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

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Chapter 7

General discussion

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In this chapter, the main findings of this thesis are summarized. Also, four main topics are discussed below:

(1) The potential role of electronic health (eHealth) interventions in chronic kidney disease (CKD) self-management in Chinese settings;
(2) The key factors influencing implementation of CKD self-management eHealth interventions;
(3) Implications for the development and implementation of CKD self-management eHealth interventions in practice
(4) Recommendations for future research

Main findings of this thesis

In Chapter 2, we systematically reviewed the existing evidence regarding the implementation and effectiveness of eHealth self-management interventions for patients with CKD. The review indicated that eHealth self-management interventions have the potential to improve the health behaviours and health outcomes of patients with CKD. Also, high feasibility, usability, and acceptability of and satisfaction with eHealth self-management interventions were reported. The determinant *ability of health care professionals (HCPs) to monitor and, if necessary, anticipate on patient measurements online* was most commonly mentioned to influence patients' adherence to interventions. However, data on eHealth self-management interventions for patients with CKD in low- and middle-income countries are still lacking such as in China, which is the largest low-income and middle-income country with a current population of 1.4 billion. In Chapter 3, the extent of the burden of CKD in Chinese settings was demonstrated; a high prevalence of reduced kidney function and kidney function decline in the Chinese primary care population was found and associated risk factors were identified. To reduce the burden of CKD in Chinese settings, we used an Intervention Mapping (IM) approach comprising six steps to guide the development and tailoring of the evidence-based Dutch 'Medical Dashboard' (MD) eHealth self-management intervention for patients with CKD in China. We also developed an evaluation plan for its implementation process and its effectiveness (Chapter 4). Following step 1 of IM (needs assessment), two qualitative studies were performed (Chapters 5 and 6). The first qualitative study examined the beliefs, perceptions and needs of Chinese patients with CKD and HCPs towards CKD self-management (Chapter 5). Chapter 5 showed that most patients and HCPs solely mentioned medical management of CKD, and self-management was largely unknown or

misinterpreted as adherence to medical treatment. A paternalistic patient-HCP relationship was often present. Additionally, the barriers, facilitators and needs towards CKD self-management were frequently related to (lack of) knowledge and environmental context and resources. The second qualitative study examined the perceptions, attitudes and needs of Chinese patients with CKD and HCPs towards eHealth based (self-management) interventions in general and the Dutch MD intervention in specific (Chapter 6). Chapter 6 showed that both patients and HCPs recognized, had experience with and expressed potential benefits for CKD eHealth self-management intervention as a means to 'inform, monitor and track'. eHealth interventions 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 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.

The potential role of eHealth interventions in CKD self-management in Chinese settings

CKD poses a severe health and socioeconomic burden to the Chinese population. The burden of CKD is related to the increased prevalence of non-communicable diseases (NCDs) such as diabetes and hypertension [1-5]; these NCDs lead to a high prevalence of CKD (Chapter 3), a lower life expectancy and high costs of medical care [6-9]. Also, patients report severe physical, psychosocial and lifestyle consequences of CKD (Chapter 5). For instance, the overwhelming fatigue, complex treatment regimens, liquid and diet restrictions constrain patients' lives (Chapter 5). Additionally, there is a lack of a strong primary care system in rural China to provide adequate health care for patients with (early) CKD; most of the high-quality resources in medical care such as human capital and modern diagnostic and therapeutic technologies are concentrated in Chinese hospitals. As there is a lack of gatekeeping roles and mandatory referrals in primary care, patients are able to freely self-refer to higher-level of providers according to ability and willingness to pay. Therefore, people visit the hospital directly if they have complaints or for check-ups, and the care for patients with CKD relies heavily on HCPs who work in the Department of Nephrology (Chapters 5 and 6).

China is implementing major reforms in health care services with a focus on strengthening primary health care. The primary health care reforms, first announced in

2009, aim to deliver chronic disease care through community health services with a referral of complex cases to the tertiary hospital system [10]. To cope with the growing burden of CKD and other NCDs, the chronic illness management approaches in Chinese primary health care include engaging a patient central role in the self-management of their condition [11]. The goal of self-management is to identify strategies to help patients manage their condition(s) while leading active and productive lives. Patients with CKD who adequately perform self-management, such as high adherence to medication, exercise and diet recommendations, have fewer doctor visits and hospitalizations [12-14]. Therefore, interventions supporting CKD self-management have great potential to improve the patients' health outcomes, decrease health care costs and increase patient satisfaction.

eHealth-based interventions are increasingly being developed to support CKD self-management in China. In specific, patients with CKD and HCPs indicated that eHealth technology facilitates remote patient-provider communication and exchange of (health) data. Also, eHealth increases healthcare accessibility and efficiency (for patients in a rural area) (Chapter 6). Policymakers and care experts in China have recently launched the national health strategy 'Healthy China 2030' [15]. This strategy describes eHealth technology as an essential pillar to improve disease self-management as well as the accessibility and cost-effectiveness of care in rural areas. Also, patients and HCPs expressed the need towards CKD self-management for better access to and provision of disease-related knowledge, especially through eHealth mediums (Chapter 5). Thus, there is a high need and significant momentum for the implementation of eHealth-based interventions to support CKD self-management in China.

The key factors influencing implementation of CKD self-management eHealth interventions

Evidence regarding the key factors influencing implementation of CKD self-management eHealth interventions is accumulated from our systematic review (global information in Chapter 2) and two qualitative studies conducted in Chinese settings (Chapters 5 and 6). To this end, key factors found (i.e. barriers and facilitators) influencing implementation of CKD self-management eHealth interventions in Chinese settings are structured and categorized following the five domains of the Consolidated Framework for Implementation Research (CFIR) [16, 17]:

- the intervention characteristics, which are the features of an intervention (e.g. stakeholders' perceptions about the relative advantage of implementing the intervention, complexity).

- the outer setting, which includes the features of the external context or environment (e.g. external policy and incentives).
- the inner setting, which includes features of the implementing organization (e.g. implementation climate).
- the characteristics of the individuals involved in the intervention (e.g. knowledge and beliefs of patients with CKD and HCPs about the intervention).
- the implementation process, which includes strategies or tactics that might influence implementation.

The CFIR provides a pragmatic structure for identifying potential implementation strategies for interventions in health systems at multiple levels [18-22]. Also, it has been successfully used to identify determinants of behaviour change and optimize the design and effectiveness of self-management interventions [23]. Figure 1 presents an overview of the CFIR domains and offers insight into the most essential factors in each domain influencing the implementation of CKD self-management eHealth interventions in Chinese settings. Also, it is important to realize that certain factors can be considered both a facilitator and a barrier. For example, knowledge was frequently mentioned as a factor affecting CKD self-management intervention. When there was a lack of knowledge for patients, knowledge was a barrier to CKD self-management; however, patients' sufficient knowledge can be considered as a facilitator.

When comparing the factors critical to CKD self-management eHealth intervention in Chinese setting with other settings reported in our systematic review (Chapter 2) [24], mostly, performed in western wettings, findings were highly similar. The factor "Knowledge & Beliefs" in the domain "Individuals characteristics" corresponds to factors related to the "Users" (e.g. availability of sufficient skills/knowledge of users) in the review. Also, the factors "Quality and advantage of eHealth intervention" in the domain "Intervention characteristics" and "Compatibility" in the domain "Inner setting" correspond to factors related to 'Innovation' (e.g. Interventions are compatible with existing work) in the review. Additionally, the factor of evidence-based implementation strategy such as 'Instruction and educational meetings' in the domain 'Implementation process' corresponds to factors related to 'Innovation strategies' (e.g. well planned/structured implementation process) in the review. The similarity between these findings suggests that although eHealth is a rapidly changing field, several challenges such as clinical compatibility of implementing eHealth intervention remain constant across different geographic regions and over time.

Domain	Factor	Direction	
Intervention	• **Complexity (of eHealth)**[6]		–
	• **Quality and advantage of eHealth intervention**		
	-Trustworthiness and safety of eHealth[6]		–
	-Information barriers of eHealth[6]		–
Outer setting	• **Cultural context**		
	-A paternalistic patient–HCP relationship[5]	+	–
	• **Needs & Resources**		
	-Patients' and HCPs' needs towards CKD self-management eHealth intervention[5,6]	+	–
	-Infrastructure of (primary) health care[5,6]	+	–
Inner setting	• **Compatibility**		
	-Clinical compatibility of eHealth[6]		–
	• **Training and support**		
	-Patients' and HCPs' skills/ knowledge[5,6]	+	–
Individuals	• **Knowledge & Beliefs**		
	-Patients' and HCPs' attitudes and beliefs of CKD self-management eHealth intervention[5,6]	+	–
	-Patients' and HCPs' knowledge of CKD self-management eHealth intervention[5,6]	+	–
	• **Patients' and HCPs' concerns about privacy, security, and liability**[6]		–
Process	• **Planning**[5,6]	+	
	• **Engaging**		
	-Instruction and educational meetings[6]	+	

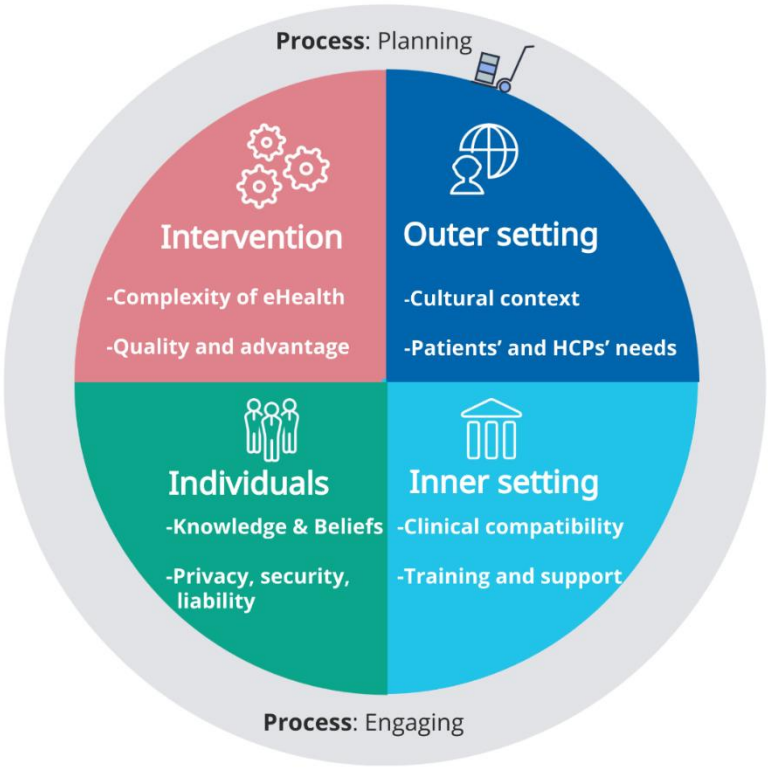

Figure 1. Overview of the different domains of Consolidated Framework for Implementation Research (CFIR) related to CKD self-management eHealth intervention implementation in Chinese settings. [5] chapter 5, [6] chapter 6. +: if the factor is present/considered as a facilitator. -: if the factor is present/considered as a barrier. HCP: Health care professional; CKD: Chronic kidney disease.

However, our findings also indicated that several factors differ from studies conducted in Western settings (Chapter 2) [24], namely 'Cultural context (i.e. paternalistic patient-HCPs relationship)' and "Needs and resources" (i.e. patients' and HCPs' specific needs in Chinese settings, infrastructure of (primary) health care) in the domain "Outer setting". For instance, patient autonomy is a core principle of the patient-doctor interaction in western cultures [25, 26]. However, the appreciated paternalistic relationship in our study can be valuable and even essential to improving health outcomes and treatment adherence in some cultural contexts [27, 28]. Under certain conditions, a paternalistic relationship has been shown to provide high-quality health care in some cultural contexts, for instance, if patients prefer and express needs for a paternalistic approach over autonomy [27, 28]. Additionally, there is a high need for an improved infrastructure of primary health care to support CKD self-management in Chinese settings. For instance, patients expressed needs for HCPs' guidance on daily lifestyle behaviours in primary care (Chapter 5). These identified factors could be leveraged to accelerate the implementation of CKD self-management eHealth interventions in countries sharing similar contextual characteristics with Chinese settings.

All influencing factors in different domains seemed to interact to affect the implementation process and effectiveness of eHealth self-management interventions. For instance, tailoring CKD self-management eHealth interventions to patients' and HCPs' attitudes, beliefs and needs can improve the compatibility and solve the concerns, which can therefore increase the perceived quality and advantage of the intervention. Therefore, to increase the success of the implementation of eHealth interventions, the complexities of multiple, interacting domains (e.g. the organization, and the implementation process) need to be addressed [29].

Implications for the development and implementation of CKD self-management eHealth interventions in practice

In this section, several practical implications are provided for future development, adaptation, and implementation of CKD self-management eHealth interventions in Chinese settings and beyond.

Future researchers and eHealth intervention developers should be aware of the identified factors that influence implementation. Also, researchers and eHealth intervention developers need to be aware of local context-specific factors in the settings where CKD self-management eHealth interventions are developed and implemented. For instance, in Chinese settings, when patients prefer a paternalistic approach, the paternalistic guidance on self-management provided by HCPs can help patients become aware of the

importance and potential benefits of self-management. As such, an optimal effect of the self-management intervention can be achieved.

Possible approaches are suggested to address the key influencing factors (Figure 2) based on literature specific to eHealth interventions [30] and additional general implementation literature [31]. Essential aspects for these approaches include involving stakeholders (i.e. patients with CKD and HCPs) in the development and implementation process (i.e. a participatory design), adjusting eHealth design features to fit the clinical workflows, and providing the needed support and training. Specifically, developing personalized eHealth instead of applying a one-size-fits-all approach is important to increase the success of the implementation of eHealth intervention [32]. Stakeholder involvement in the development and implementation of eHealth via a co-creation process can achieve this by understanding relevant stakeholders' requirements and needs throughout the process of eHealth development and implementation. As such, interventions can be tailored to these needs and adapted accordingly [33]. Moreover, to improve the adoption of eHealth technologies, education and training are required and should be updated for patients and HCPs to obtain sufficient knowledge of eHealth intervention and digital competency [34] of the most current and useful technologies (e.g. mobile phone applications) in CKD care. For instance, blended learning that combines e-learning and face-to-face methods is suggested to educate HCPs on how to support patient self-management through eHealth [35]. Also, it is vital to include digital competency training of HCPs in the medical curriculum [36]. To this end, the awareness about the importance of educating HCPs and patients on eHealth in medical faculties needs to be raised, which should be backed up by evidence linking the use of eHealth technologies to health, cost, and satisfaction outcomes.

Multilevel intervention components and implementation strategies (e.g. a socio-ecological model-based approach [37]) tailored to all factors related to CFIR domains may be more effective than single-level implementation strategies throughout the development and implementation of CKD self-management eHealth interventions. For instance, eHealth education should be provided for both patients and HCPs in all processes during the development and implementation of eHealth interventions to promote informed decisions on intervention adoption and ownership.

CFIR domain	Key factors	Possible approaches to address factors
Intervention 	• Complexity (of eHealth) • Quality and advantage of eHealth intervention	• Create simple and easy to use eHealth with clear navigation, involve users (low literacy) in design and development, provide guides and technical support [38-40]. • Develop trustworthy and effective (eHealth) health education resources, develop standards for eHealth [41], use eHealth evaluation approaches [42].
Outer setting 	• Cultural context • Needs & Resources	• Consider (aspects of) the paternalistic relationship, improve patient activation and empowerment [43-45]. • Explore a persuasive design to create a fit between user experience, preferences and intervention content [46].
Inner setting 	• Compatibility • Training and support	• Create a fit between intervention and routines of HCPs in clinical practice and make eHealth simple and easy to use, promote co-creation with local users [33, 47]. • Provide (online) education [48], training and tailored tutorials on eHealth and digital competency [36].
Individuals 	• Knowledge & Beliefs • Patients' and HCPs' concerns about privacy, security, and liability	• Provide a designated booklet [49] and blended learning on knowledge of self-management and eHealth, communicate intended benefits (e.g. health outcomes), provide educational activities [48], develop implementation strategies such as engaging champions and facilitating digital competency training [36].
Process 	• Planning • Engaging	• Organize instruction and educational meetings [31], provide intervention guidance for staff involved in intervention implementation, provide project information at meetings, ensure easy access to researchers and technical support in case of questions, develop implementation strategies using a practical worksheet [50].

Figure 2. An overview of suggestions to address influencing factors of CKD self-management eHealth intervention based on the literature of Health self-management interventions and implementation. CFIR: Consolidated Framework for Implementation Research; HCP: Health care professional; CKD: Chronic kidney disease.

Recommendations for future research

Recommendations are provided that are viewed as vital to improve future research on the implementation of CKD self-management eHealth interventions.

The advantages of eHealth interventions in health care of general population have been described [24, 51, 52]. However, it is unknown to what extent these interventions are effective when implemented among vulnerable groups [53, 54]. Future eHealth intervention design should consider vulnerable groups such as people with lower education level and older age and eHealth illiteracy. Many studies have demonstrated that eHealth is effective in improving health care locally, regionally, and worldwide [55]. However, eHealth could increase health inequalities such as the difference in users and nonusers [56]. A common assumption in eHealth intervention is that users are a homogenous group with similar (eHealth) skills and knowledge. However, in reality, people's level of eHealth literacy can be influenced by environmental and societal factors such as different experiences with eHealth tools, patient age, and education level [57, 58]. In our study, difficulties were experienced during eHealth use by some patients with CKD, such as non-traditional eHealth users (Chapter 6). Therefore, future researchers and eHealth intervention developers should engage in co-creation processes with vulnerable groups during eHealth development and implementation, and tailor interventions to the users' level of (eHealth) literacy, thereby reducing health inequalities.

Digital health technologies (e.g. mobile phones) should be stimulated to improve the infrastructure of primary health care in Chinese settings. The three pillars of primary health care are primary care and essential public health functions as the core of integrated health services, multisectoral policy and action, and empowered people and communities (World Health Organization. A vision for primary health care in the 21st century. 2018). Digital health technologies provide great potential in supporting these pillars and improve the accessibility, affordability and quality of health care (World Health Organization. Digital technologies: shaping the future of primary health care). Specifically, with the use of technologies such as for searching medical knowledge resources, enhancing telecommunication between patients and HCPs, and monitoring healthy behaviours, digital health can be the most suitable and wide-scaled delivery medium of timely and accessible primary health care. This could reduce the burden of CKD, particularly in China which has numerous internet and mobile phone users [59]. Furthermore, on the Chinese market, there are more than 2,000 Internet mobile Health applications and 558 million mobile health application users (http://www. Bigdata-

research.cn/). However, few health apps have been successfully implemented in clinical practice. One possible reason is that most digital health developers are companies, which know more about the commercial interest of technologies than about primary health care (e.g. staff working patterns, practice management). Therefore, to make digital health a reality in Chinese primary health care settings, it is critical that the government play key roles in collaborating with related stakeholders such as companies, innovators and scientific institutes to evolve reliable digital health into primary health care.

An eHealth living lab provides an opportunity to research, connect, share and facilitate eHealth interventions for clinical care in low resource settings. eHealth living-labs, for instance, the National eHealth Living Lab in the Netherlands (https://nell.eu/), provides a platform to bring together relevant eHealth stakeholders including HCPs, students, researchers and policymakers, from diverse institutions, organizations and universities. Within the network of the NeLL, our team from the Leiden University Medical Center and The First Affiliated Hospital of Zhengzhou University shared insights and knowledge in the field of eHealth intervention in CKD self-management. From our experience, this collaborative effort can stimulate the development of eHealth intervention at an international level and facilitate the widespread use of evidence-based eHealth to solve health(care) problems experienced by patients and HCPs in China and the Netherlands. Future collaborations on the development, implementation and evaluation of CKD self-management eHealth intervention in Chinese settings based on Dutch Medical Dashboard will continue.

A qualitative approach was used to explore the beliefs, perceptions and needs of patients and HCPs towards CKD self-management eHealth intervention in Chinese settings. However, the relative importance of influencing factors (e.g. eHealth literacy) for CKD self-management and eHealth intervention implementation was not quantified and remains unknown. Therefore, a future research with a quantitative approach could be conducted to explore the importance of the factors identified. Furthermore, involvement of a multi-stakeholder group in the identification of implementation facilitators and barriers can contribute to a tailored CKD self-management eHealth intervention. As most eHealth applications are developed by companies, it is also important to explore the beliefs, perceptions and needs of eHealth developers in companies towards CKD self-management eHealth intervention.

Conclusions

CKD self-management eHealth interventions in Chinese settings are urgent to reduce the burden of CKD. Also, specific characteristics and needs (e.g. facilitators and barriers) in Chinese settings need to be addressed to optimize the implementation of CKD self-management eHealth intervention. Emphasis should be placed on addressing the existing paternalistic patient-HCP relationship, stakeholder involvement in the development and implementation process, adjusting eHealth design features to fit the clinical workflows, and providing the needed support and training. To the best of my knowledge, the studies in this thesis are the first to focus on local contexts for CKD self-management eHealth intervention in Chinese settings. The research approach used and the results of our study can be relevant for other middle-income countries sharing similar context characteristics. This thesis is a vital step towards the design and implementation of a tailored eHealth solution to improve health outcomes of patients with CKD and address the high burden of CKD in China.

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