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

Shen, H.

Chapter 8

Summary

Samenvatting

List of publications

Curriculum Vitae

Acknowledgements

Summary

Chronic kidney disease (CKD) poses a major challenge to public health. Patients with CKD often report severe physical, psychosocial, and lifestyle consequences. Also, health-related and societal costs of CKD constitute a substantial economic burden. **Chapter 1**, the introduction, elaborates on the current state of the art evidence regarding disease self-management of patients with CKD and explains the benefits of electronic health (eHealth) interventions to support CKD self-management. However, data on eHealth self-management interventions for patients with CKD in low- and middle-income countries are lacking. China, a middle-income country, is the largest country globally with a current population of 1.4 billion. China accounts for around one fifth of the global burden of CKD. It also faces challenges in access to (CKD) care. Hence, eHealth self-management interventions are a great potential to Chinese populations. An extensively studied CKD self-management eHealth intervention is the Dutch 'Medical Dashboard (MD)'. It has been demonstrated effective in decreasing the burden of CKD. Therefore, the overall aim of this thesis is to inform the adaptation and evaluation of a tailored CKD self-management eHealth intervention in China based on the Dutch MD intervention.

To examine the effectiveness of eHealth interventions for CKD self-management, we first made an overview of the evidence to date. The aim of **Chapter 2** was to systematically review the existing evidence regarding the implementation and effectiveness of eHealth self-management interventions for patients with CKD. A total of 24 articles comprising 23 studies were included in this review. The most frequently reported effect outcome indicators were specific laboratory tests and blood pressure (BP), whereas satisfaction was the most frequently reported process outcome indicator. Beneficial effects were found for proximal outcomes (e.g. BP control and medication adherence), and variable effects – both beneficial and no effect – were found for more distal outcomes (e.g. quality of life). High feasibility, usability, and acceptability of and satisfaction with eHealth self-management interventions were reported. The determinant *ability of health care professionals to monitor and, if necessary, anticipate on patient measurements online* was most commonly cited to influence patients' adherence to interventions. To conclude, it has been demonstrated that eHealth self-management interventions can improve disease self-management. Also, when health outcomes are closely related to the scope and duration of the intervention implemented, they are most likely to be improved. As mentioned above, data on eHealth self-management interventions for patients with CKD in low- and middle-income countries such as China were lacking.

To understand the burden of CKD in Chinese settings, the **Chapter 3** presented a repeated cross-sectional study in a primary health care population in China. Electronic records were included of 18273 adults who underwent routine health check-ups between 2004-2020 in three primary health care centers in Zhengzhou city, Henan Province in China. Follow-up serum creatinine was available for 3314 participants, with a mean follow-up duration of 1.5 years. Results revealed a prevalence of reduced kidney function of 17.9% and a prevalence of kidney function decline of 19.3%. The prevalence of rapid estimated glomerular filtration rate decline was 22.8%. Female sex, older age, hypertension, overweight, obesity, diabetes, left ventricular hypertrophy and dyslipidemia were independent predictors of reduced kidney function. Moreover, older age and a reduced kidney function at baseline were independent predictors of kidney function decline.

As the burden of CKD is high in China, and eHealth self-management interventions have the potential to improve the health-related quality of life and health outcomes of patients suffering from CKD, CKD intervention could be highly beneficial in China. Therefore, **Chapter 4** used an Intervention Mapping (IM) approach comprising six steps to guide the development and tailoring of an existing evidence-based eHealth self-management intervention for patients with CKD in China – the Dutch 'MD'. We also developed an evaluation plan for its implementation process and its effectiveness. The output of this study will be used to develop a culturally tailored, standardized eHealth self-management intervention that we plan to conduct among patients with CKD in China, which has the potential to optimize patients' self-management skills and improve health status and quality of life. Furthermore, it will inform future research on the tailoring and translation of evidence-based eHealth self-management interventions in various contexts.

Previous literature demonstrates that beliefs, perceptions, and needs of both patients and health care professionals (HCPs) can influence their display of health behaviors and uptake of (self-management) interventions. Therefore, following step 1 of IM - a needs assessment - **Chapter 5** examined the beliefs, perceptions, and needs of Chinese patients with CKD and HCPs towards CKD self-management. A basic interpretive, cross-sectional qualitative study comprising semistructured interviews and observations was conducted in one major tertiary referral hospital in the Henan province in China. A total of 11 adults with a diagnosis of CKD and 10 HCPs who worked in the Department of Nephrology were included in this study. Results showed that most patients and HCPs solely mentioned medical management of CKD; self-management was largely unknown or misinterpreted as adherence to medical treatment. A paternalistic patient-HCP relationship was often present. Finally, the barriers, facilitators and needs towards CKD self-management were

frequently related to (lack of) knowledge and environmental context and resources. Future researchers and intervention developers should consider the specific characteristics and needs reported within the Chinese context to guide the development or tailoring of CKD self-management interventions.

Chapter 6 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. A basic interpretive, cross-sectional qualitative study was conducted comprising semi-structured interviews with 11 patients with CKD and 10 HCPs, and two focus group discussions with nine patients with CKD. Results showed that both patients and HCPs recognized, had experience with and expressed potential benefits of CKD eHealth self-management interventions as a means to 'inform, monitor and track'. eHealth interventions to support 'interaction' and 'data utilization' were not frequently mentioned. 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. Also, suggestions regarding the 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. Future research needs to increase eHealth literacy and credibility of eHealth (as information resource) among patients and health care professionals, ensure eHealth to be easy to use and well-integrated into HCPs' workflows.

In the general discussion, **Chapter 7**, the main findings of this thesis are presented. It also provides a further explanation for the potential role of eHealth interventions in CKD self-management in Chinese settings. Furthermore, the key factors influencing implementation of CKD self-management eHealth interventions are consolidated from each of the studies in this thesis; 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. In addition, implications are discussed for the development and implementation of CKD self-management eHealth interventions in practice and recommendations are provided for future research. 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 countries sharing similar contextual characteristics. This thesis is a vital step towards the design and implementation of a tailored eHealth solution to improve the health outcomes of patients with CKD and address the high burden of CKD in China.