviews, min	
Range	40-111
Mean \pm SD	55.5 \pm 20.8
Health care professional interviews	
No. of health care professionals interviewed/invited	10/11
Reason for non participation	Lack of time due to work obligations
Duration of interviews with health care professionals, min	
Range	46-136
Mean \pm SD*	67.3 \pm 26.4

*SD, standard deviation.

Appendix 5. An overview of theme and subthemes

Themes and subthemes	Main constructs mentioned	Frequency coded	Percentage mentioned*			Percentage observed†
			Percentage	P (n=11)	HCP (n=10)	
CKD illness perceptions						
Anticipated concerns on diagnosis		28	91%	10/11	10	-‡
Physical consequences		21	48%	10/21	6	4
Psychosocial consequences		78	81%	17/21	8	9
Lifestyle consequences		19	43%	9/21	6	3
Understanding of and motivation towards CKD SM						
Understanding of CKD SM		59	90%	19/21	9	10
	- Adherence to medical advice, treatment as prescribed	13	60%	6/10	5	6
	- Disease knowledge	6	50%	5/10	0	5
Motivation towards CKD SM						
	- Importance of SM	31	67%	14/21	5	9
	- HCP medical advice	11	55%	6/11	6	0
	- Adherence	5	50%	5/10	-	5
	- Follow medical advice	10	45%	5/11	5	-
Current CKD practice						
Current SM practice by patients						
● Medical management						
	-Disease controlling behavior	44	82%	9/11	9	-
	- Medication use	9	64%	7/11	7	-
	- Regular follow-up	10	45%	5/11	5	-
	- Self-monitoring	13	36%	4/11	4	-
	- Symptom management	6	36%	4/11	4	-
	- Peritoneal dialysis	6	27%	3/11	3	-
	-Healthy behavior	39	73%	8/11	8	-
	- Diet restriction	20	73%	8/11	8	-
	- Suggested precautions	12	36%	4/11	4	-
● Role management						
● Emotional management						
● SM skills						
	-Problem-solving and decision Making	58	73%	8/11	8	31%
	-Using resources	49	67%	14/21		
	- Internet	20	73%	8/11	8	-
	- HCP	15	82%	9/11	9	-
	- Hospital brochures	2	18%	2/11	2	-
	- Other patients	3	27%	3/11	3	-

-Partnership with HCP	11	36%	4/11	4	-		
-Goals, action, evaluating	13	36%	4/11	4	-		
Implementation of SM intervention by HCPs	- Health education	6	50%	5/10	-	5	54% 14/26
Barriers, (anticipated) facilitators and needs							
Barriers							
● Knowledge		53	76%	16/21	9	7	
	- General knowledge of CKD	19	57%	12/21	6	6	
	- Knowledge of diet restrictions	21	52%	11/21	7	4	
	- Knowledge of treatment	12	38%	8/21	5	3	
● Environmental context and resources		49	90%	19/21	9	10	
	- Limited resources	31	52%	11/21	4	7	
	- Time constraints	14	90%	9/10	1	9	
● Behavioral regulation		15	55%	6/11	6	-	
● Emotion		9	60%	6/10	-	6	
● Social influence		15	90%	9/10	-	9	
	- Lack of family support	5	50%	5/10	-	5	
	- Communication barrier	8	50%	5/10	-	5	
(anticipated) Facilitators							
● Knowledge		52	57%	12/21	4	8	
● Environmental context and resources		49	71%	15/21	6	9	
	- Access to resources	23	43%	9/21	4	5	
	- Electronic Health	19	48%	10/21	5	5	
● Social influence		42	76%	16/21	7	9	
	- Family support	13	48%	10/21	5	5	
	- Patient-HCP communication	19	43%	9/21	3	6	
● Behavioral regulation		9	45%	5/11	5	-	
Needs							
● Environmental context and resources	- Electronic Health	10	38%	8/21	4	4	
● Knowledge		36	57%	12/21	5	7	31% 8/26

CKD, chronic kidney disease; SM, self-management; P: patient; HCP: health care professional.

* Percentage of stakeholder mentioning the topic in interviews.

† Percentage of observed constructs in observations.

‡ Not applicable.

Appendix 6. Definitions of current self-management practice by patients

Concepts	Definitions in Van de Velde D <i>et al.</i> ¹ and Audulv Å <i>et al.</i> ²
Self-management behaviors	Strategies individuals perform to live well with long-term conditions, including medical, role and emotional management
<ul style="list-style-type: none"> ● Medical management <ul style="list-style-type: none"> -Disease-specific controlling behavior -Healthy behavior ● Role management ● Emotional management 	<ul style="list-style-type: none"> ● It is often disease-specific and includes both very complex and technical tasks (e.g., dialysis at home), as well as quite simple tasks (e.g., taking medicine). <ul style="list-style-type: none"> - Strategies to control symptoms, limit complications and/or disease progression. - Behaviors enacted to enhance health and limit the risk of lifestyle related illness. ● It is deemed to maintain, change or create new meaningful behaviors or life roles with the purpose of managing the disease and its associated effects. It also includes reviewing the roles of an individual and afterwards accomplishing the essential adaptations or changes. ● Emotional management represents the ability to deal with emotions³⁰ such as uncertainty, anger, depression, stress, etc.
Self-management skills	To be able to fulfil this lifetime task, five skills recur when it comes to self-management
<ul style="list-style-type: none"> ● Problem-solving ● Decision-making ● Using resources ● Forming a patient-healthcare professional partnership ● Goal-setting, taking action and evaluating the attainment of goals 	<ul style="list-style-type: none"> ● This consists of problem definition, the generation of possible solutions, solution implementation and the evaluation of results. ● This skill is related to making informed choices. This skill can also be linked to the patient and healthcare professional partnership as self-management entails collaborative decision-making. ● Learning how to find and use the right resources. Such resources could include websites, libraries, community agencies and so on. ● In the partnership between patients and healthcare professionals, the professionals are experts about the disease and the patients are experts about their lives. The patient and the professional occupy equal positions and co-operatively work together. ● It is based on making a short-term action plan and implementing it. Eventually, the person should be able to evaluate whether the goals are met.

1. Van de Velde D, De Zutter F, Satink T, *et al.* Delineating the concept of self-management in chronic conditions: a concept analysis. *BMJ open* 2019;9(7):e027775
2. Audulv A, Ghahari S, Kephart G, *et al.* The Taxonomy of Everyday Self-management Strategies (TEDSS): A framework derived from the literature and refined using empirical data. *Patient Educ Couns* 2019;102(2):367-75.

Appendix 7. Stakeholder-related needs towards CKD practice to support self-management

Domain	Category	Specific needs	Stakeholder group
Environmental context and resources	Electronic Health	● Online video to deliver knowledge during hospitalization	HCP
		● Online consultation between patients and HCPs	HCP
		● Official accounts of Wechat to deliver knowledge	HCP
		● Official website established by the hospital for knowledge search	P
		● Online search for patients' test results	P
		● Online training for patients' self-management knowledge and skills	HCP
		● Practical tools for patients' self-monitoring (e.g., wearable device)	HCP
Knowledge	Healthy behavior knowledge	● Diet restriction (e.g., knowledge of the daily diet required)	HCP, P
		● Precautions in daily life (e.g., avoid smoking and drinking wine)	HCP, P
		● Limiting water intake and how	P
		● The extent for exercise and how	P
	Disease-specific controlling behavior related knowledge	● Medication taking (e.g., side effects of medication)	HCP, P
		● Preventing from anomalies in physiological parameters (e.g., the increase of creatinine)	P
		● Detailed explanation of test results	P
	General knowledge	● General knowledge of CKD (e.g., definition, disease stage)	HCP, P
		● Renal puncture and related precautions	HCP, P

Note: Needs based on responses to interview questions "For patient: Is there anything else that should be done to support you to self-manage CKD? For health care professional, is there anything else that should be done to support you to facilitate patients' self-management?"

CKD, chronic kidney disease; P: patient; HCP: health care professional.