Reducing the chronic disease burden in China: tailoring a self-management intervention among Chinese people with chronic lung disease

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Addendum

Summary

Chronic lung disease (CLD) and hypertension can cause significant disease burdens, and people with chronic diseases are more likely to report experiencing severe physical, psychosocial, and lifestyle consequences. In addition, the health-related costs of chronic disease represent a substantial economic burden. **Chapter 1**, the Introduction, summarizes the current evidence regarding the self-management of patients with chronic disease. This chapter also discusses the benefits of self-management intervention (SMI) for reducing the disease burden. Most research on SMIs for people with chronic diseases has been conducted in high-income countries, while low- and middle-income countries face a high chronic disease burden.

Given the high disease burden of chronic diseases in low- and middle-income countries, for example, China, it is essential to identify effective SMIs that can improve the health of these patients and reduce the disease burden. Existing SMIs have mainly been developed and studied in high-income countries, where they have shown promising effects on health. However, Implementing such intervention in China may fail if the (healthcare) context, such as cultural background and the economy, needs to be considered. To successfully implement SMIs that have shown positive effects in high-income countries in the Chinese context, it is necessary to tailor the intervention to tackle CLD in China. Therefore, this thesis aims to tailor a proven effective SMI for implementation in China. To do this, four steps are taken, namely (1) identifying the Chinese context, (2) selecting the SMI and the mode to deliver the SMI, (3) identifying factors influencing the implementation of the SMI, and (4) integrating the SMI in the Chinese context. The thesis focuses on SMIs for CLD. The method applied and the knowledge gained can also be used by researchers for other chronic conditions.

Chapter 2 examined the disease burden of Chinese people with chronic disease. It focused on the disease burden experienced by Chinese people with hypertension. The prevalence of frailty among these patients and the risk factors contributing to the high disease burden were identified. The identification was made through a cross-sectional study in Chinese primary care. Nine hundred and ninety-five participants completed the quantitative survey. It was shown that the prevalence of frailty among Chinese people with hypertension was 46.5%. Factors associated with frailty were: higher age, female gender, co-morbidity, alcohol use, and having no partner. The results showed that multiple risk factors were associated with the disease burden in Chinese people with hypertension. To address the disease burden of hypertension and other chronic diseases in China, effective interventions must be implemented to address the previously identified risk factors.

In **Chapter 3**, a systematic literature review and meta-analysis was conducted to gain insight into the effectiveness of blended interventions for people with a CLD. A total of 22 randomized controlled studies were included. These studies examined SMIs that combined face-to-face treatment

with eHealth. The results showed that these interventions could positively affect physical functioning, body mass index (BMI), and quality of life. SMIs can potentially improve health outcomes in people with a CLD, but tailored intervention strategies are needed to optimize the effectiveness of these interventions. As described in **Chapter 1**, the included studies were mostly conducted in high-income countries. In contrast, research on the effectiveness of SMIs for people with CLD in low- and middle-income countries, such as China, needs to be completed.

To successfully implement a proven effective SMI in another context (i.e., China), it is necessary to identify the local context. In **Chapter 4**, mixed-method research was conducted among people with CLD and healthcare providers in Chinese primary and secondary care. In total, 52 participants completed semi-structured interviews, and 48 of the 52 also completed a questionnaire. The results showed that Chinese people with CLD have poor disease perception. They often lack knowledge about the condition and have poor disease control. Furthermore, most participants needed better self-management skills, preventing them from promptly recognizing exacerbations and taking action. Several factors were identified that influence the self-management skills of patients in China, such as insufficient knowledge about the disease and limited ability to bear medical costs. Finally, the needs for self-management were mapped out. Increasing knowledge about the disease was an identified need among patients and healthcare providers and can help facilitate patient self-management. Additionally, eHealth and an individualized self-management plan were mentioned as possible strategies for improving skills. The findings from this chapter can be taken into account when developing SMIs. Finally, the identified factors and needs for self-management have provided information for the next tailoring step, namely selecting the SMI and the mode of delivery.

In **Chapter 5**, the REducing Delay through edUcation on eXacerbations (REDUX) program was selected as the intended SMI for two reasons. First, REDUX, as an individualized self-management plan, is easy to use and promotes interaction between patients and healthcare providers. Second, the paper version of REDUX has shown a positive effect on the self-management of exacerbations in the Netherlands. Since blended interventions can improve physical function in people with CLD, this chapter will also investigate which mode of delivery of REDUX is preferred in the Chinese context (e.g. digital or paper-based).

To tailor REDUX to the Chinese context, **Chapter 5** identifies the factors that can influence the implementation of REDUX in China. The level of support for REDUX, factors influencing support, and preferred mode of providing REDUX were identified in patients, caregivers, and policymakers. Additionally, the necessary conditions for developing and implementing a digital version of REDUX were investigated among app developers and cyber security officers. A stakeholder analysis was applied using qualitative interviews with patients, healthcare providers and policymakers (n = 35) and

a quantitative questionnaire among app developers and cyber-security officials (n = 87). Most patients, healthcare providers, and policymakers supported REDUX to a high degree. Multiple facilitators (e.g. interaction between patient and healthcare provider, involvement of doctors) and barriers (e.g. patients being unable to afford medication, lack of policy support) were identified. The preferred mode to deliver REDUX varied for different reasons. Most app developers and cyber security officers agreed that their processes for developing and implementing health apps align with related international guidelines. The identified factors can help with the successful implementation of REDUX.

To integrate REDUX in the Chinese context, a small-scale pilot study is needed to evaluate the REDUX program's effectiveness and preconditions (i.e., feasibility, acceptability, and suitability). The research protocol for the pilot study is described in **Chapter 6**. Forty-four patients and 24 healthcare providers will be included in Chinese primary care. The intervention starts when a patient, after an exacerbation, is referred to the nurse for a post-exacerbation consultation. The research ends when the patient, after a subsequent exacerbation, presents again for a second post-exacerbation consultation. The study is to identify whether the intervention reduces the time between the onset of an exacerbation and its recognition and whether it reduces the time between the onset of the exacerbation and the moment a patient seeks medical help. The preconditions will be measured to evaluate whether REDUX is sufficiently adapted to the Chinese context. The results of this pilot study can indicate whether a large-scale REDUX implementation (study) is feasible. Implementing the REDUX program in the Chinese context can help Chinese healthcare providers to provide efficient care and reduce their workload. Moreover, the proposed study will facilitate future research into tailoring SMIs in different contexts.

The general discussion, **Chapter 7**, presents the main findings of this dissertation. Additionally, future research recommendations on implementing SMIs in the Chinese context and optimizing tailoring steps are discussed. Practical implications and recommendations are also presented - on increasing knowledge of the disease and awareness of SMI, improving the technology and mode to deliver SMIs and expanding networks with different stakeholders - to support the successful implementation of SMIs. This thesis is critical for tackling CLD and tailoring SMIs, which can improve the health outcomes of patients and promote the use of local resources. This thesis is also the first to focus on tailoring SMIs for Chinese individuals with CLD. The research methods and results can be used to develop and implement culturally sensitive SMIs.