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

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Chapter 1

General introduction

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The burden of chronic kidney disease

Chronic kidney disease (CKD) is a severe public health problem [1, 2]. Globally, around 698 million individuals are affected by CKD [3]. CKD is defined as kidney damage or a measured glomerular filtration rate (GFR) ≤ 60 mL/min/1.73m^2 for more than three months, and is classified into five stages based on the decline in GFR and level of albuminuria [4]. Numerous detrimental health outcomes are linked to CKD including kidney failure, accelerated cardiovascular disease (CVD) and premature death [5-7]. A recent study reported that globally, 1.4 million CVD-related deaths and 25.3 million CVD disability-adjusted life years are attributable to impaired kidney function [8]. Also, living with CKD involves challenges associated with CKD management, including dealing with symptoms and disability; monitoring physical indicators; managing complex medication regimens; maintaining proper levels of nutrition, diet, and exercise; adjusting to the psychological and social demands [9, 10]. After CKD progression, patients with end stage renal disease (ESRD) rely on dialysis treatment or kidney transplantation; those receiving maintenance dialysis suffer from physical and emotional symptoms, exhibit a high prevalence of depression, and experience substantial impairments in quality of life [11]. Additionally, health-related and societal costs of CKD constitute a substantial economic burden [1, 12, 13].

Disease self-management of patients with CKD

The World Kidney Day Steering Committee has declared 2021 as the year of "Living Well with Kidney Disease." Empowering patients in their CKD management may help deal with the involved challenges and minimize the burden and consequences of CKD-related symptoms to enable increased life participation (i.e. the ability to do meaningful activities of life) [14, 15]. Patients' involvement in the management of their own care is referred to as disease self-management (hereafter referred to as 'self-management'), which is defined as "*an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent to the life with a chronic condition*" [16]. As previously noted, self-management is comprised of three main tasks: medical, emotional, and role management. Hence, self-management is not limited to medical management but also aims to optimize the uptake of new meaningful behaviors or life roles and it promotes adequate coping with disease consequences [16]. The benefits of CKD self-management are well documented. Appropriate self-management has the potential to optimize a patient's ability to perform the cognitive, behavioral, and emotional behavior necessary to maintain a satisfactory health-related quality of life [17]. Also, for patients with CKD,

interventions supporting self-management can not only improve self-management behaviors [18-20], but also health outcomes and quality of life [21, 22], and may even slow disease progression [23-26]. Hence, optimizing CKD self-management is of utmost importance to reduce disease burden, optimize health outcomes and control health care expenditures [24].

eHealth to support CKD self-management

Electronic health (eHealth) based interventions are being increasingly developed to support CKD self-management. The most cited definition of eHealth is that of Eysenbach [27]: "*e-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology.*" eHealth can be operationalized into three types following previous categorizations [28, 29]. The first is 'inform, monitor and track', encompassing the use of eHealth technologies to observe and study health parameters. The second type is 'interaction', covering the use of eHealth to facilitate communication between all users. The final type of eHealth is 'data utilization', referring to the collection, management, and use of health and medical data sources to inform decision making and intervention development. eHealth can help patients to achieve personal health goals, and make patients feel more responsible for their own health status [30]. Moreover, eHealth can facilitate remote patient communication and exchange of (health) data. In this way, eHealth can help to increase health care efficiency while maintaining a wide-scale, cost-effective health care approach [31]. Previous evidence suggests that eHealth self-management interventions have the potential to improve healthy behaviors and health outcomes of patients with CKD [32-36], and are found to be feasible and acceptable for patients with CKD and healthcare professionals (HCPs) [35].

Translation of effective CKD self-management eHealth intervention to Chinese settings

However, research on CKD self-management eHealth interventions has mostly focused on high-income countries, whereas CKD burden is highest in low- and middle-income countries (LMICs) [37]. A systematic review reported that 388 million adults had CKD in LMICs [37]. The burden of CKD is particularly high in China, with the highest number of patients being affected by CKD (132 million) [3]. Around one fifth of the global burden of CKD is in China [3, 38]. Patients and HCPs face challenges in the accessibility of CKD care

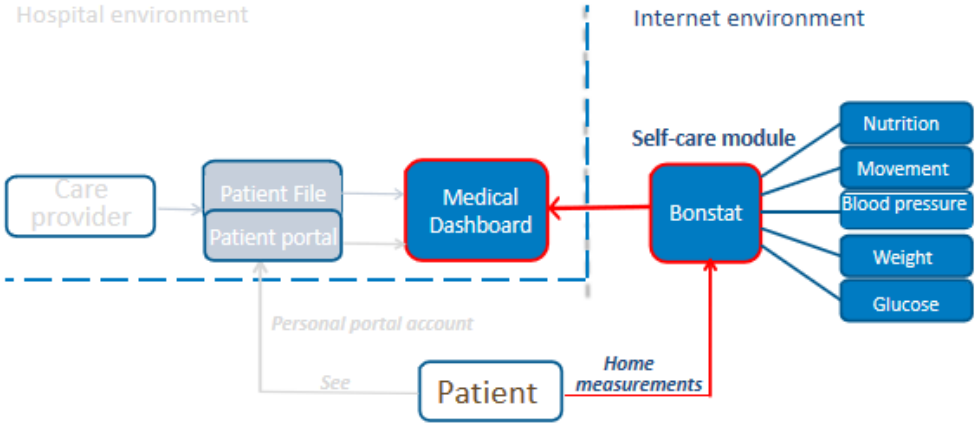
due to the lack of a strong primary care system in China. For instance, in rural China, the long distance to healthcare facilities is a significant problem for patients with CKD. eHealth interventions provide great potential to address these challenges such as so-called 'internet hospitals' allowing patients to receive high-quality care from a top-tier hospital from either their own home or a local clinic, through a video or telephone connection [39]. Hence, eHealth self-management interventions have a great potential to decrease the burden of CKD in countries with fewer resources, including in China.

One possible solution to decrease the burden of CKD is to translate CKD self-management eHealth interventions proven effective in high resource settings to low resource settings. An example of an extensively studied and effective CKD self-management eHealth intervention is 'Medical Dashboard (MD)' [40-42]. The MD, developed in the Netherlands, enables patients and HCPs to monitor and track healthy behaviors and disease parameters. It was used in the Outpatient Clinic Kidney Transplant of the Leiden University Medical Center since February 2016. In a randomized controlled trial (RCT), the use of MD has been shown to improve patients' adherence to sodium restriction intake and blood pressure control [40, 42]. Also, patients reported being highly satisfied with the online disease management system used on the platform [41]. Our research team is closely working with its developers to amend and upscale the intervention to Chinese settings. All core intervention components of MD are presented in Textbox 1 and Figure 1.

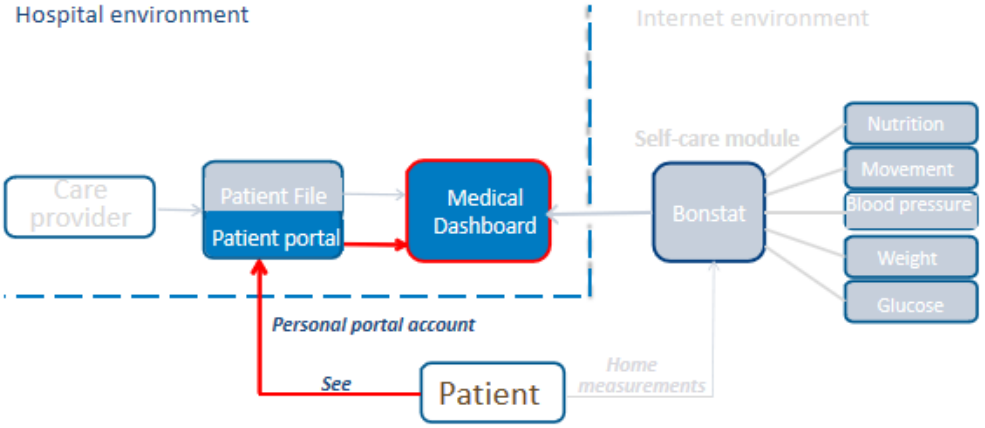
Textbox 1. Core intervention components and functionalities of Medical Dashboard.

- **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.

A



B



C

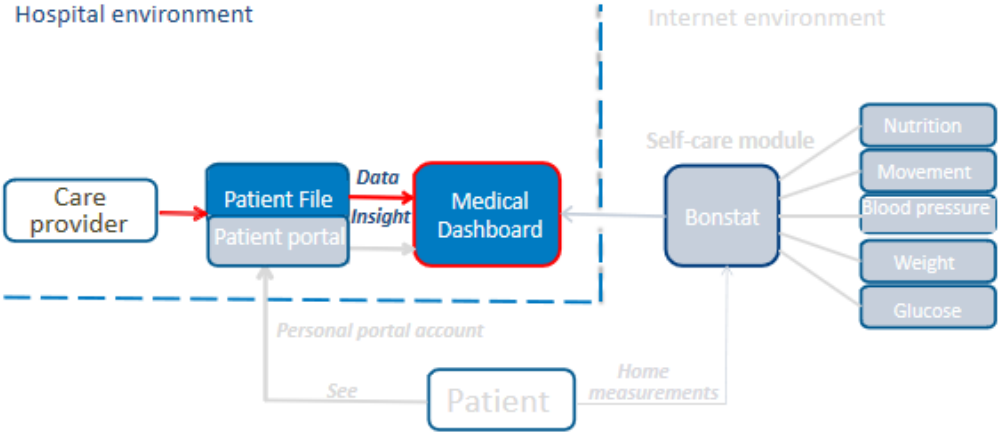


Figure 1. Medical Dashboard. (A) self-monitoring; (B, C) combination of home and hospital measurements in the Medical Dashboard, online information support.

Knowledge to inform CKD self-management eHealth intervention in Chinese settings

As self-management occurs in a social context [43], applying a 'one-size-fits-all' approach and simply translating the intervention as a whole to a different context is not sufficient. Based on the SETTING-tool used for mapping local contexts for (lung) health interventions in diverse low-resource settings [44], key contextual elements including local beliefs (i.e. an idea or principle judged to be true), 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) of the target population towards CKD self-management eHealth intervention should be assessed and integrated into implementation strategies of CKD self-management eHealth intervention in China [44, 45]. Also, the prevalence of CKD and which group of people are at high risk of having CKD in real settings need to be examined. However, as of yet, this knowledge about local contexts for CKD self-management eHealth intervention in China is not available.

Aim of this thesis

To 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. **Chapter 2** provides an overview of the literature regarding the implementation and effectiveness of eHealth self-management interventions for patients with CKD. **Chapter 3** describes the extent of the burden of CKD in Chinese settings assessed by a repeated cross-sectional study; it shows the prevalence of reduced kidney function, kidney function decline and related risk factors in a Chinese primary care population. **Chapter 4** presents the research methods used to develop and tailor a MD intervention for Chinese settings by using the Intervention Mapping approach. **Chapter 5** examines the beliefs, perceptions and needs of Chinese patients with CKD and HCPs towards CKD self-management. **Chapter 6** presents the perceptions, attitudes and needs of Chinese patients with CKD and HCPs towards eHealth/digital tools to support CKD self-management. Finally, I discuss the major findings described in Chapters 2-6 and their implications for development and implementation of CKD self-management eHealth intervention in China and for future research.

References

1. Webster AC, Nagler EV, Morton RL, *et al.* Chronic Kidney Disease. *Lancet* 2017;389:1238-52.
2. George C, Mogueo A, Okpechi I, *et al.* Chronic kidney disease in low-income to middle-income countries: the case for increased screening. *BMJ Glob Health* 2017;2:e000256.
3. Bikbov B, Purcell CA, Levey AS, *et al.* Global, regional, and national burden of chronic kidney disease, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet* 2020;395:709-33.
4. Kasiske BL, Wheeler DC. KDIGO Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease Foreword. *Kidney Int Suppl* 2013;3:2-.
5. Go AS, Chertow GM, Fan DJ, *et al.* Chronic kidney disease and the risks of death, cardiovascular events, and hospitalization. *New Engl J Med* 2004;351:1296-305.
6. Chin HJ, Song YR, Lee JJ, *et al.* Moderately decreased renal function negatively affects the health-related quality of life among the elderly Korean population: a population-based study. *Nephrol Dial Transplant* 2008;23:2810-7.
7. Etgen T, Chonchol M, Forstl H, *et al.* Chronic kidney disease and cognitive impairment: a systematic review and meta-analysis. *American journal of nephrology* 2012;35:474-82.
8. Global, regional, and national burden of chronic kidney disease, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet* 2020;395:709-33.
9. Teasdale EJ, Leydon G, Fraser S, *et al.* Patients' Experiences After CKD Diagnosis: A Meta-ethnographic Study and Systematic Review. *Am J Kidney Dis* 2017;70:656-65.
10. Tong A, Sainsbury P, Chadban S, *et al.* Patients' experiences and perspectives of living with CKD. *Am J Kidney Dis* 2009;53:689-700.
11. Wang R, Tang C, Chen X, *et al.* Poor sleep and reduced quality of life were associated with symptom distress in patients receiving maintenance hemodialysis. *Health Qual Life Outcomes* 2016;14:125-.
12. Wyld M, Lee CMY, Chadban SJ, *et al.* Cost of Ckd in Australia. *Nephrology* 2014;19:23-.
13. Honeycutt AA, Segel JE, Zhuo XH, *et al.* Medical Costs of CKD in the Medicare Population. *J Am Soc Nephrol* 2013;24:1478-83.
14. Tong A, Manns B, Wang AYM, *et al.* Implementing core outcomes in kidney disease: report of the Standardized Outcomes in Nephrology (SONG) implementation workshop. *Kidney Int* 2018;94:1053-68.
15. Carter SA, Gutman T, Logeman C, *et al.* Identifying Outcomes Important to Patients with Glomerular Disease and Their Caregivers. *Clin J Am Soc Nephrol* 2020;15:673-84.
16. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med* 2003;26:1-7.
17. Barlow J, Wright C, Sheasby J, *et al.* Self-management approaches for people with chronic conditions: a review. *Patient Educ Couns* 2002;48:177-87.
18. Nguyen NT, Douglas C, Bonner A. Effectiveness of self-management programme in people with chronic kidney disease: A pragmatic randomized controlled trial. *J Adv Nurs* 2019;75:652-64.
19. Choi ES, Lee J. Effects of a face-to-face self-management program on knowledge, self-care practice and kidney function in patients with chronic kidney disease before the renal replacement therapy. *J Korean Acad Nurs* 2012;42:1070-8.
20. Peng S, He J, Huang J, *et al.* Self-management interventions for chronic kidney disease: a systematic review and meta-analysis. *BMC Nephrol* 2019;20:142.
21. Zimbudzi E, Lo C, Misso ML, *et al.* Effectiveness of self-management support interventions for people with comorbid diabetes and chronic kidney disease: a systematic review and meta-analysis. *Syst Rev* 2018;7:84.
22. Meuleman Y, Hoekstra T, Dekker FW, *et al.* Sodium Restriction in Patients With CKD: A Randomized Controlled Trial of Self-management Support. *Am J Kidney Dis* 2017;69:576-86.
23. Lee MC, Wu SV, Hsieh NC, *et al.* Self-Management Programs on eGFR, Depression, and Quality of Life among Patients with Chronic Kidney Disease: A Meta-Analysis. *Asian Nurs Res (Korean Soc Nurs Sci)* 2016;10:255-62.
24. Lin MY, Liu MF, Hsu LF, *et al.* Effects of self-management on chronic kidney disease: A meta-analysis. *Int J Nurs Stud* 2017;74:128-37.
25. Lopez-Vargas PA, Tong A, Howell M, *et al.* Educational Interventions for Patients With CKD:

A Systematic Review. *Am J Kidney Dis* 2016;68:353-70.
26. McManus RJ, Mant J, Haque MS*, et al.* Effect of self-monitoring and medication self-titration on systolic blood pressure in hypertensive patients at high risk of cardiovascular disease: the TASMIN-SR randomized clinical trial. *JAMA* 2014;312:799-808.
27. Eysenbach G. What is e-health? *J Med Internet Res* 2001;3:E20-E.
28. van der Kleij R, Kasteleyn MJ, Meijer E*, et al.* SERIES: eHealth in primary care. Part 1: Concepts, conditions and challenges. *The European journal of general practice* 2019;25:179-89.
29. Shaw T, McGregor D, Brunner M*, et al.* What is eHealth (6)? Development of a Conceptual Model for eHealth: Qualitative Study with Key Informants. *J Med Internet Res* 2017;19:e324.
30. Barello S, Triberti S, Graffigna G*, et al.* eHealth for Patient Engagement: A Systematic Review. *Front Psychol* 2016;6:2013-.
31. Black AD, Car J, Pagliari C*, et al.* The impact of eHealth on the quality and safety of health care: a systematic overview. *PLoS medicine* 2011;8:e1000387.
32. Ong SW, Jassal SV, Miller JA*, et al.* Integrating a Smartphone–Based Self–Management System into Usual Care of Advanced CKD. *Clinical Journal of the American Society of Nephrology* 2016;11:1054.
33. Reese PP, Bloom RD, Trofe-Clark J*, et al.* Automated Reminders and Physician Notification to Promote Immunosuppression Adherence Among Kidney Transplant Recipients: A Randomized Trial. *Am J Kidney Dis* 2017;69:400-9.
34. Shen H, van der Kleij R, van der Boog PJM*, et al.* Electronic Health Self-Management Interventions for Patients With Chronic Kidney Disease: Systematic Review of Quantitative and Qualitative Evidence. *J Med Internet Res* 2019;21:e12384.
35. Ong SW, Jassal SV, Miller JA*, et al.* Integrating a Smartphone-Based Self-Management System into Usual Care of Advanced CKD. *Clin J Am Soc Nephro* 2016;11:1054-62.
36. Reese PP, Bloom RD, Trofe-Clark J*, et al.* Automated Reminders and Physician Notification to Promote Immunosuppression Adherence Among Kidney Transplant Recipients: A Randomized Trial. *Am J Kidney Dis* 2017;69:400-9.
37. Mills KT, Xu Y, Zhang W*, et al.* A systematic analysis of worldwide population-based data on the global burden of chronic kidney disease in 2010. *Kidney Int* 2015;88:950-7.
38. Wang F, He K, Wang J*, et al.* Prevalence and Risk Factors for CKD: A Comparison Between the Adult Populations in China and the United States. *Kidney International Reports* 2018;3:1135-43.
39. Xie X, Zhou W, Lin L*, et al.* Internet Hospitals in China: Cross-Sectional Survey. *J Med Internet Res* 2017;19:e239.
40. Meuleman Y, Hoekstra T, Dekker FW*, et al.* Sodium Restriction in Patients With CKD: A Randomized Controlled Trial of Self-management Support. *Am J Kidney Dis* 2017;69:576-86.
41. van Lint CL, van der Boog PJ, Wang W*, et al.* Patient experiences with self-monitoring renal function after renal transplantation: results from a single-center prospective pilot study. *Patient preference and adherence* 2015;9:1721-31.
42. Humalda JK, Klaassen G, de Vries H*, et al.* A Self-management Approach for Dietary Sodium Restriction in Patients With CKD: A Randomized Controlled Trial. *Am J Kidney Dis* 2020;75:847-56.
43. Sadler E, Wolfe CDA, McKevitt C. Lay and health care professional understandings of self-management: A systematic review and narrative synthesis. *SAGE Open Med* 2014;2:2050312114544493-.
44. Brakema EA, van der Kleij RM, Poot CC*, et al.* A systematic approach to context-mapping to prepare for health interventions: development and validation of the SETTING-tool in four countries. *BMJ Glob Health* 2021;6.
45. Sperati CJ, Soman S, Agrawal V*, et al.* Primary care physicians' perceptions of barriers and facilitators to management of chronic kidney disease: A mixed methods study. *PLoS One* 2019;14:e0221325.