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Patients' and care providers' beliefs, perceptions and needs towards chronic kidney disease self-management in China: a qualitative study

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Title page

Title

Patients' and care providers' beliefs, perceptions and needs towards chronic kidney disease self-management in China: a qualitative study

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ABSTRACT

Objectives

Optimizing disease self-management skills can improve health-related outcomes of patients suffering from chronic kidney disease (CKD). Current research on disease self-management has almost exclusively focused on high-income, Western countries. To support the adaptation and translation of an evidence-based CKD self-management intervention to the Chinese context, we examined the beliefs, perceptions, needs of Chinese CKD patients and health care providers (HCPs) towards CKD self-management.

Design

A qualitative study using semi-structured face-to-face interviews and observations.

Setting

One major tertiary referral hospital in Henan province, China.

Participants

11 adults with a diagnosis of CKD with CKD stage 1-5 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 self-management practice, and (4) barriers, (anticipated) facilitators of and needs towards CKD self-management. Patients and HCPs almost solely mentioned the 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 controlling behaviors and not for instance coping with emotional problems. A paternalistic patient-provider relationship was often present. Finally, the barriers, facilitators of, and needs towards CKD self-management were frequently related to knowledge and environmental context and resources.

Conclusions

The limited understanding of CKD self-management 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, and self-management components

should be tailored by taking into account the existing paternalistic patient-provider 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 chronic kidney disease (CKD) self-management of patients and health care providers in China.
- ▶ The triangulation of data source and framework analysis optimized the internal validity and reliability of our results.
- ▶ As our findings were not quantified, the relative importance of influencing factors (e.g., paternalistic patient-provider relationship) for CKD self-management could not be determined.
- ▶ The health care providers who provided CKD care in the institution were predominantly female and this group may not be representative of all health care providers in Nephrology practice.
- ▶ As we only included participants in China, the transferability and generalizability of the findings to other different cultural contexts were uncertain.

INTRODUCTION

Chronic kidney disease (CKD) is a severe public health problem.^{1, 2} Globally, 697.5 million individuals were 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 characterized by a gradual and irreversible loss of renal function, and categorized into five stages based on the glomerular filtration rate decline.⁵ Patients with CKD often report significant impairment in quality of life⁶ and experience adverse health outcomes.⁷ Also, CKD imposes a substantial economic burden due to its considerable health-related and societal costs.⁸

Disease self-management (hereafter referred to as self-management) is vital to reduce disease burden and control the health care expenditures of patients with chronic disease.^{9, 10} As previously noted,¹¹ self-management comprises three main tasks: medical, emotional, and role management. Hence, self-management is not limited to medical management but also aims to optimize the uptake of new meaningful behaviors or life roles, and promotes adequate coping disease consequences.¹¹ Appropriate self-management has the potential to optimize one's ability to perform the cognitive, behavioral, and emotional responses necessary to maintain a satisfactory quality of life.¹² Also, for patients suffering from CKD, interventions supporting self-management behaviors may improve quality of life and health outcomes.^{13, 14}

Although the potential of self-management interventions to improve CKD patients' health and quality of life is tremendous, mixed results on its effectiveness have been reported.¹⁵ Moreover, research on CKD self-management interventions has mostly focused on high-income countries, whereas CKD disease burden is highest in low- and middle-income countries.¹⁶ To produce meaningful change in these high-burden, low resource countries, we need to tailor the CKD self-management interventions proven effective in high-income settings to the context characteristics of the specific settings. Hence, understanding context-specific needs, beliefs (i.e., an idea or principle judged to be true) and perceptions (i.e., the organized cognitive representations that individuals have about a subject) towards CKD (self-management) is vital for implementation success.¹⁷⁻²²

Therefore, to adapt and prepare an existing evidence-based CKD self-management intervention for implementation in China, we performed a qualitative study to examine the needs, beliefs, perceptions of CKD patients and health care providers (HCPs) towards CKD (self-management) in China. In specific, our aim was to:

- Examine the illness perceptions towards CKD of HCPs and patients;
- Examine the understanding of CKD self-management and the motivation to implement

- CKD self-management of HCPs and patients;
- Examine the current self-management practice of HCPs and patients;
 - Examine the facilitators, barriers, and needs of HCPs and patients towards the implementation of CKD self-management.

METHODS

Overview

This study aimed to gather knowledge on the beliefs, perceptions, needs of CKD patients and HCPs towards CKD (self-management) in China. This knowledge will inform the adaptation and evaluation of a tailored electronic health (eHealth) self-management intervention for CKD patients in China, based on the Dutch Medical Dashboard intervention.^{23, 24} Details on the study protocol have been described elsewhere (<https://www.researchsquare.com/article/rs-13310/v1>, 2020).

We followed the Consolidated Criteria for Reporting Qualitative Health Research (see online supplementary appendix 1).²⁵ This study was approved by the Ethics Committee of the First Affiliated Hospital of Zhengzhou University (reference number 2019-KY-52).

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 16.4% (12 million) of adults in rural areas in Henan suffer from CKD.²⁶ The Department of Nephrology of the hospital has approximately 276 beds; more than 60,000 CKD patients visit the Outpatient Clinic of this department each year.

Individuals eligible for inclusion were 1) patients with a diagnosis of CKD with CKD stage 1-5 and 2) HCPs who worked in the Department of Nephrology. Participants needed to be 18 years or older and spoke Chinese. We followed principles of ‘purposive and convenience sampling’²⁷ to capture diverse samples concerning demographic- (e.g., age) and clinical (e.g., CKD stage) characteristics. Also, we used snowball sampling²⁸ to identify additional participants. 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 the written informed consent to participate. Also, patients and HCPs received a reimbursement (20 RMB of telephone credits) for their time spent on the study.

Data collection

One researcher (HS, Msc, female) conducted semi-structured face-to-face interviews and observations between January 2019 to April 2019. The interviewer had no prior contact with participants. The semi-structured interview guide and observation forms were developed based on the FRESH AIR study,²⁹ examples of similar studies,³⁰ and research team discussions (see online supplementary appendix 2). Also, the interview guide was theory-driven; 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 HCP and a patient 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, observations were conducted with HCPs and patients during patient outpatient clinic follow-up or routine care. Data collection continued until data saturation was reached, and no new concepts or codes emerged from the data. All interviews were audiotaped digitally. After each interview, the interviewer made field notes detailing the interview setting, atmosphere, and participants' non-verbal behaviors. Additionally, we collected participants' demographic- and clinical characteristics via the patient medical records.

Data analysis

A Framework Method³¹ was used to guide our qualitative analysis.

Stage A&B: Transcribing and Familiarization

All audio-taped interviews were anonymized and transcribed verbatim. Also, observation forms were digitalized 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, all transcripts were read the full text to become familiar with the data set.

Stage C: Development of an analytical framework& coding

Atlas.ti for Windows version 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 (<https://www.researchsquare.com/article/rs-13310/v1>, 2020) and the Theoretical Domains Framework (TDF).³² Three transcripts were coded using the initial tree. New codes that emerged were added to the tree, and after discussion with the research team, a final coding tree was agreed upon. Then, one researcher coded all transcripts and observation forms using the final coding tree; codes assigned were verified by a second researcher (WW).

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Stage D: Charting data into the framework matrix

Data were further reduced by formulating within-cases and cross-cases.³³ Next, data were charted into matrices per research question using Microsoft Excel 2010 and reviewed by all authors. The matrix comprised of 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 organized 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.

Patient and public involvement

Patients or the public were not involved in the design, conducting, or participant recruitment in this study.

RESULTS

Participant and Interview Characteristics

A total of 21 face-to-face interviews and 26 observations were conducted (tables 1, 2, see online supplementary appendix 3 for interview characteristics).

Table 1 Characteristics of health care providers

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

*Mean ± standard deviation (range).

Table 2 Characteristics of patients in face-to-face interview

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

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

*Mean ± standard deviation (range).

†Median (inter-quartile range).

Complete data available with the exception of the following variables, with data of body weight available for 9 patients (82%), serum creatinine for 8 patients (73%), eGFR for 9 patients (82%).

Themes

Four major themes emerged for both HCPs and patients; Themes and respective subthemes are described in the following sections with reference to relevant quotes (see table 3-4, online supplementary appendix 4).

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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	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. (Patient 7, female, 32y, CKD 5 with peritoneal dialysis).</i> Q2. <i>I have not even had a cold before. Why do I get this CKD? (Patient 3, female, 40y, CKD 5 with peritoneal dialysis).</i> 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. (Patient 5, male, 35y, CKD 3).</i> 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. (Patient 9, male, 53y, CKD not dialysis).</i>
Physical consequences	Q5. <i>Patients are very weak, and the symptoms of fatigue are more prominent. (HCP6, female, 33y).</i> Q6. <i>[I had] retching and vomiting. Also, I smell the urea when I breathe out. It is really uncomfortable. (Patient 10, CKD 5 with peritoneal dialysis).</i>
Psychosocial consequences	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. (Patient 8, female, 45y, CKD 1).</i> Q8. <i>The biggest impact [of CKD] is being unable to work. I can not make money to support my family. (Patient 5, male, 35y, CKD 3).</i> 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. (Patient 10, 40y, CKD 5 with peritoneal dialysis).</i>
Lifestyle consequences	Q10. <i>The first [influence] is [that I need] to take medicines at home every day and stay at home. (Patient 8, female, 45y, CKD 1).</i> Q11. <i>Because I need to conduct dialysis several times every day, I can not go anywhere. (Patient 7, female, 32y, CKD 5 with peritoneal dialysis).</i>
Understanding of and motivation towards CKD SM	
Understanding of CKD SM	Q12-16 in TextBox1.
Motivation towards CKD SM	Q17. <i>CKD SM is very important...patients with peritoneal dialysis...are with severe symptoms... But patients with good</i>

adherence can even lead the whole family to travel abroad. (HCP1, female, 31y).

Q18. *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.* (Patient 6, male, 34y, CKD 5 not dialysis).

Q19. *We as health care providers 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.* (HCP4, female, 35y).

Q20. *Doctors and nurses are the leading roles, such as...deciding taking medicine. I need to listen to the [medical care of] doctors and nurses.* (Patient 4, male, 37y, CKD 2).

Q21. *I should actively cooperate with treatment, follow the taboos or precautions that the doctors recommended, and cooperate with treatment much better.* (Patient 5, male, 35y, CKD 3).

CKD, chronic kidney disease; HCP: health care provider; Q: quote; SM, self-management.

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

Themes and Subthemes		Representative Quotation
Current CKD SM practice		
SM behavior		
Medical management		Q22. <i>I took medications very regularly. Otherwise, my blood pressure will be high and I can not control it.</i> (Patient 7, female, 32y, CKD 5 with peritoneal dialysis).
		Q23. <i>I paid attention to the [chronic kidney] disease. If I felt uncomfortable, I quickly measured my blood pressure.</i> (Patient 4, male, 37y, CKD 2).
		Q24. <i>My legs were swollen. I started to restrict water [intake]. Then, the edema slowly disappeared.</i> (Patient 8, female, 45y, CKD 1).
		Q25. <i>I eat food based on doctor's requirements every day, low salt and low fat, and high-quality protein.</i> (Patient 5, male, 35y, CKD 3).
		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, female, 51y, CKD 3).
Role and emotional management		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, male, 35y, CKD 3).
		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, male, 42y, CKD 5 with peritoneal dialysis).
		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, female, 51y, CKD 3).
		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, male, 35y, CKD 3).
SM skills		Q31. <i>There is a diet list [for CKD]. Also, I searched the information by asking other patients during hospitalization.</i> (Patient 6, male, 34y, CKD 5 not dialysis).
		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, male, 42y, CKD 5 with peritoneal dialysis).
		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, male, 37y, CKD 2).
		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, female, 31y).
Implementation of CKD SM		

**Barriers, (anticipated)
facilitators and needs
toward CKD SM**

Barriers

Knowledge

Q35. *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. (Patient 7, female, 32y, CKD 5 with peritoneal dialysis).*

*Environmental context and
resources*

Q36. *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. (HCP3, female, 27y).*

Q37. *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. (HCP9, female, 39y).*

Social influence

Q38. *Patients' families do not follow the strict rules such as dietary habits to assist patients to manage themselves. (HCP2, female, 30y).*

Q39. *Some patients want to give CKD treatment up. Then, it can be challenging to communicate with them. They would not adhere to lifestyle changes. (HCP3, female, 27y).*

(anticipated) Facilitators

Knowledge

Q40. *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. (HCP3, female, 27y).*

*Environmental context and
resources*

Q41. *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. (HCP4, female, 35y).*

Social influence

Q42. *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. (Patient 11, female, 51y, CKD 3).*

Q43. *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. (Patient 3, female, 40y, CKD 5 with peritoneal dialysis).*

Needs

Knowledge

Q44. *Patients need related knowledge like the diet [restrictions]...such as he can not eat this food or eat less. (HCP4, female, 35y).*

*Environmental context and
resources*

Q45. *I need clear information online...what food I can eat online is not clear and not detailed...The information is conflicting... (Patient 6, male, 34y, CKD 5 not dialysis).*

CKD, chronic kidney disease; HCP: health care provider; Q: quote; SM, self-management.

Theme 1: CKD Illness Perceptions

CKD diagnosis and anticipated consequences of illness (Patient Generated)

More than half of the patients mentioned that they had a ‘late’ CKD diagnosis, and attributed this to their limited awareness and recognition of CKD symptoms (table 3, Q1). CKD patients mentioned that initially, it was difficult to understand and accept 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).

Physical, Psychosocial and Lifestyle Consequences of CKD (HCP and Patient Generated)

Patients frequently mentioned they felt ‘discomfort’ and ‘weakness’ because of symptoms such as fatigue (table 3, Q5), especially those with CKD stage 4-5 (table 3, Q6). Also, both HCPs and patients 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 they lost their job and faced difficulties to re-enter 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 supplementary appendix 4).

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

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

Understanding of CKD self-management (HCP and Patient Generated)

HCPs and patients both mentioned to considered CKD self-management solely as ‘medical management’. However, how they expressed this understanding differed significantly (textbox 1).

More than half of HCPs and patients described CKD self-management as ‘adherence to medical advice and treatment as prescribed’ (textbox 1, Q12). Patients also described CKD self-management as ‘being obedient’, literally quoting their HCPs medical advice (textbox 1, Q14-16). Also, HCPs expressed that improving patient disease knowledge as the priority of CKD self-management (textbox 1, Q13).

Textbox 1. Understanding of CKD Self-Management with Example Responses**Health care providers' responses towards the understanding of CKD SM**

- Adherence to medical advice and treatment as prescribed Q12. *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.* (HCP3, female, 27y).
- Disease knowledge Q13. *[CKD] patients 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...* (HCP5, female, 34y).

CKD Patients' responses towards the understanding of CKD SM

- Adherence to medical advice and treatment as prescribed Q14. *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.* (Patient 7, female, 32y, CKD 5 with peritoneal dialysis).
- Quoting care providers' medical advice Q15. *Doctors said that I can not exercise too much, eat spicy [food], and should eat less salt.* (Patient 2, female, 18y, CKD 1).
- Q16. *I hear from nurses that I need to take care of self-protection, paying attention to the sanitation of environment of dialysis.* (Patient 1, male, 42y, CKD 5 with peritoneal dialysis).

Note: Responses to interview questions: "Do you know what self-management is? what do you think self-management entails for patients with chronic kidney disease?"

Abbreviation: CKD, chronic kidney disease; SM, self-management.

Motivation towards CKD self-management (HCP and Patient Generated)

More than half of HCPs considered CKD self-management as a necessity to control patients' symptoms and improve health-related outcomes (table 3, Q17). Patients expressed the belief that self-management could slow down their disease progression and optimize health status (table 3, Q18).

Half of the HCPs 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, Q19). Patients believed that HCPs were sufficiently knowledgeable to help them manage their disease (table 3, Q20), and named their responsibilities within CKD self-management as 'strictly following medical advice' (table 3, Q21).

Theme 3: Current CKD self-management practice

All concepts related to self-management are operationalized in online supplementary appendix 5.^{34, 35}

Self-management behaviors (Patient Generated)

When asked about their current CKD self-management, patients mostly named concepts related to medical management, such as Disease-specific Controlling Behaviors (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), symptom management (table 4, Q24). Additionally, more than half of the patients mentioned the performance of healthy behaviors, such as diet restrictions (table 4, Q25). The discussion of patients' DCBs was frequently observed in consultations (see online supplementary appendix 4).

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).

Self-management Skills (Patient Generated)

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 via various sources including their HCPs, the internet, hospital brochures, and via contact with other patients (table 4, Q30-31). These findings were consistent with observation data (see online supplementary appendix 4).

Other aspects of CKD self-management skills, such as partnering with their HCPs 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).

Implementation of CKD self-management (HCP Generated)

HCPs named 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 supplementary appendix 4).

Theme 4: Barriers, (anticipated) facilitators and needs toward CKD self-management

Identified barriers, facilitators, and needs towards CKD self-management were classified using the TDF³² (details provided in Table 5 and online supplementary appendix 6).

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

TDF domain		HCP	Patient	Operationalization
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
Behavioral regulation			X	Patients' insufficient information on lifestyle behavior 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-care provider 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-care provider communication
Behavioral regulation			X	Patients' being able to adhere to the lifestyle changes prescribed

TDF, Theoretical Domains Framework; HCP: health care provider.

* Domain mentioned by stakeholder.

Barriers

HCPs and patients frequently named a lack of knowledge of CKD (e.g., symptoms) and difficulties making necessary lifestyle changes as barriers to patients’ self-management outcomes (table 4, Q35). Moreover, HCPs and patients 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 they felt patients’ emotional problems interfered with the patient-care provider communication, impeding CKD patients’ self-management (table 4, Q39).

(anticipated) Facilitators & needs

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

DISCUSSION

The beliefs, perceptions, and needs of CKD patients and HCPs regarding CKD self-management were examined. Textbox 2 presents our main findings and their implications.

Textbox 2. Main findings and implications for this study.

- Patients and HCPs almost solely mention the medical management of CKD. Self-management is largely unknown or misinterpreted as adherence to medical treatment.
- Considering the heavy psychosocial impact of CKD mentioned by patients and HCPs, self-management support should focus on enhancing patients’ role management and emotional skills.
- A paternalistic provider-patient relationship is often present. Self-management intervention developers should tailor self-management components by taking into account this existing relationship.
- Enhancing patient self-management-knowledge, -motivation and -behavioral skills should be considered for successful development or adaptation of CKD self-management interventions.

Self-management comprises medical, emotional, and role management.¹¹ It aims to optimize the uptake of meaningful behaviors or life roles, promoting adequate coping with disease consequences.¹¹ In our study, we found that self-management was largely unknown or misinterpreted as adherence to medical treatment. This limited understanding might influence patients' and HCPs' display of self-management behaviors and uptake of interventions.^{35, 36}

The vast majority of patients indicated they only performed DCBs. Coping with psychosocial problems was not mentioned, or solely its absence was noted. This lack of psychosocial-related self-management behaviors might be due to insufficient knowledge of psychosocial problems by patients and the lack of skills of HCPs to manage psychosocial issues.^{37, 38} Noteworthy is also that essential skills to improve patients' self-efficacy and ultimately their health behaviors,³⁹⁻⁴¹ such as goal setting and action planning, were almost not mentioned by patients or HCPs.

Consistent with previous literature,⁴² we found that patients with CKD stage 4-5 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.⁴² This could be explained by the fact that patients cannot ask for things they do not know: Patients' misinterpretation of self-management could limit their expression of actual needs.

Our findings indicate that a paternalistic patient-provider relationship was often present. Within a paternalistic relationship, HCPs have greater control, and patients are mostly passive participants in their disease management.^{43, 44} Patient autonomy is a core principle of the doctor-patient interaction in Western cultures.^{44, 45} However, the paternalistic relationship can be valuable and even essential to provide high-quality health care in some cultural contexts where patients prefer a paternalistic approach over autonomy. Under certain conditions, a paternalistic relationship has been shown to improve health outcomes and treatment adherence in some cultural contexts.^{46, 47} Therefore, when translating Western CKD self-management intervention to other settings, developers should be mindful of the advantages of (aspects of) the paternalistic relationship, as opposed to try and eliminate this relationship all together.

Lack of knowledge was frequently identified as a barrier to patients' self-management behavior, as was limited social support from family and HCPs. Previous literature corroborates these findings.⁴⁸⁻⁵⁰ Furthermore, according to health behavior models such as the Health Belief Model and the Information-motivation-behavioral skills model, individuals who have well-informed knowledge, strong motivation to act, and possess the requisite behavioral skills will be likely to improve health behavior and related outcomes.⁵¹ Although patients and HCPs put the focus

on CKD (self-management) health education, only increasing patients' knowledge was insufficient to modify their behavior.⁵² Thus, we highlighted the importance of improving patients' motivation and behavioral skills to facilitate their CKD self-management.

Our research provides several implications for the development, adaptation, and implementation of self-management interventions for CKD patients in China, and beyond.

First, education on the core principles, application, and benefits of self-management is needed, for both HCPs and patients. For instance, a designated self-management booklet and related e-learning module may be developed for China and beyond, providing an overview of self-management concepts and its benefits for patients and providers.⁵³ Second, we advise future research and developers in China to focus on the psychosocial aspects of CKD, contemplating the use of cognitive-behavioral therapy elements.^{54, 55} Third, we suggest to include goal setting and action planning elements.⁵⁶

Considering the possible preference for, and potential benefits of, the paternalistic provider-patient relationship in China, we advise not to try and eliminate but to incorporate aspects of the paternalistic relationship in the self-management intervention. For instance, as patients prefer paternalistic medical advice, pre-formulated checklists of self-management tasks may be developed for patients. Also, eHealth might be the designated medium to introduce self-management practice,⁵⁷ in specific for developing countries,^{58, 59} as it is accessible, easy, and affordable, and can support the relationship between patients and HCPs. Additionally, digital decision aids⁶⁰ for HCPs and patients might effectively guide patients to make informed decisions and improve self-management and autonomy.^{61, 62} Moreover, the use of eHealth is supported by HCPs and patients: they also expressed the need for eHealth to optimize self-management.

We furthermore suggest creating a national, trustworthy health education resource platform to address the needs expressed by patients for access to reliable medical information. For instance, an evidence-based health information website (<http://www.thuisarts.nl>) in the Netherlands has effectively improved self-management and reduced healthcare usage.⁶³ Also, serious gaming has the potential to improve CKD patients' motivation and behaviors of self-management. China has numerous internet and mobile phone users,⁶⁴ and serious gaming is cost-effective, flexible, portable, and can evoke intense interest among HCPs and patients to engage in regular self-management (implementation) for a long time.^{65, 66}

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. One major strength of our study is the

triangulation of data sources, optimizing the internal validity of our results. Other strategies to improve the reliability and internal validity were furthermore adopted; all interviews were recorded and transcribed verbatim, and data analysis was performed via a framework approach³¹ using analytical software. Data was reduced in multiple steps through the formulation of narratives and within- and cross-case comparisons.³³ Additionally, the research approach used and the results of our study might apply to other developing countries that have similar context characteristics.

Nevertheless, there are also limitations. First, we only included participants in China. The transferability and generalizability of the findings to other different cultural contexts were uncertain. Second, as our findings were not quantified, the relative importance of influencing factors (e.g., paternalistic patient-provider relationship) for CKD self-management could not be determined. Third, 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 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 summarized her interpretation of participants' answers to ask for clarifications and confirmation. Also, the triangulation of data sources could ensure the reliability and internal validity of our results.

CONCLUSION

This study provides a comprehensive overview of patients' and HCPs' beliefs, perceptions, and needs towards CKD self-management in China. To optimize 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. In this approach, selected self-management intervention elements can be implemented using eHealth medium.

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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. RK, PB, 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.

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Competing interests

None declared.

Patient consent for publication

Not required.

Ethics approval

The study has been approved by the Ethics Committee of the First Affiliated Hospital of Zhengzhou University, reference number (2019-KY-52). Written informed consent were obtained from all study participants before they were enrolled in the study.

Data availability statement

Extra data is available upon reasonable request by emailing the corresponding author HS.

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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 7-8
<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 8
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Online supplementary appendix 3
<i>Setting</i>		

14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Page 6-7
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 9-10
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 7 and Online supplementary appendix 2
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	No, see online supplementary appendix 3
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 3
22. Data saturation	Was data saturation discussed?	Page 7 and Online supplementary appendix 3
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 7
25. Description of the coding tree	Did authors provide a description of the coding tree?	Page 7
26. Derivation of themes	Were themes identified in advance or derived from the data?	Page 7
27. Software	What software, if applicable, was used to manage the data?	Page 7
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. Semi-structured interview guide and observation forms

Appendix 2a. Interview guide: Healthcare provider

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 CKD patients? 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 CKD patients?
(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 CKD patients?

(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?)

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Appendix 2b. Interview guide: Chronic Kidney Disease Patients

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

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3 9. How do you feel of your CKD care or the current care provided to you?
4 (Probe: What are good aspects of CKD care? What are the problems, challenges of CKD
5 care? What are the problems, challenges of managing the CKD by yourself?)
6
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8 Needs of CKD self-management
9

- 10 10. Is there anything else that should be done to support you to manage CKD?
11 (Probe: What for CKD management should be done in the future, when, and from whom?
12 What support should be done to support your self-management of CKD?
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Appendix 2c. 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 3

If more than one option is observed, please circle every applicable option

- 1) Belief, perception toward disease
- a) Care providers: 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) Care providers: 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 healthcare 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 care providers?; Why?

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

4) Needs of CKD self-management

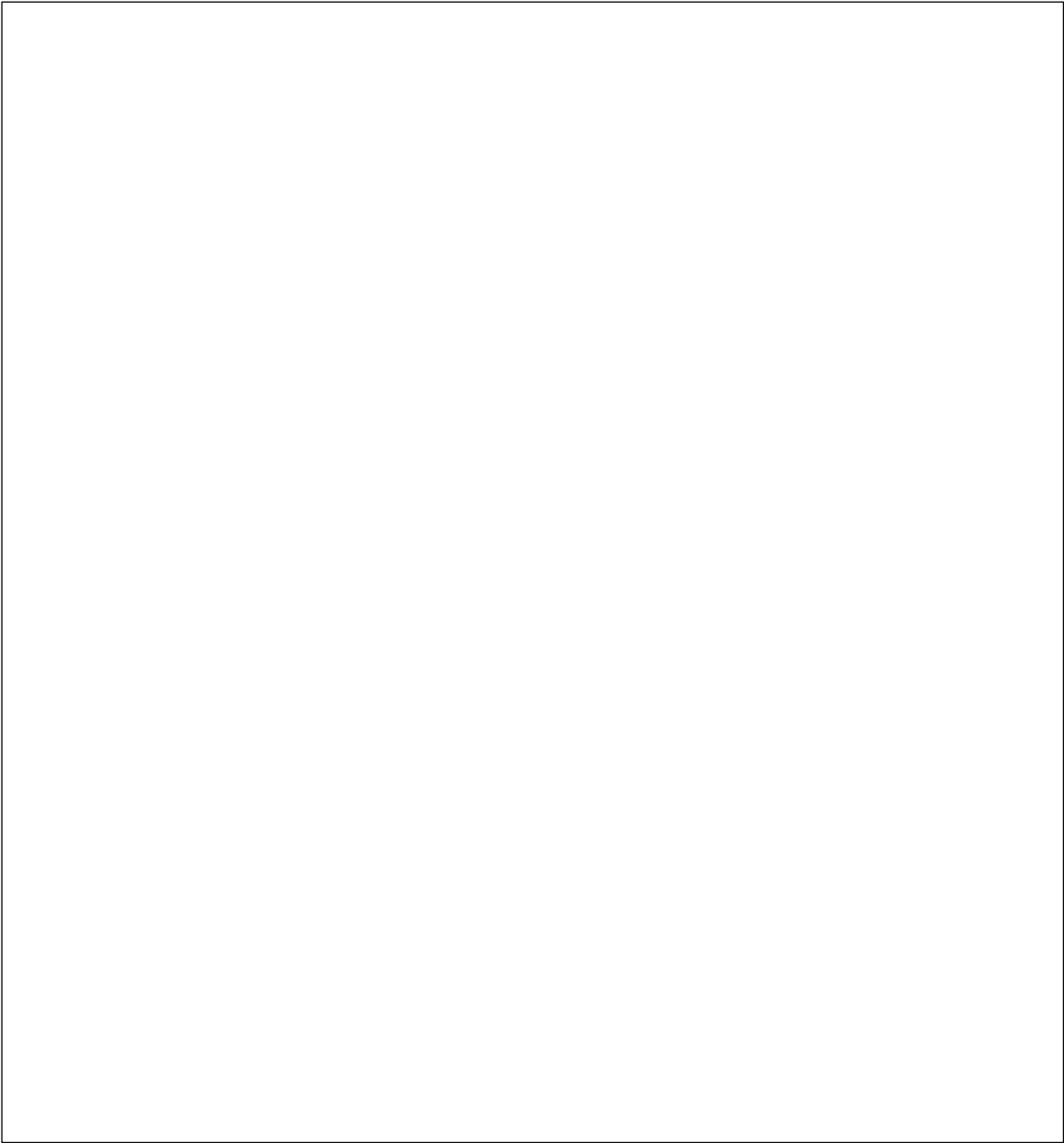
a) Care providers: 1. Current care 2. Challenges and barriers 3. Needs

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

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Appendix 3. Description of interviews and saturation Tables

	Value
Interviews	
Patient face-to-face interviews	
No. of patients participating/invited	11/15
Reasons for non participation	Lack of time due to waiting for patient rounds or Intravenous infusion; Lack of interest in research; Lack of physical strength to participate in research
Duration of patient interviews, min	
Range	40-111
Mean \pm SD	55.5 \pm 20.8
Health care provider interviews	
No. of health care providers interviewed/invited	10/11
Reason for non participation	Lack of time due to medical work
Duration of interviews with health care providers, min	
Range	46-136
Mean \pm SD	67.3 \pm 26.4
Saturation tables	
Patient saturation table	
No. of codes generated in face-to-face interviews	148
Point of data saturation	11th interview
Health care provider saturation table	
No. of codes generated	107
Point of data saturation	10th interview

SD, standard deviation.

Appendix 4. An overview of theme and subthemes

Themes and subthemes	Main constructs mentioned	Frequency coded	Percentage mentioned*				Percentage observed†	
			Percentage		HCP (n=10)	P (n=11)		
CKD illness perceptions								
Anticipated concerns on diagnosis		28	91%	10/11	-‡	10		
Physical consequences		21	48%	10/21	4	6	35%	9/26
Psychosocial consequences		78	81%	17/21	9	8	15%	4/26
Lifestyle consequences		19	43%	9/21	3	6		
Understanding of and motivation towards CKD SM								
Understanding of CKD SM		59	90%	19/21	10	9		
	- Adherence to medical advice, treatment as prescribed	13	60%	6/10	6	5		
	- Disease knowledge	6	50%	5/10	5	0		
Motivation towards CKD SM								
	- Importance of SM	31	67%	14/21	9	5		
	- HCP medical advice	11	55%	6/11	0	6		
	- Adherence	5	50%	5/10	5	-		
	- Follow medical advice	10	45%	5/11	-	5		
Current CKD SM practice								
SM behavior								
• Medical management								
-Disease controlling behavior		44	82%	9/11	-	9	46%	12/26
	- Medication use	9	64%	7/11	-	7	27%	7/26
	- Regular follow-up	10	45%	5/11	-	5	12%	3/26
	- Self-monitoring	13	36%	4/11	-	4		
	- Symptom management	6	36%	4/11	-	4	23%	6/26
	- 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		8	27%	3/11		3		
• Emotional management		2	18%	2/11		2		
SM skills								
• Problem-solving and decision Making		58	73%	8/11		8	31%	8/26
• Using resources		49	67%	14/21				
	- Internet	20	73%	8/11	-	8	4%	1/26
	- HCP	15	82%	9/11	-	9	35%	9/26
	- 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 CKD SM	6	50%	5/10	5	-	54% 14/26
Barriers, (anticipated) facilitators and needs						
Barriers						
● Knowledge	53	76%	16/21	7	9	
- General knowledge of CKD	19	57%	12/21	6	6	
- Knowledge of diet restrictions	21	52%	11/21	4	7	
- knowledge of treatment	12	38%	8/21	3	5	
● Environmental context and resources	49	90%	19/21	10	9	
- Limited resources	31	52%	11/21	7	4	
- Time constraints	14	90%	9/10	9	1	
● 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	8	4	
● Environmental context and resources	49	71%	15/21	9	6	
- Access to resources	23	43%	9/21	5	4	
- Electronic Health	19	48%	10/21	5	5	
● Social influence	42	76%	16/21	9	7	
- Family support	13	48%	10/21	5	5	
- Patient-HCP communication	19	43%	9/21	6	3	
● Behavioral regulation	9	45%	5/11	-	5	
Needs						
● Environmental context and resources	10	38%	8/21	4	4	
● Knowledge	36	57%	12/21	7	5	31% 8/26

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

* Percentage of stakeholder mentioning the topic in interviews.

† Percentage of observed constructs in observations.

‡ Not applicable.

Appendix 5. Definitions of current self-management practice

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
• Medical management	• 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).
-Disease-specific controlling behavior	- Strategies to control symptoms, limit complications and/or disease progression.
-Healthy behavior	- Behaviors enacted to enhance health and limit the risk of lifestyle related illness.
• Role management	• 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	• Emotional management represents the ability to deal with emotions ³⁰ 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
• Problem-solving	• This consists of problem definition, the generation of possible solutions, solution implementation and the evaluation of results.
• Decision-making	• This skill is related to making informed choices. This skill can also be linked to the patient and healthcare provider partnership as self-management entails collaborative decision-making.
• Using resources	• Learning how to find and use the right resources. Such resources could include websites, libraries, community agencies and so on.
• Forming a patient-healthcare provider partnership	• In the partnership between patients and healthcare providers, the professionals are experts about the disease and the patients are experts about their lives. The patient and the provider occupy equal positions and co-operatively work together.
• Goal-setting, taking action and evaluating the attainment of goals	• 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 6. Stakeholder-related needs towards for CKD self-management practice

Domain	Category	Specific needs	Stakeholder group
Environmental context and resources	Electronic Health	• Online video to deliver knowledge during hospitalization	HCP
		• Online consultation between HCPs and patients	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
Knowledge	Healthy behavior knowledge	• Practical tools for patients' self-monitoring (e.g., wearable device)	HCP
		• 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 care provider, 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 provider.

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 7-8
<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 8
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Online supplementary appendix 3
<i>Setting</i>		

14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Page 6-7
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 9-10
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Page 7 and Online supplementary appendix 2
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No, see online supplementary appendix 3
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 3
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Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	Page 7
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<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

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Secondary Subject Heading:	Public health, Qualitative research
Keywords:	PUBLIC HEALTH, Chronic renal failure < NEPHROLOGY, QUALITATIVE RESEARCH

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Title page**Title**

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

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1 ABSTRACT

2 Objectives

3 To support the adaptation and translation of an evidence-based CKD self-management
4 intervention to the Chinese context, we examined the beliefs, perceptions and needs of Chinese
5 patients with CKD and health care professionals (HCPs) towards CKD self-management.

6 Design

7 A basic interpretive, cross-sectional qualitative study comprising semi-structured interviews
8 and observations.

9 Setting

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

11 Participants

12 11 adults with a diagnosis of CKD with CKD stages G1-G5 and 10 HCPs who worked in the
13 Department of Nephrology.

14 Results

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

24 Conclusions

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

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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 health care professionals in China.
- ▶ The triangulation of data sources and framework method analysis optimized the internal validity and reliability of our results.
- ▶ As our findings were not quantified, the relative importance of influencing factors (e.g., paternalistic patient-health care professional relationships) for CKD self-management could not be determined.
- ▶ The health care professionals who provided CKD care in the institution were predominantly female and this group may not be representative of all health care 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 characterized by a gradual and irreversible loss of renal function and is categorized 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 health care expenditures for patients with chronic disease.^{9, 10} As previously noted,¹¹ self-management is comprised of three main tasks: medical, emotional, and role management. Hence, self-management is not limited to medical management but also aims to optimize the uptake of new meaningful behaviors or life roles and it promotes adequate coping disease consequences.¹¹ Appropriate self-management has the potential to optimize one's ability to perform the cognitive, behavioral, and emotional behavior necessary to maintaining a satisfactory health-related quality of life.¹² Also, for patients with CKD, self-management interventions may not only improve self-management behaviors,¹³⁻¹⁵ but also disease-specific knowledge,¹³ health-related quality of life,¹⁶ 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 met²⁴ 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- 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 optimize chances of

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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 health care 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 (<https://www.researchsquare.com/article/rs-13310/v1>, 2020).

We followed the Consolidated Criteria for Reporting Qualitative Health Research (see online supplementary appendix 1).³¹ This study was approved by the Ethics Committee of the First Affiliated Hospital of Zhengzhou University (reference number 2019-KY-52).

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.³² 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.^{33, 34} 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’³⁵ to capture a diverse sample. Two sampling frames were used. The sampling frame for patients comprised the following variables: CKD stage, gender, age range. The sampling frame of HCPs comprised the variables: work experience, profession, gender and age. Also, we

used snowball sampling³⁶ 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 semi-structured face-to-face interviews and observations (see online supplementary appendix 2) between January 2019 to April 2019. The interviewer had no prior contact with participants. The semi-structured interview guide and observation forms were developed based on the FRESH AIR study,³⁷ examples of similar studies³⁸ and research team discussions (see online supplementary 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 a 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 observations³⁹ were conducted during patient outpatient clinic follow-up or during routine care visits. The behavior by and conversation between patient and HCP were both observed. The observations were used to triangulate the interview data, to identify potential differences and similarities between what was said to happen when considering self-management behaviors (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.⁴⁰ All interviews were audiotaped digitally. After each interview, the interviewer made field notes detailing the interview setting, atmosphere, and participants' non-verbal behaviors. Additionally, we collected demographic- and clinical characteristics of the participants from the patient medical records.

Data analysis

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1 A Framework Method⁴¹ was used to guide our qualitative analysis.

2 Stage A&B: Transcribing and Familiarization

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

8 Stage C: Development of an analytical framework& coding

9 Atlas.ti for Windows version 7.5.18 (Scientific Software development, Berlin) was used for
10 data analysis. We built initial coding trees based on the theoretical framework developed in our
11 study protocol and the Theoretical Domains Framework (TDF).⁴² Three transcripts were coded
12 using the initial tree. New codes that emerged were added to the tree. After discussion among
13 the research team, a final coding tree was agreed upon. Then, one researcher coded all
14 transcripts and observation forms using the final coding tree. The assigned codes were verified
15 by a second researcher (WW).

16 Stage D: Charting data into the framework matrix

17 Data were further reduced by formulating within-cases and cross-cases.⁴³ Next, data were
18 charted into matrices per research question using Microsoft Excel 2010 and reviewed by all
19 authors. The matrix comprised of one row per participant and one column per code.

20 Stage E: Interpreting the data

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

26 **Establishing rigor in the data collection and analysis process**

27 Rigor in data collection and analysis, by ensuring credibility, confirmability, dependability,
28 transferability and authenticity, was achieved in the following ways.⁴⁴ Two team members most
29 closely involved in the fieldwork (HS, WW) met frequently to discuss the constancy of the data
30 collection process and (preliminary) analysis. At regular intervals, meetings were held with
31 members of the wider research team with extensive qualitative (RK) and clinical (PB)

1 experience to discuss codes and categories emerging from the analysis. Also, the framework
2 approach to data analysis allowed data to be compared through the formulation of narratives
3 (in-depth focus) and within- and cross-case comparisons (comparative focus). Additionally,
4 during data analysis, the two fieldwork researchers kept a research diary and made reflective
5 notes.

6 **Reflexivity**

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

17 **Patient and public involvement**

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

21 **RESULTS**

22 **Participant and Interview Characteristics**

23 A total of 21 face-to-face interviews and 26 observations were conducted (tables 1-2). Out of
24 15 approached patients, 11 patients (73%) agreed to participate in the interview study. Out of
25 11 approached HCPs, 10 (91%) HCPs agreed. Reasons for refusal to participate included a lack
26 of time due to patients' extended waiting time for a physician consultation or intravenous
27 infusion, or lack of interest in the research presented. Reasons reported by HCPs included a
28 lack of time due to work obligations (see online supplementary appendix 4 for interview
29 characteristics). No significant differences were observed between the final sample and those
30 who refused to participate.

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

Characteristics	Value (N = 11)
Age,y*	38.9 ± 9.6 (18-53)
Age category	
18-28y	1 (9%)
29-39y	4 (36%)
40-50y	4 (36%)
51-61y	2 (19%)
Sex	
Male	5 (46%)
Female	6 (54%)
Marital status	
Never married	1 (9%)
Married	9 (82%)
Divorced	1 (9%)
Highest level of education completed	
≤Primary school	3 (27%)
Middle school	3 (27%)
≥High school graduate	5 (46%)
Employment status	
Employed (full time & part-time)	2 (18%)
Not employed	7 (64%)
Farming	0 (0%)
Student	1 (9%)
Retired	1 (9%)
Time since CKD diagnosis	
<1y	5 (46%)
1-5y	3 (27%)
>5y	3 (27%)
Current CKD stage	
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)
Hemoglobin, g/L *	105.8±28.5 (53.1-158)
Serum creatinine, ummol/L *	523.6±519.3 (62-1380)
eGFR, ml/min/1.73m ² †	13.7 (3.6-92.7)

CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate.
*Mean ± standard deviation (range).
†Median (inter-quartile range).
Complete data available with the exception of the following variables, with data of body weight available for 9 patients (82%), serum creatinine for 8 patients (73%), eGFR for 9 patients (82%).

Table 2 Characteristics of health care professionals

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

*Mean ± standard deviation (range).

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 table 3-4, online supplementary appendix 5).

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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	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. (Patient 7, 29-39y, CKD G4-G5).</i> Q2. <i>I have not even had a cold before. Why do I get this CKD? (Patient 3, 40-50y, CKD G4-G5).</i> 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. (Patient 5, 29-39y, CKD G1-G3).</i> 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. (Patient 9, 51-61y, CKD G4-G5).</i>
Physical consequences	Q5. <i>Patients are very weak, and the symptoms of fatigue are more prominent. (HCP6, 29-39y).</i> Q6. <i>[I had] retching and vomiting. Also, I smell the urea when I breathe out. It is really uncomfortable. (Patient 10, 40-50y, CKD G4-G5).</i>
Psychosocial consequences	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. (Patient 8, 40-50y, CKD G1-G3).</i> Q8. <i>The biggest impact [of CKD] is being unable to work. I can not make money to support my family. (Patient 5, 29-39y, CKD G1-G3).</i> 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. (Patient 10, 40-50y, CKD G4-G5).</i>
Lifestyle consequences	Q10. <i>The first [influence] is [that I need] to take medicines at home every day and stay at home. (Patient 8, 40-50y, CKD G1-G3).</i> Q11. <i>Because I need to conduct dialysis several times every day, I can not go anywhere. (Patient 7, 29-39y, CKD G4-G5).</i>
Understanding of and motivation towards CKD SM	
Understanding of CKD SM Patients' responses towards the understanding of CKD SM	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. (Patient 7, 29-</i>

- 39y, CKD G4-G5).
- Q13. *Doctors said that I can not exercise too much, eat spicy [food], and should eat less salt.* (Patient 2, 18-28y, CKD G1-G3).
- Q14. *I hear from nurses that I need to take care of self-protection, paying attention to the sanitation of environment of dialysis.* (Patient 1, 40-50y, CKD G4-G5).
- HCPs' responses towards the understanding of CKD SM Q15. *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.* (HCP3, 18-28y).
- Q16. *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...* (HCP5, 29-39y).
- Motivation towards CKD SM Q17. *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.* (Patient 6, 29-39y, CKD G4-G5).
- Q18. *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.* (HCP1, 29-39y).
- Q19. *Doctors and nurses are the leading roles, such as...deciding taking medicine. I need to listen to the [medical care of] doctors and nurses.* (Patient 4, 29-39y, CKD G1-G3).
- Q20. *I should actively cooperate with treatment, follow the taboos or precautions that the doctors recommended, and cooperate with treatment much better.* (Patient 5, 29-39y, CKD G1-G3).
- Q21. *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.* (HCP4, 29-39y).

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

1 **Table 4 Representative quotations on current CKD practice, barriers, (anticipated) facilitators**
2 **and needs toward CKD self-management**

Themes and Subthemes		Representative Quotation
Current CKD practice		
Current SM practice by patients		
Medical management		Q22. <i>I took medications very regularly. Otherwise, my blood pressure will be high and I can not control it.</i> (Patient 7, 29-39y, CKD G4-G5).
		Q23. <i>I paid attention to the [chronic kidney] disease. If I felt uncomfortable, I quickly measured my blood pressure.</i> (Patient 4, 29-39y, CKD G1-G3).
		Q24. <i>My legs were swollen. I started to restrict water [intake]. Then, the edema slowly disappeared.</i> (Patient 8, 40-50y, CKD G1-G3).
		Q25. <i>I eat food based on doctor's requirements every day, low salt and low fat, and high-quality protein.</i> (Patient 5, 29-39y, CKD G1-G3).
		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, 51-61y, CKD G1-G3).
Role and emotional management		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, 29-39y, CKD G1-G3).
		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, 40-50y, CKD G4-G5).
		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, 51-61y, CKD G1-G3).
SM skills		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, 29-39y, CKD G1-G3).
		Q31. <i>There is a diet list [for CKD]. Also, I searched the information by asking other patients during hospitalization.</i> (Patient 6, 29-39y, CKD G4-G5).
		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, 40-50y, CKD G4-G5).
		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, 29-39y, CKD G1-G3).
		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, 29-39y).
Implementation of SM intervention by HCPs		

**Barriers, (anticipated)
facilitators and needs
toward CKD SM**

Barriers

Knowledge

Q35. *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. (Patient 7, 29-39y, CKD G4-G5).*

*Environmental context and
resources*

Q36. *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. (HCP3, 18-28y).*

Q37. *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. (HCP9, 29-39y).*

Social influence

Q38. *Patients' families do not follow the strict rules such as dietary habits to assist patients to manage themselves. (HCP2, 29-39y).*

Q39. *Some patients want to give CKD treatment up. Then, it can be challenging to communicate with them. They would not adhere to lifestyle changes. (HCP3, 18-28y).*

(anticipated) Facilitators

Knowledge

Q40. *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. (HCP3, 18-28y).*

*Environmental context and
resources*

Q41. *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. (HCP4, 29-39y).*

Social influence

Q42. *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. (Patient 11, 51-61y, CKD G1-G3).*

Q43. *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. (Patient 3, 40-50y, CKD G4-G5).*

Needs

Knowledge

Q44. *Patients need related knowledge like the diet [restrictions]...such as he can not eat this food or eat less. (HCP4, 29-39y).*

*Environmental context and
resources*

Q45. *I need clear information online...what food I can eat online is not clear and not detailed...The information is conflicting... (Patient 6, 29-39y, CKD G4-G5).*

1 CKD, chronic kidney disease; HCP: health care professional; Q: quote; SM, self-management.

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1 Theme 1: CKD Illness Perceptions

2 *CKD diagnosis and anticipated consequences of illness (Patient Generated)*

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

8 *Physical, Psychosocial and Lifestyle Consequences of CKD (Patient and HCP Generated)*

9 Patients frequently mentioned that they felt ‘discomfort’ and ‘weakness’ because of symptoms
10 such as fatigue (table 3, Q5), especially those with CKD stage G4-G5 (table 3, Q6). Also, both
11 patients and HCPs highlighted the psychosocial impact of CKD. Patients expressed frustration
12 and depression due to their deteriorating health status and impairments in their social life (table
13 3, Q7). Also, patients mentioned losing their job and facing difficulties in re-entering the
14 workforce as a consequence of CKD; making them feel anxious about their financial situation
15 (table 3, Q8). Additionally, they felt guilt and regret about the burden their disease imposed on
16 family members (table 3, Q9). All these impacts were also observed in the consultations (see
17 online supplementary appendix 5).

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

22 Theme 2: Understanding of and motivation towards CKD self-management

23 *Understanding of CKD self-management (Patient and HCP Generated)*

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

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

1 *Motivation towards CKD self-management (Patient and HCP Generated)*

2 Patients expressed the belief that self-management could slow down their disease progression
3 and optimize their health status (table 3, Q17). More than half of HCPs considered CKD self-
4 management as a necessity to control patients' symptoms and for improving health-related
5 outcomes (table 3, Q18).

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

11 Theme 3: Current CKD practice

12 *Theme 3a: Current self-management practice by patients (Patient Generated)*

13 All concepts related to self-management practice by patients are operationalized in online
14 supplementary appendix 6.^{45, 46}

15 When asked about their current CKD self-management, patients mostly named concepts related
16 to medical management, such as Disease-specific Controlling Behaviors (DCBs). The most
17 frequently mentioned DCBs were: Adhering to medical advice on medication use (table 4, Q22),
18 treatment and regular follow-up, self-monitoring (table 4, Q23) and symptom management
19 (table 4, Q24). Additionally, more than half of the patients mentioned the performance of
20 healthy behavior, such as diet restrictions (table 4, Q25). The discussion of patients' DCBs was
21 frequently observed in consultations (see online supplementary appendix 5). Other aspects of
22 self-management, such as role- and emotional management, were not frequently mentioned.
23 Some patients described a shift towards a more passive 'patient role' (table 4, Q26). Two
24 patients mentioned the experience of coping with emotional problems (table 4, Q27-28).

25 Patients frequently named the use of problem-solving- and decision-making skills when
26 experiencing physical symptoms (table 4, Q29). Patients searched and obtained disease-related
27 knowledge from various sources including their HCPs, the internet, hospital brochures and
28 contact with other patients (table 4, Q30-31). These findings were consistent with observation
29 data (see online supplementary appendix 5). Other aspects of CKD self-management skills,
30 such as partnering with their HCPs and action planning based on goal setting, were not
31 frequently mentioned. Some patients mentioned that HCPs provided advice on how to cope
32 with symptoms (table 4, Q32), or stated to have created and modified self-management action
33 plans (table 4, Q33).

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1 *Theme 3b: Implementation of self-management intervention by HCPs (HCP Generated)*

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

6 Theme 4: Barriers, (anticipated) facilitators and needs toward CKD self-management

7 Identified barriers, facilitators, and needs towards CKD self-management were classified using
8 the TDF⁴² (details provided in Table 5 and online supplementary appendix 7).

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

TDF domain		Patient	HCP	Operationalization
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
Behavioral regulation		X		Patients' insufficient information on lifestyle behavior 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
Behavioral regulation		X		Patients' being able to adhere to the lifestyle changes prescribed

TDF, Theoretical Domains Framework; HCP: health care professional.

*Domain mentioned by stakeholder.

1 Barriers

Patients and HCPs frequently named a lack of knowledge of CKD (e.g., 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).

10 *(Anticipated) facilitators & 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 emphasized 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).

20 **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 management¹¹ and it aims to optimize the uptake of meaningful behaviors 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.^{46, 47} A recent review examined the effectivity of

interventions to educate professionals on how to support patient self-management through eHealth.⁴⁸ For example, blended learning that combines e-learning and face-to-face methods is suggested to support self-management skills development for HCPs.⁴⁸ Also, improving health literacy, namely the ability to access, process, comprehend, utilize health information and to effectively communicate with HCPs about health information, has been associated with successful disease self-management of patients with CKD.⁴⁹ An intervention that not only focusses on education about self-management, but also aims to improve health literacy, may improve the chances of successful uptake of self-management behaviors.

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-behavioral therapy elements⁵⁰ to help manage this impact. Also, patients' self-efficacy and ultimately their self-management health behaviors,⁵¹⁻⁵³ 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,⁵⁴ 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.⁵⁴ 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.^{55, 56} 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.^{57, 58} We advise not to try and eliminate this paternalistic relationship, but to incorporate its potentially positive aspects in self-management interventions. Also, stimulating patient activation has been an important factor for successful self-management and should be fostered.^{59, 60} Previous literature has showed that a higher level of patient activation is associated with higher levels of self-care in patients with CKD.⁶⁰ Hence, we argue that it is important to focus on and stimulate patient activation before implementing self-management intervention,

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1 especially considering the current dominant patient-HCP relationship. For example, an
2 intervention can be developed by building patients' skills in posing more and better questions
3 to their doctors and in recognizing the importance of asking questions in the decision-making
4 process.⁶¹ Additionally, increasing patients' empowerment can be an effective way to facilitate
5 shared decision-making. A more individualized and specialized empowerment intervention is
6 needed,⁶² for instance, by providing patients with tailored education and psychosocial support
7 including a focus on self-confidence. Such an intervention can increase patients' awareness of
8 self-management behaviors and strengthen their ability to successfully manage their disease
9 and life.

10 A barrier to adequate self-management that was frequently reported by patients is a lack of
11 knowledge. We found that the use of eHealth was largely supported by patients and HCPs to
12 address this barrier. As such, we advocate the development of a national, trustworthy health
13 education resource platform to address the needs expressed by patients for access to reliable
14 medical information. As an example, an evidence-based health information website
15 (<http://www.thuisarts.nl>) in the Netherlands has effectively improved self-management and
16 reduced healthcare usage.⁶³ However, previous literature showed that only increasing patients'
17 knowledge was insufficient to modify their behavior.⁶⁴ Thus, we highlight the importance of
18 also improving both patients' motivation and their behavioral skills to facilitate their CKD self-
19 management. As an example, serious gaming has the potential to improve patients' motivation
20 and behaviors of self-management. China has numerous internet and mobile phone users,⁶⁵ and
21 serious gaming is cost-effective, flexible, portable, and could invoke intense and durable
22 interest among patients and HCPs in engaging in regular self-management (implementation).⁶⁶

23 To our knowledge, this is the first study to describe the beliefs, perceptions and needs towards
24 CKD self-management of patients and HCPs in China. We performed an exploratory, cross-
25 sectional study taking a basic interpretive (generic) qualitative research approach.²⁹ We argue
26 that this approach is most suitable for examining the individual beliefs, perceptions and needs
27 towards CKD self-management, as it allows us to provide a low-inference description of the
28 phenomenon of interest, allows us to combine in- and deductive reasoning while building on
29 the existing knowledge base on this topic mostly derived from research performed in western
30 countries. We also considered taking a phenomenological approach. However, we were not
31 primarily interested in the inner dimensions or essence of the concepts and processes that we
32 investigated. Instead, we were interested in the participants' interpretation of the beliefs,
33 perceptions and needs themselves. In other words, we wanted to know what patients believed,
34 and not necessarily how these beliefs came to be. Grounded theory was not an option, as we
35 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,^{67, 68} we therefore adhere to the ‘big-tent’ criteria for excellent qualitative research. Tracy et al⁶⁹ 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^{67, 68} to optimize 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.⁷⁰ It is furthermore especially suitable for multidisciplinary health research that includes both patients and HCPs.⁴¹ The framework method can be used for both in- 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 in- 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’.⁷¹ Additionally, other strategies to optimize quality and the validity of the results were adopted. As our study includes the triangulation of data sources, rigor 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 (e.g., 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 summarized 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 optimize the implementation of self-

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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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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. RK, PB, XS, ZL, XL, and NC contributed to the design of the study and editing of this manuscript.

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5 **Competing interests**

6 None declared.

7 **Patient consent for publication**

8 Not required.

9 **Ethics approval**

10 The study has been approved by the Ethics Committee of the First Affiliated Hospital of
11 Zhengzhou University, reference number (2019-KY-52). Written informed consent were
12 obtained from all study participants before they were enrolled in the study.

13 **Data availability statement**

14 Extra data is available upon reasonable request by emailing the corresponding author HS.

15 **License statement**

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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?)

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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?)

For peer review only

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?

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(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

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

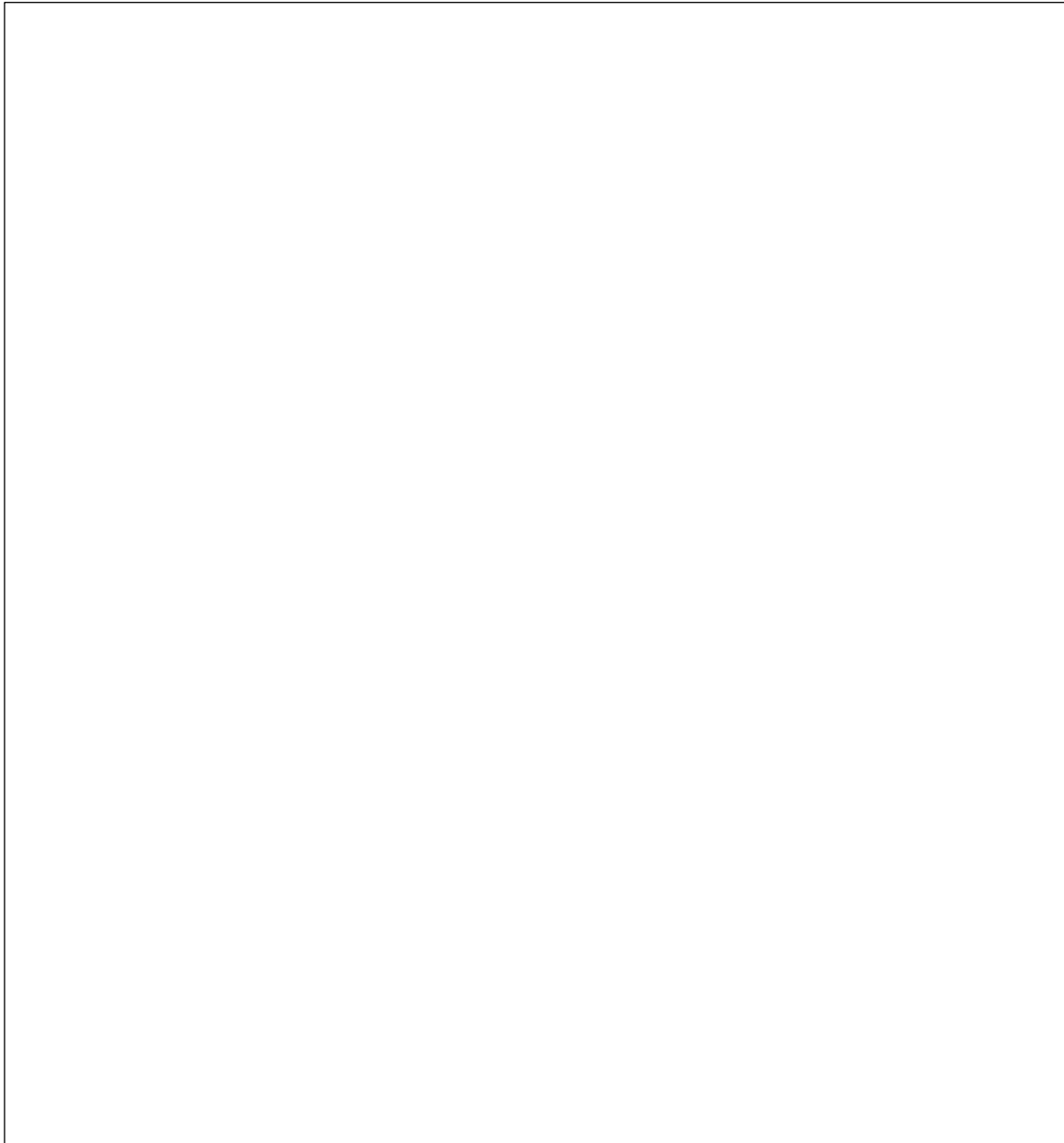
b) Patients: 1. Attitude 2. Subjective norms 3. Perceived control 4. Professional role

- 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



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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 ± SD	55.5±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 ± SD*	67.3±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	35%	9/26
Psychosocial consequences		78	81%	17/21	8	9	15%	4/26
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	-	46%	12/26
	- Medication use	9	64%	7/11	7	-	27%	7/26
	- Regular follow-up	10	45%	5/11	5	-	12%	3/26
	- Self-monitoring	13	36%	4/11	4	-		
	- Symptom management	6	36%	4/11	4	-	23%	6/26
	- 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		8	27%	3/11	3			
● Emotional management		2	18%	2/11	2			
● SM skills								
	-Problem-solving and decision Making	58	73%	8/11	8		31%	8/26
	-Using resources	49	67%	14/21				
	- Internet	20	73%	8/11	8	-	4%	1/26
	- HCP	15	82%	9/11	9	-	35%	9/26
	- Hospital brochures	2	18%	2/11	2	-		
	- Other patients	3	27%	3/11	3	-		

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