# Living well with chronic kidney disease: ehealth interventions to support self-management in China

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# Chapter 5

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

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## Abstract

### Background

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 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 patients with CKD and health care providers (HCPs) towards CKD self-management.

### Methods

A basic interpretive, cross-sectional qualitative study comprising semistructured interviews and observations was conducted in one major tertiary referral hospital in Henan province, China. A total of 11 adults with a diagnosis of CKD with CKD stages G1–G5 and 10 HCPs who worked in the Department of Nephrology were included in our study. Data collection continued until data saturation was reached. Interviews were audiotaped, transcribed verbatim, and all data were analyzed using a framework approach.

### Results

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

### Conclusions

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

## INTRODUCTION

Chronic kidney disease (CKD) is a severe public health problem [1, 2]. Globally, 698 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 life [6] 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 composed 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 improve self-management behaviors [13-15], and disease-specific knowledge [13], health-related quality of life [16] and health outcomes [16, 17], while it may also slow disease progression [9, 18-20]. Despite these reported successes, many existing self-management interventions are prescriptive and deliver information without taking into account the patients' understanding of self-management [21, 22] or the fact that self-management occurs in a social context [23]. Patients' needs for self-management support are not always known or met [24], and there is very little knowledge on how people with CKD would like to receive self-management interventions [25].

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

To adapt and prepare an existing evidence-based CKD self-management intervention for implementation in China, we performed a qualitative study to examine the beliefs, perceptions and needs of patients with CKD and 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 [31].

We followed the Consolidated Criteria for Reporting Qualitative Health Research (see Additional file 1: https://bmjopen.bmj.com/content/11/3/e044059.info) [32].

### Study Setting and Participant Selection

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

Previous literature indicates that patients with CKD G1 or G2 report a multitude of symptoms and fairly high disease burden [34, 35]. Therefore, we anticipated that all patients with CKD (regardless of the CKD stage) have a great need for self-management interventions. Individuals eligible for inclusion were: (1) patients with a diagnosis of CKD with CKD stages G1-G5 and (2) HCPs who worked in the Department of Nephrology. Participants needed to be 18 years or older and speak Chinese. We followed the principles of ‘purposive and convenience sampling’ [36] to capture a diverse sample. Two sampling frames were used. The sampling frame for patients comprised the following variables: CKD stage, gender and age range. The sampling frame of HCPs comprised the variables: work experience, profession, gender and age. Also, we used snowball sampling [37] to identify additional participants, in which current participants were asked if they knew any other individual who could participate in the study. For instance, participant AW knew another patient via WeChat who was severely ill and therefore did not visit the hospital often. This patient had not heard about the study. We asked participant AW to contact this patient and provide information on study participation. The patient then agreed to participate in our study. Study invitation strategies included: provision of flyers and face-to-face verbal invitations for both patients and HCPs and an online invitation for HCPs. All participants provided written informed consent to participation. Also, patients and HCPs received a reimbursement (20 RMB of telephone credit) for their time spent on the study.

### Data collection

One researcher (HS, Msc, female) conducted semistructured face-to-face interviews and observations (see Additional file 2: https://bmjopen.bmj.com/content/11/3/e044059.info) between January 2019 to April 2019. The interviewer had no prior contact with participants. The semistructured interview guide and observation forms were developed based on the FRESH AIR (Free Respiratory Evaluation and Smoke-exposure reduction by primary Health cAre Integrated gRoups) study [38], examples of similar studies [39] and research team discussions (see Additional file 3: https://bmjopen.bmj.com/content/11/3/e044059.info). Also, the interview guide was theory-driven as concepts of the Health Belief Model and the Theory of Planned Behavior were used to develop the topic list. A pilot interview was conducted with both a patient and an HCP to evaluate its content, length, and understandability.

The interviewer was trained and had ample experience with qualitative research. To ensure confidentiality and privacy, face-to-face interviews were performed in a private room in the department. Also, the passive participant observations [40] 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 and 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 [41]. 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

A Framework Method [42] was used to guide our qualitative analysis.

#### *Stage A and 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, each transcription was read as full text by the researchers in order to become familiar with the data set.

#### *Stage C: Development of an analytical framework and coding*

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

#### *Stage D: Charting data into the framework matrix*

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

#### *Stage E: Interpreting the data*

Themes were generated from codes derived from the data set by reviewing the matrix and making connections within and between participants and codes. Emergent themes were then 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.

### Establishing rigor in the data collection and analysis process

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

### Reflexivity

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

### Patient and public involvement

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

## RESULTS

### Participant and Interview Characteristics

A total of 21 face-to-face interviews and 26 observations were conducted (tables 1 and 2). Out of 15 approached patients, 11 patients (73%) agreed to participate in the interview study. Out of 11 approached HCPs, 10 (91%) HCPs agreed. Reasons for refusal to participate included a lack of time due to patients' extended waiting time for a physician consultation or intravenous infusion or lack of interest in the research presented. Reasons reported by HCPs included a lack of time due to work obligations (see Additional file 4 for interview characteristics: https://bmjopen.bmj.com/content/11/3/e044059.info). No significant differences were observed between the final sample and those who refused to participate.

### Themes

Four major themes emerged for both patients and HCPs. These themes and respective subthemes are described in the following sections with reference to the relevant quotes (see tables 3-4, Additional file 5: https://bmjopen.bmj.com/content/11/3/e044059.info).

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

| **Characteristics** | **Value (N = 11)** |
|---|---|
| Age, years* | 38.9 ± 9.6 (18-53) |
| Age category (years), n (%) | |
| 18-28 | 1 (9) |
| 29-39 | 4 (36) |
| 40-50 | 4 (36) |
| 51-61 | 2 (19) |
| Sex, n (%) | |
| Male | 5 (46) |
| Female | 6 (54) |
| Marital status, n (%) | |
| Never married | 1 (9) |
| Married | 9 (82) |
| Divorced | 1 (9) |
| Highest level of education completed, n (%) | |
| ≤Primary school | 3 (27) |
| Middle school | 3 (27) |
| ≥High school graduate | 5 (46) |
| Employment status, n (%) | |
| Employed (full time and part-time) | 2 (18) |
| Not employed | 7 (64) |
| Farming | 0 (0) |
| Student | 1 (9) |
| Retired | 1 (9) |
| Time since CKD diagnosis (years), n (%) | |
| <1 | 5 (46) |
| 1-5 | 3 (27) |
| >5 | 3 (27) |
| Current CKD stage, n (%) | |
| CKD stages G1-G3 | 5 (46) |
| CKD stages G4-G5 | 6 (54) |
| Body weight, kg* | 56.8±13.2 (35-79) |
| Serum albumin, g/L* | 35.1±3.9 (29.9-41.9) |
| 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, years* | 33 ± 6.1 (25-46) |
| Age category (years), n (%) | |
| 21-30 | 4 (40) |
| 31-40 | 5 (50) |
| 41-50 | 1 (10) |
| Female sex, n (%) | 9 (90) |
| Job occupation, n (%) | |
| Nurse | 7 (70) |
| Nephrologist | 3 (30) |
| Marital status, n (%) | |
| Never married | 2 (20) |
| Married | 8 (80) |
| Highest level of education completed, n (%) | |
| Bachelor's degree | 5 (50) |
| Master's degree | 3 (30) |
| Doctoral degree | 2 (20) |
| Years of work experience in medical practice, n (%) | |
| <5 | 2 (20) |
| 5-10 | 3 (30) |
| >10 | 5 (50) |
| Years of work experience in nephrology practice, n (%) | |
| <5 | 3 (30) |
| 5-10 | 3 (30) |
| >10 | 4 (40) |

*Mean ± standard deviation (range).

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 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).<br>Q2. *I have not even had a cold before. Why do I get this CKD?* (Patient 3, 40-50y, CKD G4-G5).<br>Q3. *The first is that it is difficult to accept that I am sick. I have a feeling that I would be useless in the rest of my life*. (Patient 5, 29-39y, CKD G1-G3).<br>Q4. *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). |
| Physical consequences | Q5. *Patients are very weak, and the symptoms of fatigue are more prominent.* (HCP6, 29-39y).<br>Q6. *[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). |
| Psychosocial consequences | Q7. *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).<br>Q8. *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).<br>Q9. *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). |

| | |
|---|---|
| Lifestyle consequences | Q10. *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).<br>Q11. *Because I need to conduct dialysis several times every day, I can not go anywhere*. (Patient 7, 29-39y, CKD G4-G5). |
| **Understanding of and motivation towards CKD SM** | |
| Understanding of CKD SM | |
| *Patients' responses towards the understanding of CKD SM* | Q12. *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, 29-39y, CKD G4-G5).<br>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).<br>Q14. *I hear from nurses that I need to take care of self-protection, pay attention to the sanitation of dialysis environment.* (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).<br>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).<br>Q18. *CKD SM is very important...But (peritoneal dialysis) patients with good adherence can lead the whole family to travel abroad*. (HCP1, 29-39y).<br>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).<br>Q20. *I should actively cooperate with treatment, follow the taboos or precautions that the doctors recommended.* (Patient 5, 29-39y, CKD G1-G3).<br>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.

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

| Themes and Subthemes | Representative Quotation |
|---|---|
| **Current CKD practice** | |
| Current SM practice by patients | |
| *Medical management* | Q22. *I took medications very regularly. Otherwise, my blood pressure will be high and I can not control it.* (Patient 7, 29-39y, CKD G4-G5).<br>Q23. *I paid attention to the [chronic kidney] disease. If I felt uncomfortable, I quickly measured my blood pressure.* (Patient 4, 29-39y, CKD G1-G3).<br>Q24. *My legs were swollen. I started to restrict water [intake]. Then, the edema slowly disappeared.* (Patient 8, 40-50y, CKD G1-G3).<br>Q25. *I eat food based on doctor's requirements every day, low salt and low fat, and high-quality protein.* (Patient 5, 29-39y, CKD G1-G3). |
| *Role and emotional management* | Q26. *I took medicines on time and had a rest every day. I am a patient and just consider medicines every day.* (Patient 11, 51-61y, CKD G1-G3).<br>Q27. *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*. (Patient 5, 29-39y, CKD G1-G3).<br>Q28. *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.* (Patient 1, 40-50y, CKD G4-G5). |
| *SM skills* | Q29. *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.* (Patient 11, 51-61y, CKD G1-G3).<br>Q30. *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*. (Patient 5, 29-39y, CKD G1-G3).<br>Q31. T*here is a diet list [for CKD]. Also, I searched the information by asking other patients during hospitalization.* (Patient 6, 29-39y, CKD G4-G5).<br>Q32. *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*. (Patient 1, 40-50y, CKD G4-G5).<br>Q33. *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.* (Patient 4, 29-39y, CKD G1-G3). |
| Implementation of SM intervention by HCPs | Q34. *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*. (HCP1, 29-39y). |

| | |
|---|---|
| **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). |

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

### *Theme 1: CKD Illness Perceptions*

### CKD diagnosis and anticipated consequences of illness (patient Generated)

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

#### Physical, psychosocial and lifestyle Consequences of CKD (patient and HCP Generated)

Patients frequently mentioned that they felt ‘discomfort’ and ‘weakness’ because of symptoms such as fatigue (table 3, Q5), especially those with CKD stages G4-G5 (table 3, Q6). Also, both patients and HCPs highlighted the psychosocial impact of CKD. Patients expressed frustration and depression due to their deteriorating health status and impairments in their social life (table 3, Q7). Also, patients mentioned losing their job and facing difficulties in re-entering the workforce as a consequence of CKD; making them feel anxious about their financial situation (table 3, Q8). Additionally, they felt guilt and regret about the burden their disease imposed on family members (table 3, Q9). All these impacts were also observed in the consultations (see Additional file 5: https://bmjopen.bmj.com/content/11/3/e044 059.info).

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

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

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

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

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

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

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

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

### *Theme 3: Current CKD practice*

### Theme 3a: Current self-management practice by patients (patient Generated)

All concepts related to self-management practice by patients are operationalized in Additional file 6 (https://bmjopen.bmj.com/content/11/3/e044059.info) [46, 47].

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) and symptom management (table 4, Q24). Additionally, more than half of the patients mentioned the performance of healthy behavior, such as diet restrictions (table 4, Q25). The discussion of patients’ DCBs was frequently observed in consultations (see Additional file 5: https://bmjopen.bmj.com/content/11/3/e044059.info). Other aspects of self-management, such as role- and emotional management, were not frequently mentioned. Some patients described a shift towards a more passive ‘patient role’ (table 4, Q26). Two patients mentioned the experience of coping with emotional problems (table 4, Q27-28).

Patients frequently named the use of problem-solving- and decision-making skills when experiencing physical symptoms (table 4, Q29). Patients searched and obtained disease-related knowledge from various sources including their HCPs, the internet, hospital brochures and contact with other patients (table 4, Q30-31). These findings were consistent with observation data (see Additional file 5: https://bmjopen.bmj.com/content/11/3/ e044059.info). 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).

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

HCPs mentioned facilitating patients’ self-management by providing health education, especially about strict adherence to medical treatment (table 4, Q34). Observations confirmed that CKD-specific health education was frequently provided by HCPs (see Additional file 5: https://bmjopen.bmj.com/content/11/3/e044059.info).

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

Identified barriers, facilitators, and needs towards CKD self-management were classified using the TDF [43] (details provided in Table 5 and Additional file 7: https://bmjopen.bmj.com/content/11/3/e044059.info).

### 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).

### (anticipated) Facilitators and needs

Patients and HCPs commonly mentioned that sufficient disease-related knowledge might support patients' adherence to treatment and improve self-management skills (table 4, Q40). Also, patients and HCPs 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).

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<br>- Patients' lack of knowledge on lifestyle changes<br>- Patients' lack of knowledge of treatment |
| Environmental context and resources | X | X | - Limited education resources or materials for patients' knowledge<br>- Time constraints of HCPs |
| Behavioral regulation | X | | - Patients' insufficient information on lifestyle behavior change<br>- Patients' difficulties in breaking certain habits |
| Emotion | | X | - Patients' experienced fear, anxiety, and depression<br>- Patients' lack of confidence deal with heavy disease burden |
| Social influence | | X | - Inadequate support from family members<br>- Interfered patient-HCP communication |
| **(anticipated) Facilitator** | | | |
| Knowledge | X | X | - Patients' sufficient general knowledge of CKD (treatment)<br>- 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<br>- 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.

## DISCUSSION

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

Our finding that self-management is often misinterpreted as adherence to medical treatment underlines the importance of education on the core concepts and possible advantages of self-management interventions. Self-management is comprised of medical, emotional, and role management [11], and it aims to 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 [47, 48]. A recent review examined the effectivity of interventions to educate professionals on how to support patient self-management through eHealth [49]. For example, blended learning that combines e-learning and face-to-face methods is suggested to support self-management skills development for HCPs [49]. Also, improving health literacy, namely the ability to access, process, comprehend, use health information and to effectively communicate with HCPs about health information, has been associated with successful disease self-management of patients with CKD [50]. An intervention that focusses on education about self-management and aims to improve health literacy may improve the chances of successful uptake of self-management 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 elements [51] to help manage this impact. Also, patients' self-efficacy and ultimately their self-management health behaviors [52-54], are associated with psychosocial well-being, making an increased focus on the psychosocial aspects of the disease as a prerequisite for successful disease self-management in general.

Consistent with previous literature [55], patients with CKD stages G4-G5 in our study frequently mentioned a heavy symptom burden. However, these patients did not express a greater need for self-management interventions, as we would expect from previous research [55]. This may be explained by the fact that patients cannot ask for things they do not know: Patients' misinterpretation of self-management may have limited their ability to express their needs. Also, as patients with CKD G4 or G5 have often suffered from the disease for a long period, they may have adapted to living with their disease and therefore feel less need for self-management interventions.

Patient autonomy is a core principle of the patient-doctor interaction in Western cultures [56, 57]. However, under certain conditions, the paternalistic relationship we encountered in our study can be valuable and even essential to improving health outcomes and treatment adherence in some cultural contexts, for instance, if patients prefer a paternalistic approach over autonomy [58, 59]. We advise not to try and eliminate this paternalistic relationship but to incorporate its potentially positive aspects in self-management interventions. Also, improving patient activation has been an important factor for successful self-management and should be fostered [60, 61]. Previous literature has showed that a higher level of patient activation is associated with higher levels of self-care in patients with CKD [61]. Hence, we argue that it is important to focus on and improve patient activation before implementing self-management intervention, especially considering the current dominant patient-HCP relationship. For example, an intervention can be developed by building patients' skills in posing more and better questions to their doctors and in recognizing the importance of asking questions in the decision-making process [62]. Additionally, increasing patients' empowerment can be an effective way to facilitate shared decision-making. A more individualized and specialized empowerment intervention is needed [63], for instance, by providing patients with tailored education and psychosocial support including a focus on self-confidence. Such an intervention can increase patients' awareness of self-management behaviors and strengthen their ability to successfully manage their disease and life.

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

To our knowledge, this is the first study to describe the beliefs, perceptions and needs towards CKD self-management of patients and HCPs in China. We performed an exploratory, cross-sectional study taking a basic interpretive (generic) qualitative research approach [29]. We argue that this approach is most suitable for examining the individual beliefs, perceptions and needs towards CKD self-management, as it allows us to provide a low-inference description of the phenomenon of interest, allows us to combine inductive and deductive reasoning while building on the existing knowledge base on this topic mostly derived from research performed in western countries. We also considered taking a phenomenological approach. However, we were not primarily interested in the inner dimensions or essence of the concepts and processes that we investigated. Instead, we were interested in the participants' interpretation of the beliefs, perceptions and needs themselves. In other words, we wanted to know what patients believed, and not necessarily how these beliefs came to be. Grounded theory was not an option, as we did not aim to build a theory from scratch explaining (the interaction between) these concepts (like one would when applying a grounded theory approach). As we are aware of the pitfalls of generic qualitative research [68, 69], we therefore adhere to the 'big-tent' criteria for excellent qualitative research. Tracy et al [70] suggest that when designing qualitative research, developers should focus on the 'ends' rather than getting stuck in methodology-bound 'means'. Also, we follow the guidance provided on how to perform and report on generic qualitative research [68, 69] to 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 [71]. It is furthermore especially suitable for multidisciplinary health research that includes both patients and HCPs [42]. The framework method can be used for both inductive and deductive coding to understand the phenomenon of interest. In our study, we expand and falsify existing knowledge on beliefs, perceptions and needs about CKD. We thus need to combine the inductive and deductive aspects of coding, making the framework method an excellent match. By using the framework approach, we clearly and systematically detail the steps performed as well as the perspective taken on the data collection and the analysis process, hence preventing 'method slurring' [72]. Additionally, other strategies to 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.

## CONCLUSIONS

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. With this approach, selected self-management intervention elements can be implemented using eHealth mediums.

### *Authors' contributions*

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 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.

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