

Towards tailored medication self-management

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Summary

In Europe, the population's life expectancy is increasing, which means that people are living longer on average; thus, the proportion of elderly people is increasing. Approximately 80% of people aged over 65 years are affected by one or more chronic diseases. Europe's aging population is leading to a growing number of people affected by chronic disease, which will continue over the coming decades. Healthcare systems are under pressure to deliver appropriate care, partly due to the burden imposed on their limited financial and human resources by the growing number of people with (multiple) chronic diseases. Therefore, there is a strong call for patient self-management to meet these patients' healthcare needs.

Chapter 1 (Introduction) of this thesis describes how a crucial component in the management of chronic conditions is adequate pharmacotherapy. While many patients experience medication self-management as difficult, it poses additional challenges for people with limited health literacy. Health literacy encompasses people's knowledge, motivation, and competencies for accessing, understanding, appraising, and applying health information, which is used to make judgments and decisions in their everyday life concerning healthcare, disease prevention, and health promotion to maintain or improve their quality of life during their life course. To improve patients' medication self-management, it is critical to adequately support and facilitate those with limited health literacy. In general, such patients have a greater need for practical, recognizable, and simpler information as well as step-by-step explanations of how certain actions should be taken. Unfortunately, most medication self-management support interventions do not sufficiently meet these needs of people with limited health literacy. As a result, they make less use of available support programs.

This thesis aims to explore the needs of patients with a chronic disease and limited health literacy regarding medication self-management and how support for medication self-management can be tailored to those needs. Several of the studies presented in this thesis focused on multiple chronic diseases, of which diabetes was of special interest due to the extensive medication self-management behaviors that patients require. The following two research questions were formulated:

1. What are the needs of patients with chronic disease and limited health literacy regarding medication self-management?
2. How can patients with chronic disease and limited health literacy best be supported and facilitated in their medication self-management?

Empirical studies – Main findings

Chapter 2 addresses the needs of patients with limited health literacy and type 2 diabetes mellitus regarding medication self-management and their preferences for medication support. A two-stage qualitative needs assessment study was performed using in-depth individual interviews and focus groups. Patients were found to prefer to be supported in three domains. The first domain was support with information, including the provision of information that is reliable and relevant, easy to understand, and preferably presented with animations or as spoken text. The second domain was support in interactive communication: patients preferred more frequent contact with their healthcare professionals and wanted more contact with their peers to share their experiences of coping with their disease. Lastly, the third domain was stimulation and advice for adequately managing one's pharmacotherapy, which included advice on the dosing of medication in altered circumstances or positive stimuli to improve adherence to medication therapy. Future interventions should be created in co-creation with people with limited health literacy and fulfill their expressed needs regarding information, communication, and tools for improving self-management.

Chapter 3 describes the association between health literacy and beliefs about the overuse and harmful effects of medication. An online survey was sent to the 'Medication panel' of the Dutch Institute for Rational Use of Medicine. A total of 539 (25%) of the 2,157 panel members returned complete questionnaires, which were included in the analysis. The results indicated that patients with a lower level of health literacy had more concerns about the overuse and harmful effects of medication. Moreover, age, gender, and number of medications had no modifying effects on the association between health literacy and beliefs about medication. These results suggest that extra attention should

be paid to individuals with a limited health literacy to decrease their concerns about the overuse and harmful effects of medication and to improve their adherence to self-management.

Chapter 4 describes evidence regarding the effectiveness of health literacy interventions in Member States of the European Union (EU). The study presented was the first systematic review on health literacy interventions in the EU. In total, 23 intervention studies published from 1995 until 2018 were identified. The interventions described in these studies either (a) aimed to improve (aspects of) health literacy; (b) were specifically tailored to different health literacy levels; or (c) were general interventions that aimed to improve health outcomes, which referred to the specific effects for patients with different health literacy or numeracy levels. The following three factors were likely to characterize promising interventions: (1) tailoring activities to the needs of participants (with limited health literacy); (2) addressing interactive and/or critical skills (as opposed to only knowledge); and (3) presenting the information in an appropriate manner (e.g., not complicated and with animated spoken text).

Chapter 5 describes the usability of an animated diabetes information tool ('Watch your diabetes') for patients with diabetes with limited and adequate levels of health literacy. The study design was qualitative; 25 semistructured interviews were conducted with patients with diabetes. The tool seemed to meet the needs of patients with limited health literacy as it provides information that is in understandable plain language as well as practical for supporting diabetes self-management. Moreover, most of the information is presented through spoken animations. In addition to animated videos, the tool enables users to contact fellow patients with diabetes through an online platform, where they can share knowledge and experiences. They can also perform a knowledge test to check whether they have understood the information. The videos are personalized by gender, age, and the medication and blood glucose meters used; thus, a patient will only receive information that is relevant to him or her. The tool was perceived as easy to use and usable by many patients with diabetes, both those with limited and adequate health literacy levels. Those with limited health literacy indicated that they had learned from the tool and had the intention to continue using it in the future. These participants also expressed the

need for the tool to be more actively offered by healthcare professionals, while participants with adequate health literacy expressed the need for more in-depth information.

Chapter 6 describes the implementation of an animated medication information tool ('Watch your meds') in Dutch community pharmacies, with a special focus on patients with limited health literacy. A cross-sectional survey was conducted among community pharmacies in the Netherlands, which were recruited through email newsletters to pharmacy networks (N = 140). The majority of the pharmacists surveyed offered the tool to all of their patients, including those with limited health literacy. They stated that they offered the tool because the health insurance company offered them financial incentives and the tool complemented other existing medication information. According to the surveyed pharmacists, most patients are interested in using the tool. However, the main reasons why patients refuse to use the tool were reported to be a lack of affinity for or access to the required technology. The tool was mainly passively offered through sending a link to it. A more active method of offering the tool might be warranted to more effectively reach patients with limited health literacy.

Discussion and conclusion

Chapter 7 concludes the thesis by addressing and reflecting upon the main findings. It also describes practical implications and recommendations for future research. The goal of the thesis was to understand the needs of patients with chronic diseases and limited health literacy in regard to medication self-management, as well as how to most effectively tailor support to them. Medication self-management is known to be difficult for many people, especially those with limited health literacy. This thesis demonstrates that patients with limited health literacy can be supported in their medication self-management through tailored health information that is more accessible, understandable, and easier to assess. In addition to providing health information and improving knowledge, medication self-management support should also focus on helping patients to acquire skills and self-confidence. This thesis provides recommendations for the design, content, and strategies of future self-management

interventions for this group of patients. It also discusses strategies for reaching patients with limited health literacy and the importance of including them in the design of future interventions. Although healthcare professionals are willing to support medication self-management, a more active delivery approach and training are required to reach patients with limited health literacy.