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

Shen, H.

Chapter 6

Digital tools/ eHealth to support CKD self-management: a qualitative study of perceptions, attitudes and needs of patients and health care professionals in China

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Submitted

Abstract

Background

A growing body of evidence supports the potential effectiveness of electronic health (eHealth) self-management interventions in improving disease self-management skills and health outcomes of patients suffering from chronic kidney disease (CKD). However, current research on CKD eHealth self-management interventions has almost exclusively focused on high-income, Western countries. To adapt and evaluate a tailored eHealth self-management intervention for patients with CKD in China based on the Dutch Medical Dashboard (MD) intervention, we examined the perceptions, attitudes and needs of Chinese patients with CKD and health care professionals (HCPs) towards eHealth based (self-management) interventions in general and the Dutch MD intervention in specific.

Methods

We conducted a basic interpretive, cross-sectional qualitative study comprising semi-structured interviews with 11 patients with CKD and 10 HCPs, and 2 focus group discussions with 9 patients with CKD. This study was conducted in the First Affiliated Hospital of Zhengzhou University in China. Data collection continued until data saturation was reached. All data were transcribed verbatim and analyzed using a framework approach.

Results

Three themes emerged: (1) experience with eHealth in CKD (self-management), (2) needs for supporting CKD self-management with the use of eHealth, and (3) adaptation and implementation of the Dutch MD intervention in China. Both patients and HCPs had experience with and solely mentioned eHealth to '*inform*, *monitor and track*' as potentially relevant interventions to support CKD self-management, not those to support '*interaction*' and '*data utilization*'. Factors reported to influence the implementation of CKD eHealth self-management interventions included information barriers (i.e. quality and consistency of the disease-related information obtained via eHealth), perceived trustworthiness and safety of eHealth sources, clinical compatibility and complexity of eHealth, time constraints and eHealth literacy. Moreover, patients and HCPs expressed that eHealth interventions should support CKD self-management by improving the access to reliable and relevant disease related knowledge and optimizing the timeliness and quality of patient and HCPs interactions. Finally, suggestions to adaptation and implementation of the Dutch MD intervention in China were mainly related to improving

the intervention functionalities and content of MD such as addressing the complexity of the platform and compatibility with HCPs' workflows.

Conclusions

The identified perceptions, attitudes and needs towards eHealth self-management interventions in Chinese settings should be considered by researchers and intervention developers to adapt and evaluate a tailored eHealth self-management intervention for patients with CKD in China. In more detail, future research needs to increase eHealth literacy and credibility of eHealth (information resource), ensure eHealth to be easy to use and well-integrated into HCPs' workflows.

INTRODUCTION

Chronic kidney disease (CKD) is a severe public health problem [1, 2], and has a global prevalence of 9.1% [3]. CKD is categorized into five stages based on the glomerular filtration rate decline and level of albuminuria [4]. The disease burden of CKD is significant: patients with CKD often report severe impairment in health-related quality of life and experience adverse health outcomes [5, 6]. Moreover, CKD imposes a substantial economic burden due to its considerable health-related and societal cost [7, 8].

Interventions promoting adequate disease self-management (further referred to as self-management) of CKD can optimize a patient's ability to perform the cognitive, behavioral, and emotional behaviors necessary to achieve a satisfactory level of health-related quality of life [9]. Additionally, interventions supporting self-management can not only improve self-management behaviors [10-12], but also health outcomes [13], and may even slow disease progression [14-16]. Hence, optimizing CKD self-management is of utmost importance to reduce disease burden, improve health outcomes and control health care expenditures [14].

Electronic health (eHealth) based interventions are increasingly being developed to support CKD self-management. Previous evidence suggests that eHealth self-management interventions can be effective in improving healthy behaviors and health outcomes of patients with CKD [17-19], and increasing healthcare accessibility and efficiency [20]. An example of an extensively studied and effective CKD eHealth self-management intervention is 'Medical Dashboard (MD)' [21-23]. The MD, developed in the Netherlands, enables patients and health care professionals (HCPs) to monitor and track healthy behaviors and disease parameters. Such an effective MD eHealth based self-management intervention is of practical relevance for China, with the highest number of patients being affected by CKD (132 million) [24] and accounting for around one fifth of the global burden of CKD [24, 25]. Also, patients and HCPs face challenges in the accessibility of CKD care due to the lack of a strong primary care system in rural China. Therefore, it is essential to adapt and tailor effective CKD eHealth self-management interventions, for instance, the Dutch MD intervention, to decrease the CKD burden in China.

To successfully adapt and tailor effective eHealth self-management interventions for patients with CKD in China, it is important to align the interventions with key users' needs and perceptions [26, 27]. As noted in the Health Belief Model [28], the Theory of Planned Behavior [29] and Technology Acceptance Model [30], individuals' perceptions (i.e. the

organized cognitive representations that individuals have about a subject), attitudes (i.e. an individual's overall evaluation of a subject based on certain perceptions) and needs (i.e. demands and requirements that people require to address their problems) can predict their uptake and acceptance of (eHealth) interventions. However, as of yet, little knowledge is available on these perceptions, attitudes and needs towards eHealth interventions supporting CKD self-management, especially for China and other low- and middle-income countries (LMICs).

Therefore, our ultimate goal is to adapt and evaluate a tailored eHealth self-management intervention for patients with CKD in China based on the Dutch MD intervention. To inform these adaptations and evaluations, two qualitative studies were performed. The first study examined the perceptions and needs of patients with CKD and HCPs towards CKD self-management in China [31]. This paper describes the results of the second qualitative study and comprises two parts examining:

- Part A: the perceptions, attitudes and needs of patients with CKD and HCPs towards eHealth-based (self-management) interventions in general.
- Part B: the perceptions, attitudes and needs of patients with CKD and HCPs towards the Dutch MD intervention in specific.

METHODS

Study design

We performed a basic interpretive, cross-sectional qualitative study comprising semi-structured interviews and focus group discussions. The core intervention components, functionalities and supporting screenshots of MD are presented in Textboxes 1-2. The methods are further detailed in Table 1. More details on the overarching study have been described elsewhere [32]. For the reporting, we adhered to the Consolidated Criteria for Reporting Qualitative Health Research (COREQ) [33] in this study.

Ethics approval and informed consent

This study was approved by the Ethics Committee of the First Affiliated Hospital of Zhengzhou University (reference number 2019-KY-52). Participants were informed about the nature of the research project, the possible risks and benefits and their rights as research participants. If they agreed to participate, written informed consent was obtained.

Study participant and recruitment

Our study was conducted in the First Affiliated Hospital of Zhengzhou University in the Henan province in China. Participants were recruited from January to April 2019. Study invitation strategies included the provision of flyers and face-to-face verbal invitations for both patients and HCPs, and an online invitation for HCPs. Additional information regarding study setting and recruitment procedures can be found elsewhere [32]. The eligibility criteria for study inclusion of patients with CKD and HCPs are detailed in Table 2.

We followed the principles of 'purposive and convenience sampling' [34] to capture a diverse sample concerning demographic- (e.g. age) and clinical (e.g. CKD stage) characteristics. Also, we used snowball sampling [35] to identify additional participants, in which current participants were asked if they knew any other individual who could participate in the study. Patients and HCPs received a reimbursement (20 RMB of telephone credits) to compensate for their time.

Textbox 1. Core intervention components and functionalities of Medical Dashboard.

- **Motivational interviewing:** Patients are provided with a one-hour individual motivational interview, which focuses on discussing barriers, benefits, and strategies for self-management; setting personal goals, and strengthening intrinsic motivation and self-efficacy.
- **Education:** Patients are provided with education, a kidney-friendly cookbook, instructions for self-monitoring blood pressure (using a Microlife Watch blood pressure home device), dietary intake (using an online food diary) and 24-hour urinary sodium excretion (using an innovative point-of-care chip device).
- **Self-monitoring**: Patients are instructed to take health measurements at home (e.g. blood pressure, weight and glucose) and enter the results of these measurements via the secure "self-care" website www.bonstat.nl. The measurements entered via this website are linked real-time to the Medical Dashboard interface.
- **Combination of home and hospital measurements in the Medical Dashboard**: The measurements that patients take at home and the measurements performed during hospital visits are visualized jointly in the Medical Dashboard.
- **Online information support**: Patients are provided with online disease-related information, tips and suggestions focusing not only on medical knowledge, but also on how to obtain and sustain social support, refusal skills, medication adherence strategies, physical exercise, healthy eating, smoking cessation and reduced alcohol intake.
- **Personal coaching**: Patients are coupled with one of four personal coaches: three health psychologists and one dietician. Following the self-monitoring measurements, patients are provided with feedback by telephone from their coach or during hospital visits. The discussion focuses on the progression, achievements, barriers and possible solutions of self-management.

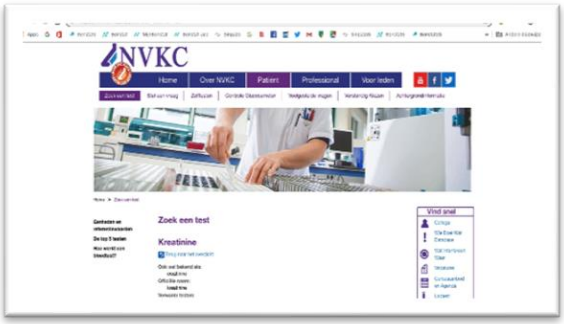
Textbox 2. Core Medical Dashboard intervention print screenshots.

Self-monitoring and combination of home and hospital measurements in the Medical Dashboard:

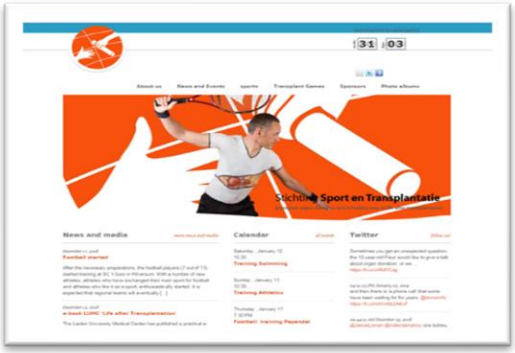
(A) Patients' self-measurements and hospital data are visualized jointly in the Medical Dashboard.

Online information support

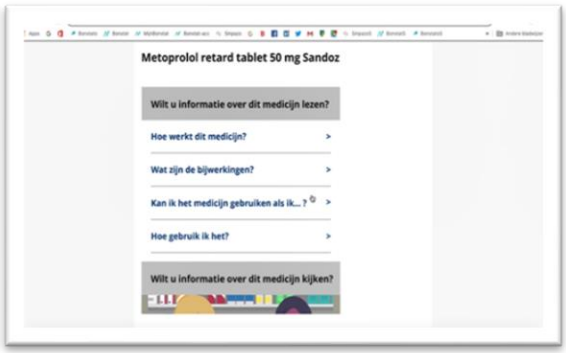
(B) Overview of online information support



(C) Information of laboratory tests (e.g. creatinine)



(D) Information of healthy lifestyle



(E) Information of medication use (e.g. Metoprolol)

Table 1. Field methods for research topics.

Method	Part A: Perceptions, attitudes and needs towards eHealth based (self-management) interventions for CKD in general		Part B: Perceptions, attitudes and needs towards the Dutch Medical Dashboard self-management intervention in specific	
	Patients	HCPs[a]	Patients	HCPs
Semi-structured interviews	X	X		X
Focus group discussions			X	

[a]HCPs, health care professionals.

Table 2. Eligibility criteria for patients with chronic kidney disease and health care professionals.

Category	Participant eligibility criteria
Inclusion criteria	• Patients: (1) aged over 18 years old; (2) a diagnosis of chronic kidney disease (CKD) with markers of kidney damage or a glomerular filtration rate of less than 60 ml/min/1.73m^2 persisting for ≥3 months based on Kidney Disease Improving Global Outcomes (KDIGO) guidelines; (3) all CKD stages (stage G1-G5) following the KDIGO staging of CKD; (4) Chinese speaking. • Health care professionals (1) who work in the Department of Nephrology of the First Affiliated Hospital of Zhengzhou University (2) are able to implement the intervention in their daily practice
Exclusion criteria	• Individuals unable to provide written informed consent and/or use the electronic application due to physical disabilities such as eyesight problems or mental disabilities such as psychosis, personality disorders or schizophrenia (final decision for exclusion to be made by the treating physician) • Individuals unable to write or read.

Research materials

The interviews and focus group topic lists were developed based on similar studies into users' perceptions and needs towards eHealth intervention implementation [36, 37] and refined through research team discussions.

- **Part A:** To examine the perceptions, attitudes and needs of patients and HCPs towards eHealth based (self-management) interventions for CKD in general, the semi-structured interview guide was theory-driven; concepts of the Health Belief

Model [28] and the Theory of Planned Behavior [29] were used to develop the topic list.

- **Part B:** To examine the perceptions, attitudes and needs of patients and HCPs towards the Dutch MD intervention in specific, participants were prompted with information and screenshots detailing the intervention content and design features of the MD intervention via a PowerPoint presentation.

Research materials were piloted to verify their feasibility and acceptability for patients and HCPs.

Data collection

One researcher (HS, female, a PhD student focusing on eHealth applications in chronic disease self-management, master's degree in nursing, expertise in qualitative research) conducted the semi-structured interviews and focus group discussions (Table 1). The interviewer had no contact or relation with any participant before the study. Also, the interviewer was formally trained and had ample experience with qualitative research. To ensure confidentiality and privacy, face-to-face interviews and focus group discussions were performed in a private room in the hospital department. Each topic started with an open-ended question, then follow-up questions, and prompts were used when needed. The sample size for the interviews and focus group discussions was not predetermined, but 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 [38]. All semi-structured interviews and focus group discussions were audio-recorded with a digital voice recorder. Field notes detailing the interview setting, atmosphere, and participants' non-verbal behaviors enabled a richer analysis of the data. Also, we collected participants' sociodemographic- and clinical characteristics via the patient medical records.

Data analysis

A Framework Method [39] was used to guide our qualitative analysis.

Stage A and B: Transcribing and Familiarization

All audio-taped semi-structured interviews and focus group discussions were anonymized and transcribed verbatim. Names and identifiers were removed to protect participant confidentiality. One researcher performed transcription, and another researcher checked transcripts to ensure content accuracy. Before coding, the two researchers independently read transcriptions full text to become familiar with the data.

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. Initial coding trees were developed based on the theoretical framework developed in our study protocol [32] and the Technology Acceptance Model [30]. The final coding tree was built in two steps. First, the independent coding of three transcripts using the initial coding tree by two researchers was compared, with differences highlighted. Next, differences were discussed in the research team until consensus was reached. After, one researcher (HS) coded all transcripts using the final coding tree; 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 [40]. 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.

RESULTS

Participant, interview and focus group discussion characteristics

A total of 21 semi-structured interviews (11 patients with CKD and 10 HCPs) and 2 focus group discussions with 9 patients were conducted (Tables 3-4, Additional file 1).

Table 3. Participant characteristics: HCPs.

Characteristics	Value (N=10)
Age (years), mean (SD)	33 (6.1)
Age (years), n (%)	
21-30	4 (40)
31-40	5 (50)
41-50	1 (10)
Gender, n (%)	
Female	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)

Table 4. Participant characteristics: patients with CKD.

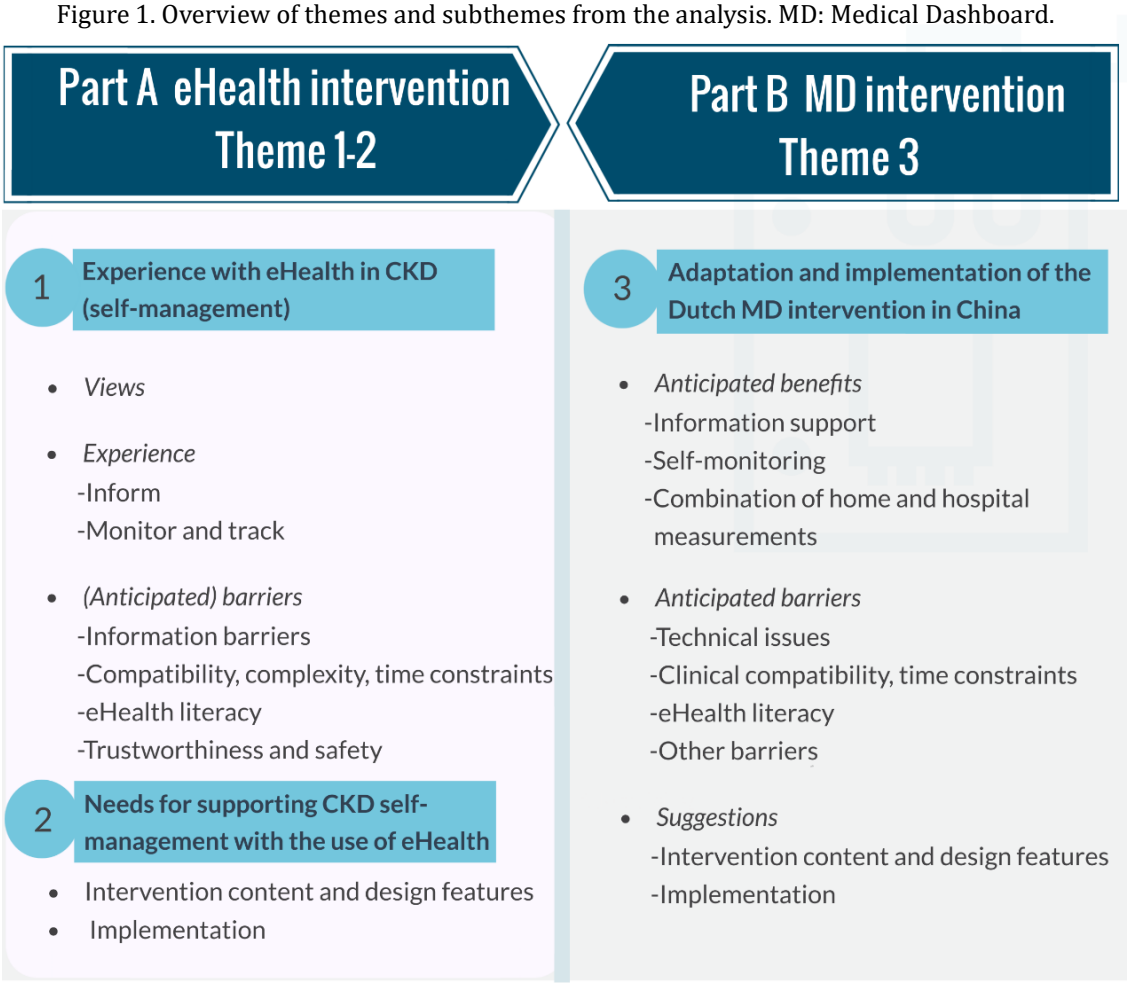
Characteristics	Value	
	Face to face interview (n=11)	Focus group discussion (n=9)
Age (years), mean (SD)	38.9 (9.6)	43.3 (13.2)
Age category (years), n (%)		
18-28	1 (9)	1 (11)
29-39	4 (36)	1 (11)
40-50	4 (36)	3 (33)
51-61	2 (19)	3 (33)
>61	0 (0)	1 (11)
Gender, n (%)		
Female	6 (54)	5 (56)
Marital status, n (%)		
Never married	1 (9)	1 (11)
Married	9 (82)	8 (89)
Divorced	1 (9)	0 (0)
Highest level of education completed, n (%)		
≤Primary school	3 (27)	5 (56)
Middle school	3 (27)	2 (22)
≥High school graduate	5 (46)	2 (22)
Employment status, n (%)		
Employed (full time & part-time)	2 (18)	2 (22)
Not employed	7 (64)	2 (22)
Farming	0 (0)	4 (45)
Student	1 (9)	1 (11)
Retired	1 (9)	0 (0)
Time since CKD[a] diagnosis, n (%)		
<1 year	5 (46)	7 (78)
1-5 years	3 (27)	2 (22)
>5 years	3 (27)	0 (0)
Current CKD[a] stage, n (%)		
Non-dialysis-dependent CKD G1-G3	5 (46)	6 (67)
Non-dialysis-dependent CKD G4-G5	3 (27)	3 (33)
Home peritoneal dialysis CKD G5	3 (27)	0 (0)

[a]CKD, chronic kidney disease.

Themes

Three major themes (Part A: Theme 1-2; Part B: Theme 3) emerged from our data for both patients and HCPs (Figure 1). Themes and subthemes are described in the following sections; illustrative quotations and frequencies are provided.

Figure 1. Overview of themes and subthemes from the analysis. MD: Medical Dashboard.



Part A

Theme 1: Experience with eHealth in CKD (self-management)

Views of eHealth in general (patient and HCP generated)

When asking patients and HCPs about their definition of eHealth, all of them had heard about eHealth. Patients described eHealth as the technology used to educate, monitor (un)healthy behaviors, and facilitate communication between patients and HCPs. When asking patients and HCPs if they could name specific examples of eHealth, they largely mentioned concepts related to telemedicine (7/21, 33%). For example, one patient stated: *eHealth is that [...] I can ask HCPs questions about treatment and diagnosis [of CKD] [...] with remote video calls [with the HCPs].* [Patient 4, male, 37y, CKD 2]

To further enquire on patients' eHealth use, we operationalized eHealth into three types following previous categorizations [41, 42] (Table 5). Patients and HCPs mostly named they frequently used eHealth to '*inform*' and '*monitor and track*'. Other types of eHealth such as those facilitating '*interaction*' and '*data utilization*' were not frequently used.

Table 5. The operationalization of types of eHealth.

Types of eHealth	Operationalization
Inform, monitor and track	eHealth technologies to observe and study health parameters
• Inform	eHealth to educate
• Monitor and track	eHealth to monitor (un)healthy behaviour
Interaction	eHealth to facilitate communication between all health care participants
Data utilization	eHealth to collect, manage, and research data on health

Experience with eHealth use

eHealth to inform (patient and HCP generated)

Patients frequently cited they used their mobile phones to obtain disease-related information through search engines (9/11, 82%) such as Baidu (a Chinese search engine) (Textbox 3, quote 1). More than half of HCPs mentioned using eHealth to provide health education such as medical advice on symptom management to patients. For instance, HCPs mostly named they frequently used mobile phone apps for providing health education (7/10, 70%), predominantly WeChat (an online social network and chat app from the Chinese company Tencent) (6/10, 60%) (Textbox 3, quote 2). Additionally, when eHealth technology was used by HCPs to 'inform', they frequently cited that it benefited their medical practice (7/11, 64%); among which 'saving time on patients' health education' (Textbox 3, quote 3) and 'improving the ability to illustrate practical medical advice with videos or animations' (Textbox 3, quote 4). Patients also mentioned benefits of eHealth use, mostly related to highly improved access to 'easily understandable information' (Textbox 3, quote 5).

eHealth to monitor & track (patient and HCP generated)

When asked about their experience with eHealth, about one-third of patients mentioned the use of eHealth to monitor and track health parameters (4/11, 36%). For example, those receiving peritoneal dialysis mentioned that they downloaded apps on their smartphone to self-monitor physiological parameters (e.g. blood pressure or weight) (Textbox 3, quote 6). Almost half of the patients also mentioned benefits of app-based self-monitoring, mostly related to 'ease of use' in comparison to tracking their measurements on paper (Textbox 3, quote 7). No patients depicted any downsides of eHealth to monitor and track. Additionally, 6 out of 10 HCPs mentioned that they anticipated that improved self-monitoring by patients improves patients' health behaviors, and also helped HCPs to provide accurate medical advice, based on the changes in parameters or symptoms tracked (5/10, 50%) (Textbox 3, quote 8).

(anticipated) Barriers to using eHealth technology

Information barriers (patient and HCP generated)

More than half of the patients (7/11, 64%) and HCPs (7/10, 70%) cited barriers related to the quality and consistency of the disease-related information obtained via eHealth. Patients and HCPs frequently named that information is 'not tailored to their personal needs', 'not practical and detailed', and they sometimes encounter that information is 'inconsistent when consulting different websites or apps' (Textbox 3, quotes 9 and 10).

Trustworthiness and safety (patient and HCP generated)

Patients (6/11, 55%) and HCPs (5/10, 50%) frequently noted barriers related to trustworthiness and safety of eHealth resources. Patients commonly expressed concerns about whether websites contained accurate information (Textbox 3, quote 11). Also, patients mentioned that they did not consult HCPs online because they did not trust unfamiliar doctors (Textbox 3, quote 12). HCPs frequently mentioned that they were reluctant to communicate with patients or provide medical advice online, as they were concerned regarding the reliability and credibility of the information patients provided in online consultations (Textbox 3, quote 13).

Compatibility, complexity of eHealth and time constraints (HCP generated)

Half of the HCPs mentioned the 'complexity of eHealth' and 'a lack of compatibility of eHealth use with their workload and scope of practice' as barriers. HCPs frequently mentioned that the extra tasks and burden eHealth introduced into their already busy daily schedule increased their work stress (4/10, 40%) (Textbox 3, quote 14).

eHealth literacy (HCP generated)

Almost half of HCPs mentioned patients' level of eHealth literacy as a barrier towards eHealth use (4/10, 40%). For example, HCPs stated they experienced that several of their patients have too little eHealth experience, knowledge, and skills to adequately use eHealth in practice (Textbox 3, quote 15).

Textbox 3. Illustrative quotations for theme 1: experience with eHealth in CKD (self-management).

eHealth to Inform

- **Quote 1**: I often search [information of] this [chronic kidney] disease using Baidu. [...] the treatment or what precautions I need to care about. (Patient 5, male, 35y, CKD G3)
- **Quote 2:** WeChat is used to meet patients' knowledge needs. (HCP2, female, 30y)
- **Quote 3**: The process of patients' asking [medical] questions can be simplified. [...] When patients asked for information, I can show them videos, which is easy. (HCP5, female, 34y)
- **Quote 4**: The animation and videos we provided during routine care [....] The content can help patients easily understand the diet restrictions and medication use. (HCP5, female, 34y)
- **Quote 5:** The articles HCPs posted are practical. [...] I can have a general understanding of the disease. (Patient 8, female, 45y, CKD G1)

eHealth to Monitor & track

- **Quote 6**: The software on the mobile phone can record my weight, how much the dialysis fluid enters and exits. (Patient 1, male, 42y, CKD G5 with peritoneal dialysis)
- **Quote 7**: [Monitoring parameters in] the app is easier and much more convenient than recording them in a notebook. (Patient 7, female, 32y, CKD G5 with peritoneal dialysis)
- **Quote 8:** Patients put their information into the apps. Then, we can develop the therapy plan that suits them better according to their status at home. (HCP6, female, 33y)

Information barriers

- **Quote 9**: The information in Baidu or other websites is not detailed. (HCP9, female, 39y)
- **Quote 10**: Online knowledge of food with high potassium is not detailed and sometimes conflicting. (Patient 6, male, 34y, CKD G5 not dialysis)

Trustworthiness and Safety

- **Quote 11**: I cannot completely trust the information online. Maybe it is not correct. (Patient 8, female, 45y, CKD G1).
- **Quote 12**: I do not know the experts on the internet and whether he or she is a real doctor [...] So I do not trust the online consultation. (Patient 4, male, 37y, CKD G2).
- **Quote 13**: Although patients submit some measurements online, the data may be not accurately measured [...] Providing medical advice online is risky. (HCP6, female, 33y).

Compatibility, complexity of eHealth and time constraints

- **Quote 14**: We now have an app for helping monitor patients' data. [...] However, we need to submit medical data in this app. [...] (HCP9, female, 39y)

eHealth literacy

- **Quote 15**: Some patients do not know how to use the internet, [...] and some [patients] find it complicated to submit data online. (HCP2, female, 30y)

Theme 2: Needs for supporting CKD self-management with the use of eHealth

Intervention content and design features

eHealth to inform (patient and HCP generated)

Patients (4/11, 36%) and HCPs (6/10, 60%) frequently expressed a need for eHealth as a medium to improve access to disease-related knowledge (Textbox 4, quote 16). More precisely, patients and HCPs frequently named the possible benefits of using eHealth to improve access to personalized information that is relevant and conducive to the specific patients' health needs (Textbox 4, quote 17).

eHealth to facilitate interaction between patients and HCPs (patient generated)

Almost half of the patients mentioned a need for eHealth to support their communication with HCPs outside of clinical visits (4/11, 36%), enabling more individualized support and advice (Textbox 4, quote 18). Moreover, they mentioned that eHealth may provide possibilities to follow-up on their physical symptoms in between consultations (Textbox 4, quote 19).

Design features of eHealth (patient and HCP generated)

Both patients and HCPs mentioned they preferred the use of mobile phone apps instead of personal computers for CKD self-management, as they found that apps were more easily accessible. To facilitate the transfer of disease-related knowledge, half of the HCPs mentioned that animations or videos without medical terminology should be included to support spoken words or text in eHealth interventions (5/10, 50%). Details are provided in Additional file 2.

Implementation and practicality

eHealth credibility (patient generated)

Patients frequently mentioned that the high perceived credibility of eHealth interventions was essential for successful uptake and implementation (4/11, 36%). Specifically, patients mentioned that if interventions were developed by credible eHealth developers such as the government or hospitals, it would facilitate their eHealth use. In more detail, patients mentioned that this would ensure them that the information came from a reputable and trusted source, as they described (their) HCPs as trusted and familiar (Textbox 4, quotes 20).

Textbox 4. Illustrative quotations for theme 2: needs for supporting CKD self-management with the use of eHealth.

Intervention content and design features

- **Quote 16**: If we can make some videos in the department [of nephrology], the patients will learn more [about disease], [...] such as the food they should eat. (HCP5, female, 34y)
- **Quote 17**: I think that it can be better if there are some detailed guidance and those are tailored for me, not for everyone. (Patient 11, female, 51y, CKD G3)
- **Quote 18**: I hope that [...] I can get a reply tailored to my condition through online consultation. [...] (Patient 2, female, 18y, CKD G1)
- **Quote 19:** It is good if patients can talk to the doctor online if they have minor problems [related to disease] at home, [...] such as getting a cold. (Patient 8, female, 45y, CKD G1)

Implementation and practicality

- **Quote 20**: eHealth applications need to be certified and trusted. For example, WeChat is trusted by everyone. [...] Also, the experts who register in the applications need to be trusted, [...] such as with a detailed introduction of their medical background. (Patient 4, male, 37y, CKD G2)

Part B

Theme 3: Adaptation and implementation of the Dutch MD intervention in China

Anticipated benefits of MD

Online information support (patient and HCP generated)

Patients frequently noted that 'online information support' feature of MD could improve their access to trusted disease-related knowledge; It would enable them to find information quickly and address their questions without a clinic visit or contacting their HCP (Textbox 5, quote 21). Also, almost half of HCPs cited the possible benefits of the component 'online information support' of MD (4/10, 40%) especially related to 'trustworthiness and safety of the information sources' (Textbox 5, quote 22), 'easy access to lab results- and related knowledge to educate patients' and 'possibilities to improve treatment adherence' (Textbox 5, quote 23).

Self-monitoring, combination of home and hospital measurements in the MD (patient and HCP generated)

Patients valued the quick access to their laboratory test results and health information before a clinic visit, enabled by the MD components 'self-monitoring, combination of home and hospital measurements in the MD' (Textbox 5, quote 24). Also, patients frequently mentioned that HCPs' access to their self-monitored health indicators made them feel being 'looked after', and that they appreciated the possibility provided by MD to get in touch with HCPs if their health parameters were deteriorating (Textbox 5, quote 25).

HCPs also cited possible benefits of the 'self-monitoring' and 'combination of home and hospital measurements in the MD' components of the MD (8/10, 80%), as they may help them to track patients' home measurements (Textbox 5, quote 26). Also, HCPs stated that

they may be able to provide a better quality of care and guidance during clinical appointments when they could review the patients' data collected before their clinic visit (Textbox 5, quote 27).

Anticipated barriers of MD use

Clinical compatibility and time constraints (HCP generated)

HCPs frequently cited barriers related to the compatibility of MD with their clinical work and time constraints (4/10, 40%). HCPs mentioned that the use of MD would lead to additional workload (e.g. reviewing patients' electronic health records continuously) and that it would be difficult to incorporate the intervention into their current work schedule (Textbox 5, quote 28).

Technical issues (HCP generated)

HCPs frequently named barriers related to the availability and use of technology necessary to implement MD (4/10, 40%). Specifically, HCPs named a lack of computers, measurement devices, and wireless internet connection at home (Textbox 5, quote 29). Another perceived barrier was the amount of technological connections to different platforms necessary for the implementation of MD (e.g. patient home measurements, laboratory tests) (Textbox 5, quote 30).

eHealth literacy (HCP generated)

HCPs frequently mentioned that patients' eHealth literacy might be a barrier to the implementation of MD in China (6/10, 60%) (Textbox 5, quotes 31).

Other barriers related to features of MD (patient and HCP generated)

HCPs frequently voiced concerns on the potential validity of the electronic data submitted by patients in MD (6/10, 60%); for instance, they named 'invalid measurements on health indicators' (Textbox 5, quote 32). Additionally, patients and HCPs frequently mentioned that the computer-based version of MD was difficult to use; for instance, the need to login to the MD via a separate website (Textbox 5, quote 33). HCPs also cited that the information support website may not provide the personalized and tailored knowledge as desired by patients and HCPs (Textbox 5, quote 34).

Suggestions for adaption and implementation of MD based self-management intervention in China

Recommendation on design and intervention content (patient and HCP generated)

Patients and HCPs mentioned potential improvements for both the design and intervention content of MD (detailed in Textbox 6). Also, more than half of HCPs recommended design adaptations to be made to MD to ensure that the intervention is easy to use by patients, fits well with and supports their clinical workflows (Textbox 5, quote 35).

Implementation strategies: instruction and educational meetings (HCP generated)

HCPs frequently named the necessity to educate patients on the correct use and potential benefits of MD (4/10, 40%). In particular, HCPs mentioned the importance to clearly instruct patients on how to correctly measure health-related indicators and upload their health measurements at home (Textbox 5, quote 36).

Textbox 5. Illustrative quotations for theme 3: adaptation and implementation of the Dutch MD intervention in China.

Online information support

- **Quote 21**: It will be great if I know the meaning of each test indicator online. (Patient 14, female, 52y, CKD G4; focus group 2)
- **Quote 22**: The health education [in Medical Dashboard] is safe. The doctors have checked the content. Patients can read the information according to their needs. (HCP2, female, 30y)
- **Quote 23**: Patients can check directly online about how to use the medication. This can [help] improve their [treatment] adherence. (HCP1, female, 31y)

Self-monitoring and Combination of home and hospital measurements in the Medical Dashboard

- **Quote 24**: It will be convenient if I can see my laboratory tests directly. [...] Especially when doctors are too busy to provide test results. (Patient 15, female, 41y, CKD G4; focus group 2)
- **Quote 25**: Doctors can know our [disease] status at home. We can communicate with doctors directly online. (Patient 20, female, 43y, CKD G2; focus group 1)
- **Quote 26**: There can be continuous care and follow-up if we can see patients' home measurements. (HCP5, female, 34y)
- **Quote 27**: Doctors can provide specific treatment plans according to patients' status at home, such as some medication use. (HCP2, female, 30y)

Clinical compatibility and time constraints

- **Quote 28**: It will lead to extra work burden and costs a lot of time [...] (HCP6, female, 33y)

Technical issues

- **Quote 29**: It seems difficult for [patients in] rural areas [to use Medical Dashboard]. Many patients do not have devices to measure blood pressure. (HCP1, female, 31y)
- **Quote 30**: It is difficult to connect different databases. (HCP6, female, 33y)

eHealth literacy

- **Quote 31**: Some patients could be unfamiliar with the use [of Medical Dashboard] and this will affect the implementation. (HCP4, female, 35y)

Other perceived barriers related to features of Medical Dashboard

- **Quote 32**: The data may not be correctly uploaded by patients, or some patients may not upload data if the values are abnormal. (HCP2, female, 30y)
- **Quote 33**: I always use the smartphone to get a call or read the news. It is difficult if I need to enter websites. (Patient 12, male, 62y, CKD G3; focus group 2)
- **Quote 34**: The information support provides knowledge [of disease] in general. [...] It can be difficult for patients to decide which knowledge is personalized for them. (HCP8, male, 46y)

Recommendation on design and intervention content

- **Quote 35**: This platform must be simple to use and convenient in practice. (HCP8, male, 46y)

Implementation strategies: Instruction and educational meetings (HCP generated)

- **Quote 36**: It is essential to teach patients to conduct the measurements in a correct way to improve the accuracy of the value they measured. (HCP5, female, 34y)

Textbox 6. A summary of needs towards improvement of Medical Dashboard.

Patient & HCP
- Delivery of MD intervention via smart mobile phone apps
- Providing tailored CKD information support
- Peer support
- A psychological module for patients
- Video or voice call to support interactions between HCPs and patients
- Reminders sent to HCPs when patients-entered data is abnormal

HCP
- The wireless tracker in a mobile application to automatically collect measurements
- A user interface platform in a mobile application to visualize data and to review progress

DISCUSSION

Main findings

We examined the perceptions, attitudes and needs of Chinese patients with CKD and HCPs towards eHealth self-management interventions. Our results showed that both patients and HCPs had experience with and expressed potential benefits for CKD eHealth self-management intervention to '*inform*, *monitor and track*', and those to support '*interaction*' and '*data utilization*' were not frequently mentioned. Barriers towards the CKD eHealth self-management intervention implementation were mentioned in relation to information barriers (i.e. quality and consistency of the disease-related information obtained via eHealth), trustworthiness and safety of eHealth resources, clinical compatibility and complexity of eHealth, time constraints and eHealth literacy. Suggestions were also provided to improve the intervention functionalities and content of MD, mainly related to complexity of the platform and compatibility with HCPs' workflows.

The understanding and potential benefit of eHealth

Our finding that eHealth is solely mentioned to '*inform, monitor and track*' as potentially relevant interventions to support CKD self-management underlines the importance of education on functionalities and possibilities of eHealth before (co)designing and implementing eHealth interventions. A recent article suggested increasing educational activities to improve knowledge of eHealth of HCPs; these activities include eLearning, blended learning, courses, simulation exercises, real-life practice, supervision and reflection, role modeling and community of practice learning [43]. Moreover, patients and HCPs should be made aware of the possible benefits but also pitfalls of eHealth, to promote informed decisions on intervention adoption and ownership [43].

Patients and HCPs expressed that easy access to disease-related information and patients' health parameters measurements via eHealth has great potential to improve CKD self-

management and care. This finding is in line with other research on eHealth interventions for people with chronic disease [44, 45]. The Health Belief Model [28] indicates that if people believe that the use of health interventions would lead to their expected positive outcomes (perceived benefits), they are more probable to use interventions. Hence, we suggest using implementation strategies based on persuasive system design (PSD) principles [46] and persuasive technology to persuade/nudge patients and HCPs to adopt eHealth, for instance, personalization and tailoring [47] to these needs and attitudes (e.g. needs towards easy access to information). Also, providing information alone is, however, not sufficient to modify behavior [48]. Thus, we highlight the importance of also improving both patients' motivation and their behavioral skills to facilitate their CKD self-management. As an example of eHealth use, 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) [49].

Barriers related to implementation of eHealth

Barriers named by both patients and HCPs were frequently related to the credibility of information provided via eHealth interventions. Several reasons may explain why barriers related to credibility are so important in China. First, patients with CKD in our study expressed a need for an online information platform established by the government or hospital. However, the eHealth information and platforms used by patients and HCPs are mostly developed by commercial eHealth companies, and could hence be considered less 'credible developers'. Second, there is a lack of uniform quality controls and standards on the accuracy of diverse online information in China. Also, patients with low eHealth literacy could not accurately evaluate the quality of eHealth information resources. Hence, a reliable, trustworthy, and literacy-appropriate information source such as a national and trustworthy health education online platform should be developed, thereby ensuring that trustworthy medical information is available for patients with CKD.

HCPs found it difficult to integrate eHealth interventions into their daily working routines in the past (i.e. lack of compatibility with clinical care, the complexity of eHealth, and time constraints). This finding is corroborated by previous research [50-52], underlining the importance of assessing intervention-workflow compatibility (e.g. staff working patterns, practice management) before and during the development and implementation of eHealth interventions [53]. To increase the clinical compatibility of eHealth interventions, based on a recent meta-analysis [54], we argue that eHealth interventions should partially replace existing care elements, instead of adding elements to care. Also, to ensure that the eHealth application is time-saving, we advise that eHealth functionalities must be simple

and easy to use and the navigation in eHealth must be clear.

Furthermore, eHealth could increase health inequalities [55]. For instance, a common assumption in eHealth interventions is that users are a homogenous group with similar (eHealth) skills and knowledge. However, patients' low eHealth literacy [56] is commonly reported as a potential barrier to implementation by HCPs in our study. Previous literature also showed that eHealth can be difficult to use for people with lower education level and low health literacy [57, 58]. To help more patients with CKD benefit from eHealth self-management interventions, we should adapt interventions to the needs of all users including vulnerable groups such as people with lower education level and older age and eHealth illiteracy. Based on principles established by the 'eHealth for All' program (https://www.pharos.nl/over-pharos/programmas-pharos/ehealth4all/), we suggest that end users, including those less digitally skilled, should be involved in the co-design of eHealth from the start. Also, it is important to conduct 'blend care' [59]; combining e-Health with face-to-face support to provide people with personal assistance and coaching on eHealth use. Additionally, previous studies showed that the effectiveness of eHealth interventions among vulnerable groups is influenced by the level of adherence to eHealth use [60]. Based on a recent review [61], we suggest that to increase the adherence of eHealth use among vulnerable groups, eHealth tools should provide multimodal content (such as videos and games) and the possibility for direct communication between patients and HCPs.

MD Specification Development

In general, patients and HCPs indicated that the Dutch MD would be helpful to support CKD self-management, especially the online information support, self-monitoring and the combined home- and hospital health measurements functionalities. Considering the anticipated barriers and needs mentioned by patients and HCPs, we argue that some surface level adaptations [62] of Dutch MD should be made to improve the fit with Chinese settings, such as extending the intervention delivery medium to a mobile phone app. Also, participants expressed a "one-size-fits-all" approach would not resonate with patients; The need to add personalized features was emphasized, such as visual aids, pictograms, and customized videos. Additionally, eHealth needs to be easy to use and well-integrated into HCPs' workflows. To ensure the continued effectiveness of MD, the core self-management intervention components that underly its effectivity, such as the provision of online information support or self-monitoring, should not be changed [62].

Transferability and implications

When comparing the identified (anticipated) barriers to CKD eHealth self-management intervention in our setting with other settings reported in our systematic review [19], mostly, performed in western wettings, findings were similar. For instance, the factors "clinical compatibility and complexity of eHealth" correspond to factors related to 'Innovation' (e.g. Interventions are compatible with existing work) in the review. Hence, the approach and findings of our study might be applicable and transferable to other eHealth interventions currently developed in China and other developing countries sharing similar contextual characteristics with Chinese settings. Also, the (anticipated) barriers mentioned by patients and HCPs to eHealth based (self-management) interventions in general and Dutch MD intervention in specific were similar. It underlines the importance of exploring the previous eHealth use experience of end users, which could influence their perceptions, attitudes and needs towards eHealth interventions. Additionally, the likelihood of successful adoption of eHealth intervention is increased as the interventions are perceived useful and fit for purpose by the actual users [63]. Therefore, it is important to involve both patients and HCPs in the co-design of eHealth interventions.

Strengths and Limitations

To our knowledge, this is the first study to explore the perceptions, attitudes and needs of patients with CKD and HCPs towards eHealth self-management interventions in Chinese settings. Our study has several strengths. First, we captured a diverse sample (i.e. CKD stage, gender, age range), which ensures that our findings reflect the view of a wide variety of patients with CKD. Second, to improve the robustness of our research, the data collection process and the (preliminary) analysis were performed by two team members who are most closely involved in the fieldwork (HS, WW) to optimize consistency. Also, the framework approach to data analysis allowed data to be compared through the formulation of narratives (in-depth focus) and within- and cross-case comparisons (comparative focus).

Nevertheless, there are also limitations. First, as our findings were not quantified, the relative importance of our findings remains unknown. Second, the HCPs who provided CKD care in the institution were predominantly female. The HCP group interviewed may not have been 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 barriers identified in this study might indicate that this bias has remained limited. Additionally, as is inherent

to qualitative study designs, this study was only performed within one Chinese setting; the generalizability of the findings to other different cultural contexts is uncertain.

CONCLUSIONS

The limited knowledge on the functionalities of eHealth underlines the need for educational efforts such as eLearning and real-life eHealth use practice before and during intervention design and implementation. To optimize the implementation of eHealth self-management interventions and tailor the evidence-based Dutch 'MD' eHealth self-management intervention for patients with CKD in China, future intervention developers should consider specific characteristics and needs within Chinese settings. Emphasis should be placed on increasing eHealth literacy and credibility of eHealth (information resource), ensuring eHealth to be easy to use and well-integrated into HCPs' workflows.

Authors' contributions

HS led the conception and design of this study and is the main contributor in writing this manuscript. RK, PB, WW, XS, ZL, EB, XL and NC contributed to the conception and design of the study and editing of this manuscript. All authors read and approved the final manuscript.

Competing interests

The authors declare that they have no competing interests.

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Additional file 1. Interview and focus group discussion 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
Patient focus group discussions	
No. of focus group participants/invitees	9/9
Duration of focus group discussion 1, min	32
Duration of focus group discussion 2, min	62

SD, standard deviation.

Additional file 2. Patients' and health care professionals' needs and reasoning of design features of eHealth interventions.

Feature	Description	Reasoning
Patient and HCP		
Mobile phone apps	Using mobile phone apps as mediums in the interventions	• Easily acceptable • Easily accessible • Convenient
HCP		
Animation or videos	Using animations or videos to facilitate information provision of patients	• Acceptable • Intuitive • Enhance the texts
Reminders	An automated prompt to remind patients to take the medications and attend hospital appointments	• Improve treatment adherence
Wearable tracker	Using a wearable fitness tracker to track changes of health indicators over time	• Useful • Convenience
Psychological module	Establishing psychological module with paying attention to patients' mental health	• Decrease patients' anxiety
Patient		
Link with electronic records	Patients get access to hospital electronic medical records	• Ask for advice on records • Review test results and records • Convenient

HCP: health care professional.