

# Getting in control

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# Summary

**Chapter 1** of this thesis describes the background and concepts of health literacy, self-management and self-management support. Currently there is too little attention in health care and self-management support for individuals with limited health literacy, while limited health literacy is an important barrier for adequately dealing with chronic diseases. This thesis focusses on the self-management of patients with limited health literacy, the problems they encounter, and their needs regarding self-management support. To investigate how patients with limited health literacy can be optimally supported, we defined the following research questions:

1. Which patient groups are vulnerable regarding health literacy in the Netherlands?
2. What difficulties do patients with limited health literacy face in relation to self-management and what are their needs with respect to self-management support?
3. Which self-management interventions (SMIs) are available for chronically ill patients with limited health literacy, and do they match the needs of these patients?
4. What recommendations can we make regarding development, design, and implementation of SMIs for chronically ill patients with limited health literacy?

### *Main findings*

To answer research question 1, **chapter 2** acquires insight into the level of health literacy of ethnic minorities in the Netherlands. A questionnaire was sent to a sample of 2.116 members of the Dutch Health Care Consumer Panel. Health literacy was measured with the Health Literacy Questionnaire (HLQ), which covers nine different domains. The levels of health literacy of ethnic minority groups were compared to the indigenous population. Significant differences in levels of health literacy were only found between the Turkish population and the indigenous Dutch population on several domains, such as finding and understanding sufficient health information, navigating the health care system and active engagement. These results might be due to the small sample size of the ethnic minority groups, as well as selection bias. The expected differences of health literacy levels between ethnic minorities and the indigenous Dutch population were larger.

For the second research question, **chapter 3** describes the importance of health literacy for self-management. The scoping review of reviews in chapter 3 aims to disentangle specific difficulties patient with limited health literacy face in relation to self-management and their associated needs with respect to self-management support. A total of 28 reviews were included. Some clear difficulties of emerged, predominantly in the are of medical management (especially adherence), communication and knowledge, but other associations between health literacy and self-management were inconclusive. The vast majority of research on health literacy and self-management focused on medical management and communication, and only few reviews addressed lifestyle change and coping. For a better understanding of the relationship between health literacy and self-management, a broader conceptualization of both health literacy and self-management is warranted.

**Chapter 4** explores the preferences regarding self-management outcomes of chronically ill patients with limited health literacy. A total of 35 patients with limited health literacy performed a concept-mapping procedure consisting of a card sorting task. Patients ranked 60 outcomes, which are often found in literature in relation to self-management, to that were important for themselves. Means were calculated for each outcome and domain. For patients with limited health literacy, satisfaction with care is the most important outcome domain. This domain includes overall satisfaction, the communication with health care providers, the provision of information and trust. At an outcome level, next to health related outcomes, patients mostly prefer to work on their competences for self-management. For health care professionals, acting on these patient preferences and building a solid relationship will enhance successful self-management.

**Chapter 5** provides a descriptive analysis of self-management interventions for chronically ill patients with limited health literacy. This study is a secondary analysis of the COMPAR-EU database, which consists SMIs addressing patients with type 2 diabetes, COPD, obesity and heart failure. The database

was searched for SMIs addressing a broad definition of health literacy, including both cognitive aspects and the capacity to act. The description of 35 studies, describing 39 SMIs showed that there was a large variety in the extensiveness of the description of the designs of the SMIs. Besides, the interventions varied in sample(size), methods, self-management techniques, outcomes and operationalization of health literacy. To answer the third research question, we combine the results of chapter 4 and chapter 5. The interventions were largely targeted on improving, for example, patient activation and self-efficacy, which underlines the importance of the capacity to act. Therefore, on outcome basis, the interventions partly match with the preferences of patients, when focusing on self-management competences.

## *Discussion*

**Chapter 6** is the concluding chapter, in which the main findings are addressed and reflected upon. It also describes methodological considerations and implications for practice and implications for research.

The main findings and reflections of this thesis provided insights to answer the fourth research question. The following recommendations are formulated regarding development, design, and implementation of SMIs for chronically ill patients with limited health literacy:

1. Patient participation  
Our recommendation is to include patients with limited health literacy during, or even before, the development, design and implementation of SMIs, so working in co-creation. When practising patient participation in the development of SMIs, their needs, preferences and capabilities are represented and match with the content and the outcomes of the SMI. During the implementation the involvement of patients is most important, with both interventions on patient as organizational level.
2. Tailoring of SMIs  
For the development of SMIs, the recommendation is to tailor the SMI to the needs and preferences of patients with limited health literacy. The needed tailoring covers both tailoring on both cognitive aspects as the capacity to act, and tailoring on preferred outcomes. The scoping review of reviews in **chapter 3** pointed out that in the development of SMIs, all four types of self-management activities should be considered important. Patients with limited health literacy experience difficulties in all four types of self-management activities and SMIs for these patients are nowadays predominantly focused on medical management, communication and knowledge.
3. Easy to understand information  
To facilitate the comprehensibility of information for patients with limited health literacy, the design of the SMI should avoid small print prescriptions and/or instructions and long texts, which are perceived as difficult. In contrast, the use of graphic illustrations and images facilitates readability and understanding for the patient. Additionally, realistic and practical instructions, such as demonstrations, can help to translate information into action.
4. The role of the health care provider  
For the implementation of self-management support for patients with limited health literacy, it is key to acknowledge the role of the health care system and the health care provider. A first step is reducing the mismatch between the patients' skills and the health care context. Secondly, the patient preferences regarding outcomes in **chapter 4** show the importance of a trustful relationship between the patients and the health care professional and the need to invest in such a relationship.
5. Uniformity in the description of SMIs  
The heterogeneity of designs and the lack of sufficient details of intervention descriptions complicate the comparison and evaluation of SMIs. The same is true for outcomes and their measures and used tools. The lack of information makes it very challenging to learn from previously developed or implemented SMIs and use them in clinical practice. To enrich available research and the implementation of SMIs regarding patients with limited health literacy, the recommendation is to describe and explain the choices regarding study characteristics. Besides, the quality of research on SMIs for patients with limited health literacy would largely improve if interventions are uniformly described, so that they can be compared, evaluated and replicated.

