Getting in control

Citation for published version (APA):

van der Gaag, M. (2023). *Getting in control: Towards optimal self-management support for chronically ill patients with limited health literacy*. [Doctoral Thesis, Maastricht University]. Maastricht University. https://doi.org/10.26481/dis.20230928mg

Document status and date:
Published: 01/01/2023

DOI:
10.26481/dis.20230928mg

Document Version:
Publisher's PDF, also known as Version of record

Please check the document version of this publication:

• A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
• The final author version and the galley proof are versions of the publication after peer review.
• The final published version features the final layout of the paper including the volume, issue and page numbers.

Link to publication

General rights
Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

• Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
• You may not further distribute the material or use it for any profit-making activity or commercial gain
• You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the “Taverne” license above, please follow below link for the End User Agreement:

www.umlib.nl/taverne-license

Take down policy
If you believe that this document breaches copyright please contact us at:

repository@maastrichtuniversity.nl

providing details and we will investigate your claim.

Download date: 29 Apr. 2024

Getting in control

Towards optimal self-management support for chronically ill patients with limited health literacy

Marieke van der Gaag

2023

The research presented in this thesis was conducted at Nivel, Netherlands Institute for Health Services Research, and CAPHRI, Care and Public Health Research Institute, Maastricht University. Nivel and CAPHRI participate in the Netherlands School of Public Health and Care Research (CaRe).

Chapter 3, 4 and 5 of this thesis were supported by COMPAR-EU, European Union's Horizon 2020 research and innovation programme under grant agreement No 754936.

ISBN: 978-94-6483-324-9

www.nivel.nl
Postbus 1568
3500 BN Utrecht
Phone: 030-27 29 700
Email: receptie@nivel.nl

Cover design: Sandra Tukker, Ridderprint
Word processing: Marion Slingerland
Printing: Ridderprint

Getting in control

Towards optimal self-management support
for chronically ill patients with
limited health literacy

DISSERTATION

To obtain the degree of Doctor at the Maastricht University,
on the authority of the Rector Magnificus, Prof. dr. Pamela Habiboviç,
in accordance with the decision of the Board of Deans,
to be defended in public on September 28th, 2023, at 13.00 hours CET

by

Marieke van der Gaag

Promotor

Prof. dr. J.J.D.J.M. Rademakers

Copromotor

Dr. M.J.W.M Heijmans

Beoordelingscommissie

Prof. dr. J.D. de Jong

Prof. dr. J.S. Burgers

Prof. dr. A.E.R.C.H. Boonen

Prof. dr. J.C.M van Weert

Dr. A.F. de Winter

Table of contents

Chapter 1

General introduction

The aging population has caused an increase in the incidence and prevalence of chronic diseases, such as diabetes, chronic lung diseases, and cardiovascular diseases. Chronic diseases are accountable for a large proportion of the worldwide mortality, and their burden will increase over the next decades [1]. The large proportion of patients with a chronic disease results in a rising demand for health care use. This leads to a growing urgency of efficient and cost effective healthcare. Furthermore, self-determination and active participation in the care process have become increasingly important for patients. As a result of these demands, the role of patients and professionals has changed. Patients have become more responsible for their own health and healthcare, and health has become the result of a co-creation process of both the healthcare professional and the patient [2]. Especially patients with one or more chronic diseases have a major role in managing their illness(es), since, for the most part, taking care of their disease(s) take place at home, work or school and not in the hospital or with a healthcare provider. These patients need to take many day-to-day decisions, which may have a great impact on their health and quality of life.

Self-management

Patients with a chronic illness have to deal with self-management tasks and the challenges related to their daily symptoms in order to prevent them from worsening [3, 4]. Chronically ill patients have to deal with challenges related to their illness and self-management tasks on a daily basis. Self-management is defined as "what individuals, families and communities do with the intention to promote, maintain, or restore health and to cope with illness and disability with or without the support of health professionals" [5]. Achieving efficient self-management is rather complex as chronically ill patients often have to deal with various symptoms and challenges during their daily life. Nevertheless, with appropriate self-management the health outcomes of patients, particularly those with chronic diseases, improve [6, 7]. Four types of self-management tasks can be distinguished [8]: medical management, lifestyle, communication and navigation through the healthcare system, and coping with the consequences of living with a chronic disease.

Medical management

As most chronic illnesses require the use of medication, this is an essential aspect of medical management. It is important to adhere to prescribed medication, and use the medication as prescribed, which can be a burden for daily life. Taking multiple medications at the right moment may be a challenge, for example due to side effects, personal habits or forgetfulness [9, 10]. Self-monitoring is also an important aspect of medical management. For example, regular weighing, blood sugar control, and self-monitoring of fluid intake have a major impact on daily life [11, 12].

Lifestyle

Another aspect of self-management is maintaining or changing to a healthy lifestyle [9, 13]. Healthy dietary habits and regular physical activity is key to maintain or improve one's health. However, living with a chronic disease can make it harder to keep up a healthy lifestyle, for example due to lack of energy or physical discomfort [14].

Communication and navigation through the healthcare system

Despite the fact that patients have an important role in the management of their own health, patients also depend on the health care system. Many patients find it difficult to navigate the health care system and to know where they should go to find the most appropriate care [15, 16]. Efficient communication with the health care provider, for example a physician or a nurse, is critical for the patient to understand their illness and the consequences. Patients often have difficulties understanding their health care provider, because information is overly clinical or impersonal [17]. An important aspect of communication with the health care provider is shared decision-making. Providers can tell patients what to do, or patients can have an active involvement regarding their care and treatment.

Coping with the consequences of living with a chronic disease

Living with the consequences a chronic disease is not easy [3, 4]. These consequences can be physical, but also psychological or social. Patients, or the people near to them, can struggle with the acceptance of their chronic disease [18]. They need to adapt their life to their possibilities, which can be disappointing [19]. The support of social resources as friends and family can help to cope with the consequences of living with a chronic disease [13].

Altogether, self-management is complex and many patients struggle with it, for example because they lack the right knowledge, skills, and motivation to perform self-management tasks [20, 21]. Knowledge, skills, motivation, and so the ability to perform self-management tasks are not equally distributed across populations. Differences have been found according to age, sex, educational level, health status, and ethnicity [22, 23]. In general, these studies showed that people that are older, less educated, coming from cultural minority groups, or who have worse self-perceived health also have less knowledge and skills that are needed to successfully cope with their chronic disease. These patient groups often score lower on for self-management important concepts, such as self-efficacy, patient activation, and health literacy. To a certain extent, these concepts are able to be learned and improved, in contrast to the more static characteristics such as age, educational level or ethnicity. Therefore, there has been a great deal of interest in these concepts as a starting point to improve the support of people with their self-management.

Health literacy

A patient group experiencing extra difficulties with self-management are patients with limited health literacy [24, 25]. Health literacy is defined as the skills needed to obtain, understand, and use health-related information [26-29]. Health literacy is an important factor to maintain or improve health. Limited health literacy is associated with poorer health outcomes and an increased use of health care services [30-33]. Health literacy skills are required by patients with chronic diseases for self-management. Patients with higher health literacy levels are more likely to have better self-management skills and experience more confidence in medical consultations [34].

Since health literacy has a major influence on health and health outcomes and is defined by the World Health Organization (WHO) as the most important determinant of health [35], improving health literacy has become a public health challenge throughout Europe. A recent meta-analysis shows that a considerable part of the European population has limited health literacy levels. The pooled prevalence of limited health literacy in Europe is one in every three, to almost one in every two Europeans [36]. More specifically, in the Netherlands around 25% of the population has limited health literacy, of which 5% insufficient [37]. It is known that within the general population, certain vulnerable subpopulations are at higher risk of having limited health literacy levels, for example, people with lower education, elderly, and people with a self-perceived poor health status [38].

Conceptualization and measurement of Health Literacy

In the last decades, the concept of health literacy has turned out to be a dynamic and quickly changing concept as many definitions and conceptualizations emerged. Health literacy emerged from general literacy, which encompasses the ability to read and write. In the 1990s, it became clear that low literacy levels were associated with a higher risk of health problems [39]. The inability of reading and writing health information, for example consent forms and information leaflets, led to mistakes in medication use and incorrect executing of instructions from healthcare professionals. Ever since, health literacy was increasingly recognized as an important concept, mostly in North America.

In the following years, increasing attention was given to health outside the medical setting, in the context of daily life. Modern society demands for knowledge and complex competences for individuals to meet the responsibility to take care of one’s health. Individuals need a wide range of cognitive and social skills to take up an active role in one’s health and healthcare [26, 28]. Therefore, the focus of health literacy on reading and writing skills only became too narrow. In the last decades, health literacy was defined in a more multidimensional way.

Health literacy research in the context of self-management often distinguishes three different types of health literacy: functional, interactive/communicative, and critical health literacy [26]. Functional health literacy describes the basic health skills that are necessary for individuals to obtain relevant information, and to be able to apply that knowledge to a limited range of prescribed activities. Interactive/communicative health literacy refers to skills that enable individuals to interact with greater confidence with their health care providers, and apply new information when circumstances change. Critical health literacy describes the advanced cognitive skills to critically analyse information and gain greater control over life events [26, 27, 34]. In 2012, the Health Literacy

Survey-Europe (HLS-EU) consortium developed another conceptual model, identifying factors that may have impact on health literacy, as well as potential consequences of health literacy in terms of behaviors, health outcomes and health services use. The model includes 12 dimensions of health literacy: four competency levels related to accessing, understanding, appraising, and applying health information in three domains of healthcare, disease promotion, and disease prevention [28, 40, 41].

Recent insights initiated the discussion about another added dimension to the concept of health literacy, which involves active behavioral actions as shared decision making and goal-setting. These insights emerged from theories of behavior change, which state that both intention and skills determine behavior. Therefore, besides the capacity to think (cognitive skills to deal with health information), the capacity to act is equally important [42]. With the capacity to act, the authors refer to skills as goal-setting, taking action, and being able to deal with temptations and adverse events or stress [42]. The distinction between cognitive skills and the capacity to act is especially important for self-management. Research on effective self-management shows that having knowledge on how to manage a chronic disease is not enough, because the difficulty is to incorporate it into daily life [43].

In the described concepts of health literacy, the focus of health literacy is on individual personal skills and characteristics. More recently health literacy is considered an interaction between the patient and the provider or the healthcare system [29, 44-46]. The extent to which limited health literacy skills are a problem for the patient depends on the complexity of the healthcare environment and the way it is structured to deal with people with limited skills. The acknowledgement that skills of healthcare providers and healthcare system factors have a major influence on the relationship between individual health literacy levels and health outcomes is important because it offers new opportunities for improving health care for people with limited health literacy, by providing better care and support and being a 'health literate' care organization, i.e. responsive to the needs of this patient group.

Self-management support

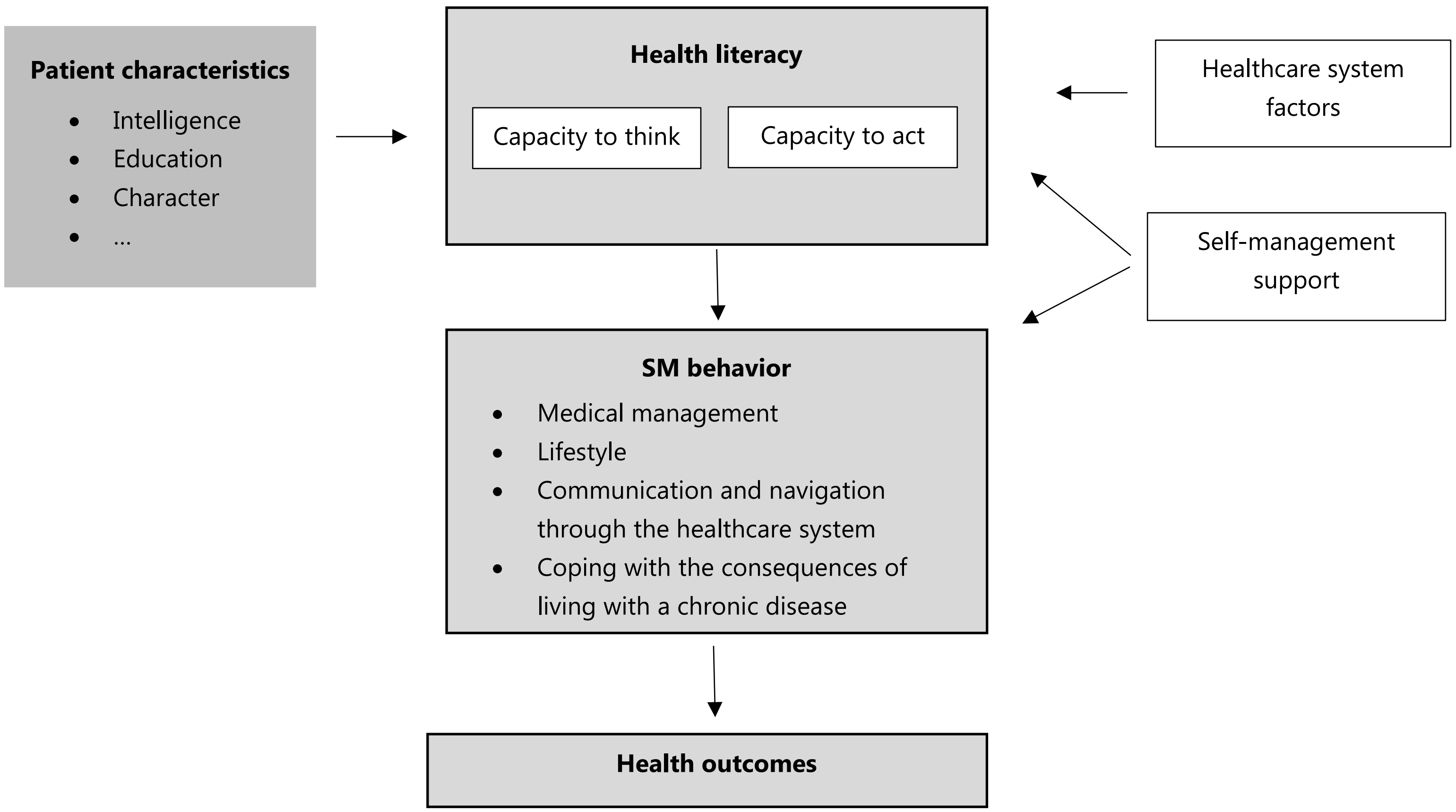
To support patients with the challenges they face in the day-to-day management of their disease, numerous self-management interventions (SMIs) have been developed. SMIs can be characterized as supportive interventions that healthcare professionals, peers, or laypersons systematically provide to increase patients' skills and confidence in their ability to manage a chronic condition. SMIs aim to equip patients (and, where appropriate, informal caregivers) to actively participate in the management of their conditions. The content of interventions ranges from the provision of information to extensive programs to promote behavioral change, and combinations thereof. SMIs have both been associated with the improvement of self-management behaviors, clinical outcomes, and patient reported outcomes, such as: quality of life, the reduction of HbA1c in patients with diabetes, dyspnea in patients with chronic obstructive pulmonary disease (COPD), or mortality in patients with heart failure [24, 47-50].

Many self-management interventions have been studied on their effectiveness the last decades, with encouraging, but varying results. Important results of recent studies are that self-management interventions applied in different target populations have substantially different results. Most SMIs are developed for 'patients in general', but this one size fits all approach is not effective for different patient groups [50]. Therefore, SMIs should be tailored to the skills and preferences of patients. Especially for patients with limited health literacy, the tailoring of interventions is important [24]. Recent research has shown that tailored SMIs, adapted to the knowledge, motivation, and skills of patients with limited health literacy, are more effective [51-54]. SMIs can be tailored to this patient group in multiple ways. For example, by tailoring the information to the reading levels of patients, or by setting treatment goals that are relevant and achievable for patients with limited health literacy. Realistic goal-setting is especially relevant in self-management, as patients themselves are responsible for the day-to-day management of their illness at home and may become demotivated when goals are not achievable or relevant from their point of view [52]. Health literacy influences the autonomous motivation of chronically ill patients, influencing the goals they want to reach. SMI outcomes should be based on the preferred goals of the participant of the intervention, but these preferences are still unknown in chronically ill patients with limited health literacy. Therefore, it is important to explore their preferred goals and how SMIs can efficiently support these patients.

Theoretical framework health literacy and self-management

Figure 1 visualizes the relationship between health literacy and self-management. This framework is inspired by previously developed models of von Wagner and Parker [55, 56]. The framework makes explicit what factors are expected to influence peoples' health literacy and how this affects their health outcomes, through their self-management behaviors. Patient's characteristics influence their health literacy levels. These characteristics include demographics such as age and sex, but also education and character aspects of the individual. Furthermore, healthcare system factors have a major influence on the fact that health literacy levels are sufficient to obtain optimal self-management behaviors. To decrease the gap between the level of health literacy needed for optimal self-management and adequate self-management behavior, self-management support is needed. Self-management support can contribute in several ways. Firstly, at aiming SMIs to improve health literacy factors of the patient, for example knowledge, patient activation, or self-efficacy. SMIs can also be aimed to directly improve self-management behaviors, while taking the health literacy skills of patients into consideration.

Figure 1: Theoretical framework health literacy and self-management



Aim and research questions

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 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 self-management interventions for chronically ill patients with limited health literacy?

Content

This thesis starts with four chapters describing studies that address the research questions presented in the previous section. The thesis is divided into 3 parts. **Part 1** focuses on the health literacy levels of different ethnic groups in the Netherlands. It contains one chapter (chapter 2) which presents the results of a study, acquiring insight into the level of health literacy of ethnic minorities in the Netherlands and examining whether the relationship between ethnicity and health care use can be (partly) explained by health literacy. **Part 2** contains two chapters. Chapter 3 presents a scoping review of reviews, describing the relationship between health literacy and self-management to disentangle the specific difficulties patients with limited health literacy face in relation to self-management and their associated needs with respect to self-management support. Then, chapter 4 explores the preferences regarding self-management outcomes of chronically ill patients with limited health literacy. **Part 3** of this thesis, focuses on self-management interventions (chapter 5). This chapter describes available self-management interventions for chronically ill patients with limited health literacy and what can be learned from the design of these studies for future research and development. In chapter 6, the overall discussion and conclusions are presented.

References

1. Mathers CD and Loncar D. Projections of Global Mortality and Burden of Disease from 2002 to 2030. *PLOS Medicine* 2006; 3: e442. DOI: 10.1371/journal.pmed.0030442.
2. D'haeseleer I, Gerling K, Schreurs D, et al. Ageing is not a disease: Pitfalls for the acceptance of self-management health systems supporting healthy ageing. In: *The 21st international ACM SIGACCESS conference on computers and accessibility* 2019, pp.286-298.
3. Jaime-Lara RB, Koons BC, Matura LA, et al. A qualitative metasynthesis of the experience of fatigue across five chronic conditions. *Journal of pain and symptom management* 2020; 59: 1320-1343.
4. Olano-Lizarraga M, Oroviogoicoechea C, Errasti-Ibarrondo B, et al. The personal experience of living with chronic heart failure: a qualitative meta-synthesis of the literature. *Journal of Clinical Nursing* 2016; 25: 2413-2429. DOI: https://doi.org/10.1111/jocn.13285.
5. Barlow J, Wright C, Sheasby J, et al. Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling* 2002; 48: 177-187. 2002/10/29. DOI: https://doi.org/10.1016/S0738-3991(02)00032-0.
6. Allegrante JP, Wells MT and Peterson JC. Interventions to support behavioral self-management of chronic diseases. *Annual review of public health* 2019; 40: 127-146.
7. Schrijver J, Lenferink A, Brusse-Keizer M, et al. Self-management for people with chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews* 2022.
8. Bayliss EA, Steiner JF, Fernald DH, et al. Descriptions of barriers to self-care by persons with comorbid chronic diseases. *The Annals of Family Medicine* 2003; 1: 15-21.
9. van Houtum L, Rijken M, Heijmans M, et al. Patient-perceived self-management tasks and support needs of people with chronic illness: generic or disease specific? *Annals of Behavioral Medicine* 2015; 49: 221-229.
10. Bhattarai B, Walpola R, Mey A, et al. Barriers and Strategies for Improving Medication Adherence Among People Living With COPD: A Systematic Review. *Respiratory Care* 2020; 65: 1738-1750. DOI: 10.4187/respcare.07355.
11. Walker RC, Tong A, Howard K, et al. Patient expectations and experiences of remote monitoring for chronic diseases: Systematic review and thematic synthesis of qualitative studies. *International Journal of Medical Informatics* 2019; 124: 78-85. DOI: https://doi.org/10.1016/j.ijmedinf.2019.01.013.
12. Chen CM and Chang Yeh M. The experiences of diabetics on self-monitoring of blood glucose: a qualitative metasynthesis. *J Clin Nurs* 2015; 24: 614-626. 2014/09/27. DOI: 10.1111/jocn.12691.
13. Noonan MC, Wingham J and Taylor RS. 'Who cares?'The experiences of caregivers of adults living with heart failure, chronic obstructive pulmonary disease and coronary artery disease: a mixed methods systematic review. *BMJ open* 2018; 8: e020927.
14. McIntosh T, Hunter DJ and Royce S. Barriers to physical activity in obese adults: A rapid evidence assessment. *Journal of Research in Nursing* 2016; 21: 271-287. DOI: 10.1177/1744987116647762.
15. Ivynian SE, DiGiacomo M and Newton PJ. Care-seeking decisions for worsening symptoms in heart failure: a qualitative metasynthesis. *Heart Failure Reviews* 2015; 20: 655-671. DOI: 10.1007/s10741-015-9511-x.
16. Brundisini F, Giacomini M, DeJean D, et al. Chronic disease patients' experiences with accessing health care in rural and remote areas: a systematic review and qualitative meta-synthesis. *Ontario health technology assessment series* 2013; 13: 1.
17. Currie K, Strachan PH, Spaling M, et al. The importance of interactions between patients and healthcare professionals for heart failure self-care: A systematic review of qualitative research into patient

perspectives. *European Journal of Cardiovascular Nursing* 2015; 14: 525-535. DOI: 10.1177/1474515114547648.

18. Rai SS, Syurina EV, Peters RMH, et al. Non-Communicable Diseases-Related Stigma: A Mixed-Methods Systematic Review. *International Journal of Environmental Research and Public Health* 2020; 17: 6657.

19. Van Houtum L, Rijken M and Groenewegen P. Do everyday problems of people with chronic illness interfere with their disease management? *BMC public health* 2015; 15: 1-9.

20. Camerini L, Schulz PJ and Nakamoto K. Differential effects of health knowledge and health empowerment over patients' self-management and health outcomes: a cross-sectional evaluation. *Patient Education and Counseling* 2012; 89: 337-344.

21. Ko D, Bratzke LC and Roberts T. Self-management assessment in multiple chronic conditions: A narrative review of literature. *International journal of nursing studies* 2018; 83: 83-90.

22. Ochieng JM and Crist JD. Social determinants of health and health care delivery: African American women's T2DM self-management. *Clinical nursing research* 2021; 30: 263-272.

23. Chen YC, Chang LC, Liu CY, et al. The roles of social support and health literacy in self-management among patients with chronic kidney disease. *Journal of Nursing Scholarship* 2018; 50: 265-275.

24. Mackey LM, Doody C, Werner EL, et al. Self-Management Skills in Chronic Disease Management: What Role Does Health Literacy Have? *Medical Decision Making* 2016; 36: 741-759. 2016/04/08. DOI: 10.1177/0272989X16638330.

25. Shah JM, Ramsbotham J, Seib C, et al. A scoping review of the role of health literacy in chronic kidney disease self-management. *Journal of Renal Care* 2021; 47: 221-233. DOI: https://doi.org/10.1111/jorc.12364.

26. Nutbeam D. Defining, measuring and improving health literacy. *総合健診* 2015; 42: 450-456.

27. Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health promotion international* 2000; 15: 259-267.

28. Sørensen K, Van den Broucke S, Fullam J, et al. Health literacy and public health: a systematic review and integration of definitions and models. *BMC public health* 2012; 12: 80. 2012/01/27. DOI: 10.1186/1471-2458-12-80.

29. Brach C and Harris LM. Healthy People 2030 Health Literacy Definition Tells Organizations: Make Information and Services Easy to Find, Understand, and Use. *Journal of General Internal Medicine* 2021; 36: 1084-1085. DOI: 10.1007/s11606-020-06384-y.

30. Berkman ND, Sheridan SL, Donahue KE, et al. Low health literacy and health outcomes: an updated systematic review. *Annals of internal medicine* 2011; 155: 97-107.

31. DeWalt DA, Berkman ND, Sheridan S, et al. Literacy and health outcomes. *Journal of general internal medicine* 2004; 19: 1228-1239.

32. Zhang F, Or PPL and Chung JWY. How different health literacy dimensions influences health and well-being among men and women: The mediating role of health behaviours. *Health Expectations* 2021; 24: 617-627. DOI: https://doi.org/10.1111/hex.13208.

33. Fan Z-y, Yang Y and Zhang F. Association between health literacy and mortality: a systematic review and meta-analysis. *Archives of Public Health* 2021; 79: 119. DOI: 10.1186/s13690-021-00648-7.

34. Heijmans M, Waverijn G, Rademakers J, et al. Functional, communicative and critical health literacy of chronic disease patients and their importance for self-management. *Patient Education and Counseling* 2015; 98: 41-48. DOI: https://doi.org/10.1016/j.pec.2014.10.006.

35. WHO. Health literacy: The solid facts. 2013.

36. Baccolini V, Rosso A, Di Paolo C, et al. What is the prevalence of low health literacy in european union member states? A systematic review and meta-analysis. *Journal of general internal medicine* 2021; 36: 753-761.

37. Willems A, Heijmans M, Brabers A, et al. Gezondheidsvaardigheden in Nederland: factsheet cijfers 2021. 2022.

38. Bøggild H, Sørensen K, Svendsen MT, et al. International Report on the Methodology, Results, and Recommendations of the European Health Literacy Population Survey 2019-2021 (HLS19) of M-POHL. *The HLS19 Consortium of the WHO Action Network M-POHL (2021): International Report on the Methodology, Results, and Recommendations of the European Health Literacy Population Survey 2019-2021 (HLS19) of M-POHL Austrian National Public Health Institute, Vienna*. 2021.

39. Murray TS, Kirsch IS and Jenkins L. *Adult literacy in OECD countries: Technical report on the first International Adult Literacy Survey*. US Department of Education, Office of Educational Research and Improvement , 1998.

40. Pelikan JM, Röthlin F, Ganahl K, et al. Measuring comprehensive health literacy in general populations: validation of instrument, indices and scales of the HLS-EU study. In: *Proceedings of the 6th Annual Health Literacy Research Conference* 2014, p.59.

41. Pelikan JM, Ganahl K, Van den Broucke S, et al. Measuring health literacy in Europe: introducing the European health literacy survey questionnaire (HLS-EU-Q). *International handbook of health literacy*. Policy Press, 2019, pp.115-138.

42. Rademakers J and Heijmans M. Beyond Reading and Understanding: Health Literacy as the Capacity to Act. *International journal of environmental research and public health* 2018; 15: 1676.

43. Dineen-Griffin S, Garcia-Cardenas V, Williams K, et al. Helping patients help themselves: a systematic review of self-management support strategies in primary health care practice. *PloS one* 2019; 14: e0220116.

44. Parnell TA, Stichler JF, Barton AJ, et al. A concept analysis of health literacy. In: *Nursing forum* 2019, pp.315-327. Wiley Online Library.

45. van der Heide I, Poureslami I, Mitic W, et al. Health literacy in chronic disease management: a matter of interaction. *Journal of Clinical Epidemiology* 2018; 102: 134-138. DOI: https://doi.org/10.1016/j.jclinepi.2018.05.010.

46. Baumeister A, Chakraverty D, Aldin A, et al. "The system has to be health literate, too"-perspectives among healthcare professionals on health literacy in transcultural treatment settings. *BMC health services research* 2021; 21: 1-16.

47. Umpierre D, Ribeiro PA, Kramer CK, et al. Physical activity advice only or structured exercise training and association with HbA1c levels in type 2 diabetes: a systematic review and meta-analysis. *Jama* 2011; 305: 1790-1799.

48. McLean S, Nurmatov U, Liu JL, et al. Telehealthcare for chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews* 2011.

49. Inglis SC, Clark RA, Dierckx R, et al. Structured telephone support or non-invasive telemonitoring for patients with heart failure. *Cochrane Database of Systematic Reviews* 2015.

50. Bos-Touwen I, Jonkman N, Westland H, et al. Tailoring of self-management interventions in patients with heart failure. *Curr Heart Fail Rep* 2015; 12: 223-235. DOI: 10.1007/s11897-015-0259-3.

51. Schapira MM, Swartz S, Ganschow PS, et al. Tailoring educational and behavioral interventions to level of health literacy: A systematic review. *MDM policy & practice* 2017; 2: 2381468317714474.

52. Visscher BB, Steunenberg B, Heijmans M, et al. Evidence on the effectiveness of health literacy interventions in the EU: a systematic review. *BMC public health* 2018; 18: 1414. DOI: 10.1186/s12889-018-6331-7.

53. Brooks C, Ballinger C, Nutbeam D, et al. The importance of building trust and tailoring interactions when meeting older adults' health literacy needs. *Disability and rehabilitation* 2017; 39: 2428-2435.

54. Craig P, Dieppe P, Macintyre S, et al. Developing and evaluating complex interventions: the new Medical Research Council guidance. *International journal of nursing studies* 2013; 50: 587-592.

55. Von Wagner C, Good A, Whitaker KL, et al. Psychosocial determinants of socioeconomic inequalities in cancer screening participation: a conceptual framework. *Epidemiologic reviews* 2011; 33: 135-147.

56. Parker RM and Ratzan S. Our future with democratization of health requires health literacy to succeed. *American Behavioral Scientist* 2019; 63: 948-954.

Chapter 2

Health literacy and primary health care use of ethnic minorities in the Netherlands

van der Gaag, M., van der Heide, I., Spreeuwenberg, P. Brabers, A., & Rademakers, J. (2017). Health literacy and primary health care use of ethnic minorities in the Netherlands. BMC health services research, 17(1), 1-9.

Abstract

Background

In the Netherlands, ethnic minority populations visit their general practitioner (GP) more often than the indigenous population. An explanation for this association is lacking. Recently, health literacy is suggested as a possible explaining mechanism. Internationally, associations between health literacy and health care use, and between ethnicity and health literacy have been studied separately, but, so far, have not been linked to each other. In the Netherlands, some expectations have been expressed with regard to supposed low health literacy of ethnic minority groups, however, no empirical study has been done so far. The objectives of this study are therefore to acquire insight into the level of health literacy of ethnic minorities in the Netherlands and to examine whether the relationship between ethnicity and health care use can be (partly) explained by health literacy.

Methods

A questionnaire was sent to a sample of 2.116 members of the Dutch Health Care Consumer Panel (response rate 46%, 89 respondents of non-western origin). Health literacy was measured with the Health Literacy Questionnaire (HLQ) which covers nine different domains. The health literacy levels of ethnic minority groups were compared to the indigenous population. A negative binomial regression model was used to estimate the association between ethnicity and GP visits. To examine whether health literacy is an explaining factor in this association, health literacy and interaction terms of health literacy and ethnicity were added into the model.

Results

Differences in levels of health literacy were only found between the Turkish population and the indigenous Dutch population. This study also found an association between ethnicity and GP visits. Ethnic minorities visit their GP 33% more often than the indigenous population. Three domains of the HLQ (the ability to navigate the health care system, the ability to find information and to read and understand health information) partly explained the association between ethnicity and GP visits.

Conclusions

In general, there are no differences in health literacy between most of the ethnic minority groups in the Netherlands and the indigenous Dutch population. Only the Turkish population scored significantly lower on several health literacy domains. Some domains of health literacy do explain the association between ethnicity and higher frequency of GP visits. Further research is recommended to understand the pathways through which health literacy impacts health care use.

Background

Internationally, several studies report differences in general practitioner (GP) visits between adults from ethnic minorities and from indigenous populations. However, these findings are not consistent [19]. In the Netherlands, ethnic minorities visit the GP relatively more often [32], whereas in other European countries ethnic minorities have less GP visits [10, 14]. Some studies have explored possible underlying mechanisms that could explain the association between ethnicity and health care use. These studies report that the association between ethnicity and health care use can be partly explained by education, knowledge, language proficiencies and access to care [2, 17, 36].

In the Dutch health care system, the GP plays an important role as he or she is the gatekeeper to specialized medical care [23, 29]. Ethnic minority populations in the Netherlands visit the GP more often compared to the indigenous population [29, 32]. Individuals of the four largest ethnic minority groups in the Netherlands (i.e., people from Morocco, Turkey, Surinam and the Netherlands Antilles) approximately have 1.5 times as much contact with their GP compared to the indigenous Dutch population [33]. However, an explanation why ethnic minority populations in the Netherlands have more contact with their GP is lacking [33].

A factor that has internationally gained attention in recent years and that is considered to be a possible explaining mechanism in the association between ethnicity and primary care use, is health literacy [4, 16]. An association between health literacy and health care use has been found in earlier studies. People with low health literacy use more health care services, including GP visits, hospitalization and emergency care [5, 34].

Several definitions of health literacy exist [24, 27]. In the present study, the definition of the World Health Organization (WHO) is used: "The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" [24]. Having lower health literacy has been associated with poorer health outcomes and contributes to health disparities [4, 5, 9, 15]. According to the WHO, in fact, health literacy predicts health outcomes better than age, educational level, income, job and cultural background [13].

Often health literacy is conceptualized as having basic reading and writing skills (i.e. functional health literacy). More advanced definitions discern different types of skills, e.g. functional, communicative and critical skills [20], or different levels, e.g. access, understand, appraise and apply health information [27]. Due to differences in the conceptualization of health literacy, a wide range of measurement instruments has been designed. The first health literacy measurement methods focused on functional health literacy only [1, 22, 28]. In recent research, more extended tools, like the Health Activities Literacy Scale (HALS), the European Health Literacy Survey (HLS-EU) and the Health Literacy Questionnaire (HLQ), have been developed and validated [21, 26, 35]. In this study, we used the HLQ, because it measures health literacy in a comprehensive way. Similar to the definition of the WHO, this multidimensional instrument distinguishes both cognitive, psychosocial and social aspects, that each may affect health behaviour, such as health care use, in a different way.

Whereas it is known that there is a link between low health literacy and health care use [5, 34], it is not known what the association is between ethnicity and health literacy in the Netherlands. In Canada and the USA, studies found that the level of health literacy is lower in ethnic minority groups compared to the indigenous population [11, 18, 25]. Although some expectations have been expressed with regard to supposed low health literacy of ethnic minority groups in the Netherlands [12], no empirical study has been done yet. The first aim of our study is therefore to acquire insight in the level of health literacy of ethnic minorities in the Dutch population.

Internationally, the associations between health literacy and health care use, and between ethnicity and health literacy have been studied separately, but so far, have not been linked to each other. This is the second aim of our study. Only Ackermann Rau and colleagues have done a study on health literacy, ethnicity and health care use in Switzerland. However, in this study health care use was defined as knowledge when to seek help [2]. Their results showed that migrants with relatively lower health literacy misinterpreted minor symptoms more often, and therefore potentially overused primary care. Only migrant groups were compared with each other, as the indigenous population was not included in the sample [2].

In summary, this study aims to: a) acquire insight into the level of health literacy of ethnic minorities in the Netherlands; b) examine whether the relationship between ethnicity and health care use is (partly) explained by health literacy. To perform this study, the following research questions were formulated:

1. 'Do health literacy skills of ethnic minority groups and of the indigenous population in the Netherlands differ?'
2. 'Do ethnic minority groups and the indigenous population in the Netherlands differ with respect to GP visits?'
3. 'Is health literacy an explanatory mechanism in the association between ethnicity and GP visits?'

Methods

The Dutch health care consumer panel

The data that were used for this cross-sectional study were obtained from the Nivel Dutch Health Care Consumer Panel [6]. This panel provides information about opinions and knowledge about health care, and expectations and experiences with health care. At the moment of this study (May 2015), the Consumer Panel consisted of approximately 12.000 people aged 18 years and older. Background characteristics from all panel members, such as ethnicity, gender, age and highest level of education completed, were assessed at the start of the panel membership. Each year, approximately eight surveys are conducted. Each individual panel member receives a questionnaire about three times a year and can resign from the panel at any time. There is no possibility of people signing up for the panel on their own initiative. The Dutch Health Care Consumer Panel is renewed on a regular basis. More details on the recruitment and selection of panel members are reported elsewhere [6]. Data are processed anonymously and the protection of the data collected is registered with the Dutch Data Protection Authority (nr. 1262949). A privacy regulation is available for the Consumer Panel. There is no legal requirement to obtain informed consent nor approval by a medical ethics committee when conducting research through the panel [7].

Study population

The present study is based on data from 2.116 members of the Dutch Health Care Consumer Panel who received a questionnaire in late May 2015. The sample consisted of all ethnic minorities (both western and non-western) included in the panel (N = 1.058) and the same number of members of the indigenous population. The group of the indigenous population was matched to the group of ethnic minorities with respect to gender, age and educational level. Subsequently, 974 responders returned the questionnaire (response rate 46%). In this study, western ethnic minorities were excluded from the final analyses, since the aim was to focus on differences in ethnic background. The ethnic background of western ethnic minorities is overall more comparable to the indigenous population and, therefore, the analyses were performed on the data of 621 responders, of which 89 of non-western origin.

Variables

Health literacy

In the present study, we approached health literacy as a broader concept, including cognitive, motivational and social skills in relation to ethnicity and health care use. To this purpose, we used the Health Literacy Questionnaire (HLQ) developed by Osborne and colleagues [21]. The HLQ measures health literacy with 44 items, divided over nine domains. These domains are: 1) “Feeling understood and supported by health care providers”, 2) “Having sufficient information to manage my health”, 3) “Actively managing my health”, 4) “Social support for health”, 5) “Critical appraisal of health information”, 6) “Ability to actively engage with health care providers”, 7) “Navigating the health care system”, 8) “Ability to find good health information” and 9) “Reading and understanding health information enough to know what to do”. In the first five scales, the respondents were asked: to what extent do you agree with the following statements? The answering options were: 1) strongly disagree, 2) disagree, 3) agree and 4) strongly agree. Examples of the statements are: “I have enough information to help me deal with my health problems” and “I always compare health information from different sources and decide what’s best for me”. For the last four scales, the respondents were asked how easy or difficult certain tasks are for them at this moment. The answering options were: 1) cannot do, 2) very difficult, 3) quite difficult, 4) quite easy, 5) very easy. Examples of the questioned tasks are: “Have good discussions about your health with doctors” and

“Read and understand written health information”. In our study, the Dutch version of the HLQ is used. This version is translated and validated by Heijmans and colleagues (Heijmans et al., in preparation). The composite reliability of all scales in the Dutch version of the HLQ is >0.74, which is comparable with the original questionnaire [21].

The mean score of the items was used to construct a scale score for each of the nine domains per respondent. If responses to more than two items in a scale were missing, the data of this scale was considered missing. Otherwise scale scores were calculated based on the remaining items. Scale scores were analysed as a continuous outcome.

General practitioner visits

Frequency of GP visits was measured with the question: “How often did you consult your GP in 2015?” Consults with a GP included visits at the general practice, visits at home and telephone consultations. Telephone consults concerning drug prescriptions were excluded. The number of GP visits was analysed as a count outcome.

Sociodemographics

The following sociodemographics were included: gender, highest level of education completed (categorical), age (continuous) and ethnicity (categorical). Highest level of education completed is categorized as low (primary school of preparatory vocational training), middle (intermediate or advanced general education or intermediate vocational training) and high (high vocational education of university). For the purpose of this study we only selected the indigenous population and non-western ethnic minorities. Someone is defined as non-western migrant if at least one of the parents is born in Turkey, Asia (excluding Japan and Indonesia), Middle or South America or Africa. In the first research question, the ethnic groups have been defined as the indigenous population and the four largest ethnic minority groups, which are: “Turks”, “Moroccans”, “Netherlands Antilleans” and “Surinamese”. In the second and third research question, ethnicity was defined as the indigenous population vs ethnic minorities. In this case, ethnic minorities also included individuals from non-western countries other than specified in the first research question.

Statistical analyses

To answer the first research question, health literacy profiles were illustrated for each of the four ethnic minority groups and the indigenous population, based on the nine health literacy scales. Multiple Analyses of Covariance (ANCOVAs) in combination with post-hoc analyses were used to examine whether the scores on the nine different health literacy scales of the four ethnic minority groups differed significantly from the indigenous population. The post-hoc analyses were performed with pairwise comparisons and the Tukey Honest Significance Difference (HSD) test [31]. Based on literature, age, level of education and gender were identified as possible confounders. In the final model only age and level of education were included, because age and level of education changed the coefficient of ethnicity with more than 10%, and gender did not.

To answer the second research question a regression analysis was performed. Due to the nature of the data, the count outcome had to be analysed using a Poisson regression or a negative binomial regression. Since the mean was not equal to the variance of the outcome, it was chosen to perform a negative binomial regression analysis. Both age, level of education and gender were added as a confounder in this model, based on significance ($p < 0.05$).

Lastly, the health literacy domains where the scores significantly differed in the first research question were put in the negative binomial regression model to examine if health literacy is an explaining variable in the association between health literacy and GP visits. Interaction terms of ethnicity and health literacy were made to examine whether the effect of this association is different for ethnic minorities and the indigenous population. In all analyses, results were considered significant when $p < 0.05$. All analyses were performed using STATA, version 14.0.

Results

Sample characteristics

Table 1 shows the sample characteristics. The mean age of the included respondents is 60.6 years (SD = 16.6) and a bit more than half of the respondents are female (51.5%). The sample reports an average of 2.33 GP visits from January until May 2015. With respect to health literacy scores, unadjusted mean scores are higher in the indigenous population compared to the ethnic minorities, except for domain five (see Table 1).

Table 1: Sample characteristics

Characteristics	Total (n=621)		Indigenous population (n=532)		Ethnic minorities (n=89)	
	%	n	%	n	%	n
Gender						
Male	48,5	301	48,9	260	46,1	41
Female	51,5	320	51,1	272	53,9	48
Ethnicity						
Turkish					18,0	16
Moroccan					13,5	12
Surinamese					31,5	28
Netherlands Antillean					11,3	10
Other non-western countries					25,9	26
Education						
Low	17,8	109	18,6	99	12,2	10
Middle	49,0	301	49,3	261	47,6	39
High	33,2	204	32,1	171	40,2	33
	Mean (SD)		Mean (SD)		Mean (SD)	
Age	60,64 (16,62)		62,50 (16,04)		49,50 (15,77)	
Health Literacy Scores						
Domain 1- Provider support	2,85 (0,46)		2,86 (0,44)		2,77 (0,59)	
Domain 2 - Sufficient information	2,85 (0,40)		2,86 (0,39)		2,80 (0,49)	
Domain 3 - Managing health	2,79 (0,43)		2,80 (0,42)		2,77 (0,49)	
Domain 4 - Social support	2,81 (0,46)		2,82 (0,45)		2,71 (0,56)	
Domain 5 – Critical appraisal	2,61 (0,47)		2,60 (0,46)		2,65 (0,55)	
Domain 6 – Active engagement	3,79 (0,61)		3,81 (0,59)		3,67 (0,73)	
Domain 7 – Navigation	3,68 (0,58)		3,71 (0,55)		3,52 (0,72)	
Domain 8 – Finding information	3,79 (0,59)		3,81(0,57)		3,69 (0,73)	
Domain 9 – Read and understand	3,87 (0,56)		3,88 (0,54)		3,80 (0,70)	

Ethnicity and health literacy

Multiple ANCOVAs with age and education as covariates revealed that there are significant differences in the means of the groups in domain two ($p < 0.01$), domain six ($p < 0.01$), domain seven ($p < 0.01$), domain eight ($p < 0.01$) and domain nine ($p = 0.02$). After the ANCOVA analyses are performed, the error variances are checked on normality. Pairwise comparisons of the adjusted means show that only the Turkish respondents significantly differ from the indigenous population (domain two ($p < 0.01$), domain six ($p < 0.01$), domain seven ($p < 0.01$), domain eight ($p < 0.01$) and domain nine ($p < 0.01$)). These comparisons are calculated with the Tukey HSD test [31]. All results obtained from these analyses are shown in Table 2. The table shows consecutively the ANCOVA results for the unadjusted and the adjusted model, the results of the different ethnic groups compared to the indigenous population with the Tukey HSD test, and subsequently the adjusted means. The adjusted means are obtained through linear prediction. Figure 1 (a, b) summarizes the health literacy scores of the different ethnic groups, divided over the nine domains. Figure 1a presents the unadjusted means, and Fig. 1b shows the means adjusted for age and education.

Figure 1: **The health literacy scores of different ethnic groups. The upper part shows the crude health literacy scores, and the bottom part the adjusted health literacy scores**

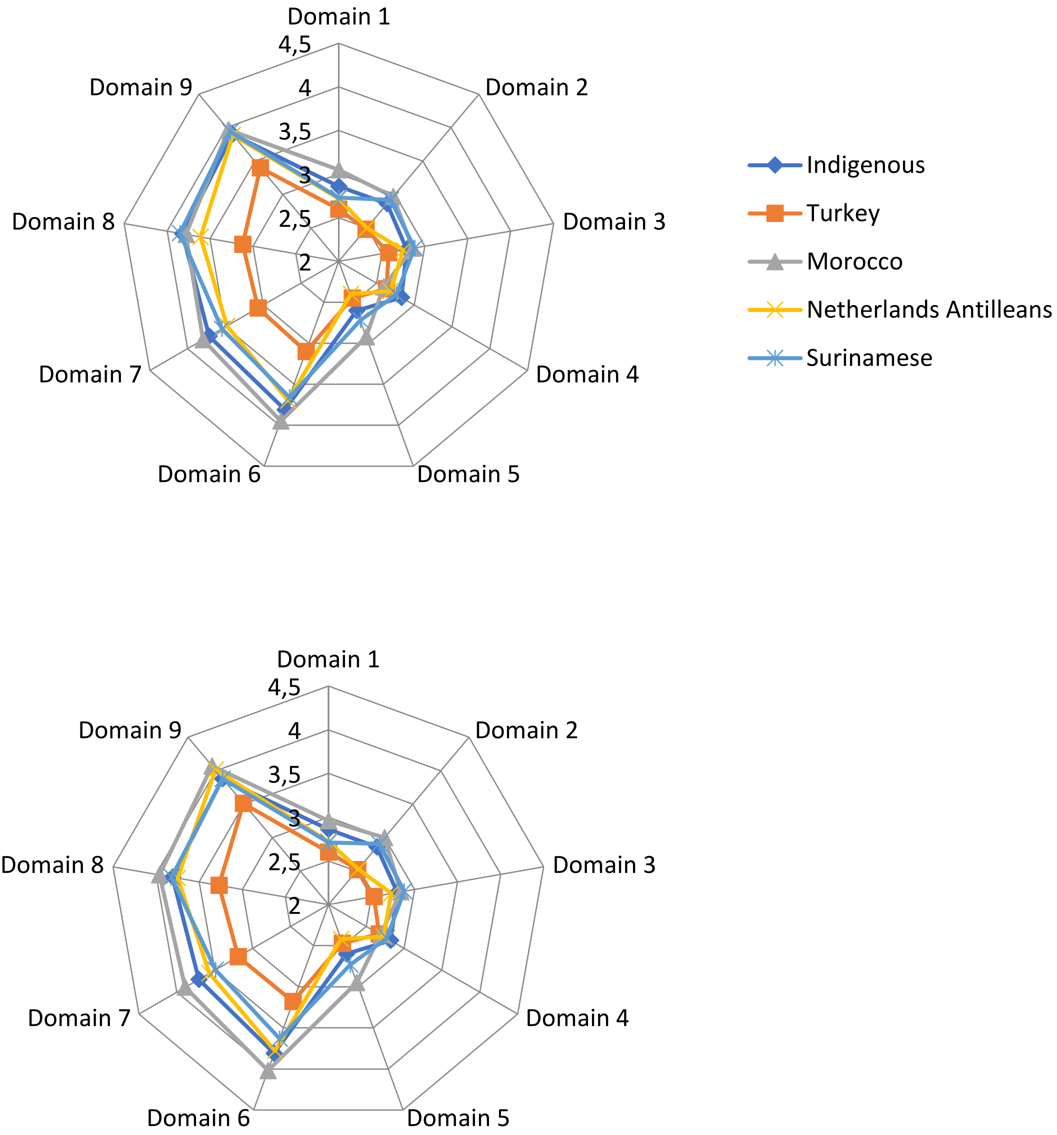


Table 2: Results of the ANCOVAs and Tukey HSD tests. Significant results are printed in bold

	ANCOVA		Tukey HSD		
	Crude model p	Adjusted model p	Ethnicity	p	Adjusted means (SD)
Domain 1 Provider support	0,117	0,107	Indigenous	ref	2,86 (0,02)
			Turkish	0,315	2,60 (0,12)
			Moroccan	0,766	3,05 (0,14)
			Surinamese	0,715	2,73 (0,09)
			Netherlands Antillean	0,933	2,72 (0,15)
Domain 2 Sufficient information	**0,002**	**0,001**	Indigenous	ref	2,86 (0,02)
			Turkish	**0,006**	2,48 (0,11)
			Moroccan	0,946	2,97 (0,12)
			Surinamese	0,979	2,92 (0,08)
			Netherlands Antillean	0,081	2,50 (0,13)
Domain 3 Managing health	0,207	0,476	Indigenous	ref	2,79 (0,02)
			Turkish	0,509	2,58 (0,12)
			Moroccan	0,998	2,86 (0,15)
			Surinamese	0,947	2,88 (0,09)
			Netherlands Antillean	1,000	2,75 (0,15)
Domain 4 Social support	0,428	0,182	Indigenous	ref	2,83 (0,02)
			Turkish	0,601	2,63 (0,12)
			Moroccan	0,540	2,59 (0,14)
			Surinamese	0,973	2,76 (0,09)
			Netherlands Antillean	0,936	2,68 (0,15)
Domain 5 Critical appraisal	0,063	0,109	Indigenous	ref	2,60 (0,02)
			Turkish	0,869	2,45 (0,13)
			Moroccan	0,301	2,92 (0,15)
			Surinamese	0,861	2,72 (0,10)
			Netherlands Antillean	0,810	2,40 (0,16)
Domain 6 Active engagement	**0,004**	**0,001**	Indigenous	ref	3,81 (0,03)
			Turkish	**<0,001**	3,10 (0,17)
			Moroccan	0,984	3,95 (0,20)
			Surinamese	0,847	3,66 (0,12)
			Netherlands Antillean	0,995	3,70 (0,21)
Domain 7 Navigation	**0,007**	**0,001**	Indigenous	ref	3,72 (0,03)
			Turkish	**0,001**	3,07 (0,16)
			Moroccan	0,999	3,80 (0,20)
			Surinamese	0,765	3,55 (0,12)
			Netherlands Antillean	0,804	3,48 (0,19)

Table 2: Continued

	ANCOVA		Tukey HSD		
	Crude model p	Adjusted model p	Ethnicity	p	Adjusted means (SD)
Domain 8 Finding information	**0,019**	**<0,001**	Indigenous	ref	3,82 (0,03)
			Turkish	**<0,001**	3,12 (0,16)
			Moroccan	1,000	3,78 (0,19)
			Surinamese	1,000	3,85 (0,12)
			Netherlands Antillean	0,893	3,61 (0,20)
Domain 9 Read and understand	0,079	**0,009**	Indigenous	ref	3,90 (0,02)
			Turkish	**0,009**	3,40 (0,14)
			Moroccan	0,999	3,97 (0,19)
			Surinamese	0,999	3,94 (0,11)
			Netherlands Antillean	1,000	3,89 (0,18)

Table 3: Models analysing relation GP-visits with ethnicity and health literacy

Domain	Ethnicity			Health literacy		
	B (SD)	*IRR*	*p*	*B (SD)*	*IRR*	*p*
2 *Sufficient information*	**0,293 (0,14)**	**1,34**	**0,044**	-0,033 (0,12)	0,97	0,776
6 *Active engagement*	0,241 (0,15)	1,27	0,100	-0,142 (0,08)	0,87	0,064
7 *Navigation*	0,248 (0,15)	1,28	0,092	**-0,222 (0,08)**	**0,80**	**0,007**
8 *Finding information*	0,230 (0,15)	1,26	0,116	**-0,255 (0,08)**	**0,77**	**0,001**
9 *Read and understand*	0,245 (0,14)	1,28	0,092	**-0,191 (0,08)**	**0,83**	**0,024**

**Significant results are printed in bold*

Ethnicity and GP visits

Negative binomial regression analysis shows that there is a significant association between ethnicity and GP visits, when adjusted for age, education and gender (B = 0.282, p = 0.049). The calculated incidence rate ratio (IRR) of 1.33 clarifies that ethnic minority groups have 1.33 times as much, or 33% more, GP visits compared to the indigenous population. In the unadjusted model, this association is not significant (B = -0.064, IRR = 0.94, p = 0.646).

Health literacy as an explaining mechanism

To answer the third research question, health literacy domains are added in the model. Only the domains where ethnic minority groups significantly differed from the indigenous population in the analyses of the first research question were added. Table 3 shows that in all health literacy domains except domain 2, the association between ethnicity and GP visits is no longer significant. By contrast, in domain seven, eight and nine the association between health literacy and GP visits is significant. This reveals that health literacy domains seven (navigation), eight (finding information) and nine (read and understand information) are better predictors of GP visits than ethnicity. Thereafter, interactions between ethnicity and health literacy domains are added to the regression model to see whether the effect of health literacy on GP visits significantly differs between the ethnic minority groups and the indigenous population. None of the interactions are significant, in respectively domain two (p = 0.701), domain six (p = 0.957), domain seven (p = 0.581), domain eight (p = 0.116), domain nine (p = 0.209). This means that people with the same health literacy score, but a different ethnicity, have an equal frequency of GP visits.

Discussion

The aims of this study were to acquire insight into the level of health literacy of ethnic minorities in the Netherlands and to examine whether the relationship between ethnicity and GP visits can (partly) be explained by health literacy. Hereby we focused on a range of skills covering several health literacy domains instead of basic reading and writing skills ('functional health literacy') only. These domains were measured with the Health Literacy Questionnaire (HLQ).

Level of health literacy of ethnic minorities in the Netherlands

In general, there were few differences in health literacy between the indigenous Dutch population and the ethnic minority groups in this study. Differences were only present in the Turkish population and exclusively in the following domains: two (Having sufficient information), six (Active engagement with health care provider), seven (Navigating the health care system), eight (Ability to find health information), and nine (Reading and understanding health information). On these domains, the Turkish respondents scored lower. There were no differences with regard to health literacy between the indigenous respondents and the Moroccan, Surinamese and Netherlands Antillean groups. The differences in the level of health literacy between the ethnic minorities and the indigenous population were smaller than expected from previous, international, research [11, 25]. This might be due to the small sample size of our study, as well as possible selection bias. Since the study sample was drawn from a panel with written questionnaires, individuals with insufficient language skills and consequently possibly lower health literacy are not included.

Relationship between ethnicity, GP visits and health literacy

With respect to health care use, our results confirm that ethnic minorities in the Netherlands visit the GP more often [33], on average 33% more compared to the indigenous population. This higher frequency of GP visits of ethnic minorities is partly explained by health literacy. Three domains (the ability to navigate, the ability to find information, and the ability to read and understand information) are most important for explaining differences in GP visits. In fact, they are more important than ethnicity itself. People with the same health literacy score on these domains, but a different ethnicity, have an equal frequency of GP visits.

Our findings correspond with another study in the Netherlands in which health literacy was examined as a possible predictor of GP visits [34]. In that study, the conceptualization of health literacy in terms of functional, communicative and critical skills was used [20]. Functional health literacy was found to be the only set of skills that significantly predicted the frequency of GP visits [34]. In line with Nutbeams' definition, the domains eight (finding information) and nine (read and understand information) in the HLQ are equivalent to functional health literacy. The ability to navigate is closely linked to these skills. Therefore also in this study, functional health literacy seems to be the most important predictor of the number of GP visits, regardless of ethnicity, and even in a sample of respondents who volunteered to participate in a panel that makes use of questionnaires.

Although differences in health literacy levels in this study are only seen in the Turkish population, Beauchamp and colleagues have found in Australia that the level of health literacy is lower in ethnic minority populations, and she regards language as a leading issue herein [3]. However, the interest towards critical and interactive health literacy increases [8, 30]. Van der Heide et al. [34], for example, demonstrated that especially communicative skills are important for self-management behaviour. The fact that different domains of health literacy impact different kind of behaviours warrants the use of multidimensional health literacy measurement instruments.

There are several strengths and limitations to this study. The biggest strength is that so far no study has been done concerning the health literacy of ethnic minorities in the Netherlands. The second strength is the fact that in this study health literacy is conceptualized and measured in a multidimensional way, using the Health Literacy Questionnaire [21]. Another strength is that the answers on questions about health literacy are self-reported. The subjectivity of these answers reveal what is important or problematic from an individual's own perspective.

The major limitations are the small sample size and the low response rate of this study. However, the percentage of ethnic minorities in our sample (9.1%) is comparable to the percentage in the Dutch population (11.7%) [6]. Furthermore, the data are obtained from the Dutch Health Care Consumer Panel. People who participate in a panel are expected to have a higher level of (health) literacy compared to the general population. This selection bias might lead to an overestimation of the level of health literacy of the respondents in our study, also in the ethnic minority subsample. For this reason, further research on ethnic minorities' health literacy is needed using different methods of data collection than panel survey research. Another limitation is that we could not control for possible confounders such as job and income. However, education is regarded as a good proxy for these social economic factors. In future research, these factors should be included. Lastly, the data are measured cross-sectional and therefore might include recall bias concerning the amount of GP visits. However, both limitations are equal in both the indigenous population and the ethnic minority populations. The findings that some health literacy domains are better predictors of GP visits than ethnicity need further attention. Important to know is how these domains impact health care use. Furthermore, future research should use a different design, which is more inclusive to people with lower (health) literacy. Lastly, measures of health care use, like GP visits, should be measured with the information from health care insurance companies or the administration of GPs. In this way, recall bias can be avoided for more adequate research.

Conclusions

In conclusion, in the Netherlands differences in the level of health literacy were found between the Turkish ethnic minority population and the indigenous population. There were no differences with people from other ethnic minorities. This study also found an association between ethnicity and GP visits. The ability to navigate the health care system, to find information and to read and understand health information partly explain the association between ethnicity and GP visits. Further research is recommended to understand the pathways through which health literacy impacts health care use.

Acknowledgements

The authors would like to thank the panel members of the Dutch Health Care Consumer Panel who participated in this study.

References

1. Abel T, Sommerhalder K. Health literacy: an introduction to the concept and its measurement. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz. 2015;58(9):923–9. doi:10.1007/s00103-015-2198-2.

2. Ackermann Rau S, Sakarya S, Abel T. When to see a doctor for common health problems: distribution patterns of functional health literacy across migrant populations in Switzerland. Int J Public Health. 2014;59(6):967–74. doi:10.1007/s00038-014-0583-5.

3. Beauchamp A, Buchbinder R, Dodson S, Batterham RW, Elsworth, GR, McPhee C, Osborne RH. Distribution of health literacy strengths and weaknesses across socio-demographic groups: a cross-sectional survey using the Health Literacy Questionnaire (HLQ). BMC Public Health. 2015;15: 678. doi:10.1186/s12889-015-2056-z.

4. Bennett IM, Chen J, Soroui JS, White S. The contribution of health literacy to disparities in self-rated health status and preventive health behaviors in older adults. Ann Fam Med. 2009;7(3):204–11. doi:10.1370/afm.940.

5. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. Ann Intern Med. 2011;155(2):97–107. doi:10.7326/0003-4819-155-2-201107190-00005.

6. Brabers AE, Reitsma-van Rooijen M, & de Jong JD. Consumentenpanel Gezondheidszorg. Basisrapport met informatie over het panel. 2015.

7. CCMO. Your research: does it fall under the WMO?.Retrieved from http://www.ccmo.nl/en/your-research-does-it-fall-under-the-wmo. Accessed March 2016.

8. Chinn D. Critical health literacy: a review and critical analysis. Soc Sci Med. 2011;73(1):60–7. doi:10.1016/j.socscimed.2011.04.004.

9. Davis TC, Wolf MS. Health literacy: implications for family medicine. Fam Med. 2004;36(8):595–8.

10. Diaz E, & Kumar BN. Differential utilization of primary health care services among older immigrants and Norwegians: a register-based comparative study in Norway. BMC Health Serv Res. 2014: 14. doi: 10.1186/s12913-014-0623-0.

11. Edward N, Walter D, Omariba R. Immigration, generational status and health literacy in Canada. Health Educ J. 2014;73(6):668–82.

12. Fransen M, Harris VC, Essink-Bot ML. Low health literacy in ethnic minority patients: understandable language is the beginning of good healthcare. Ned Tijdschr Geneeskd. 2013157(14):A5581.

13. Gilson L, Doherty J, Loewenson R, & Francis V. WHO: Challenging inequity through health systems. Final report knowledge network: WHO commission on the social determinants of health. 2007.

14. Gimeno-Feliu LA, Magallón-Botaya R, Macipe-Costa RM, Luzón-Oliver L, Cañada-Millan JL, Lasheras-Barrio M. Differences in the use of primary care services between spanish national and immigrant patients. J Immigr Minor Health. 2012;15(3):584–90. doi:10.1007/s10903-012-9647-x.

15. Howard DH, Sentell T, Gazmararian JA. Impact of health literacy on socioeconomic and racial differences in health in an elderly population. J Gen Intern Med. 2006;21(8):857–61. doi:10.1111/j.1525-1497.2006.00530.x.

16. Lindau ST, Tomori C, Lyons T, Langseth L, Bennett CL, Garcia P. The association of health literacy with cervical cancer prevention knowledge and health behaviors in a multiethnic cohort of women. Am J Obstet Gynecol. 2002;186(5):938–43.

17. Maxwell AE, Crespi CM, Antonio CM, Lu P. Explaining disparities in colorectal cancer screening among five Asian ethnic groups: a population-based study in California. BMC Cancer. 2010;10:214. doi:10.1186/1471-2407-10-214.

18. Murray, Desjardins, Shillington, Hagey, & Willms. Health literacy in Canada: A Healthy Understanding: Canadian Council on Learning. 2008.

19. Norredam M, Nielsen SS, Krasnik A. Migrants' utilization of somatic healthcare services in Europe—a systematic review. Eur J Public Health. 2010;20(5):555–63. Retrieved from http://eurpub.oxfordjournals.org/content/20/5/555.abstract.

20. Nutbeam D. Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. Health Promot Int. 2000;15(3):259–67. doi:10.1093/heapro/15.3.259.

21. Osborne RH, Batterham RW, Elsworth GR, Hawkins M, Buchbinder R. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). BMC Public Health. 2013;13:658. doi:10.1186/1471-2458-13-658.

22. Pleasant A. Advancing health literacy measurement: a pathway to better health and health system performance. J Health Commun. 2014;19(12):1481–96. doi:10.1080/10810730.2014.954083.

23. Schellevis FG, Westert GP, De Bakker DH. The actual role of general practice in the dutch health-care system. Results of the second dutch national survey of general practice. Med Klin (Munich). 2005;100(10):656–61. doi:10.1007/s00063-005-1090-5.

24. Smith BJ, Tang KC, Nutbeam D. WHO health promotion glossary: new terms. Health Promot Int. 2006;21(4):340–5. doi:10.1093/heapro/dal033.

25. Smith PC, Brice JH, Lee J. The relationship between functional health literacy and adherence to emergency department discharge instructions among Spanish-speaking patients. J Natl Med Assoc. 2012;104(11-12):521–7.

26. Sorensen K, Van de Broucke S, Pelikan JM, Fullam J, Doyle G, Slonska,…Brand. Measuring health literacy in populations: illuminating the design and development process of the European Health Literacy Survey Questionnaire (HLS-EU-Q). BMC Public Health. 2013;13:948. doi:10.1186/1471-2458-13-948.

27. Sørensen K, Van den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z & Brand H. Health literacy and public health: a systematic review and integration of definitions and models. BMC Public Health. 2012;12, 80. doi:10.1186/1471-2458-12-80.

28. Speros C. Health literacy: concept analysis. J Adv Nurs. 2005;50(6):633–40. doi:10.1111/j.1365-2648.2005.03448.x.

29. Stronks K, Ravelli AC, Reijneveld SA. Immigrants in the Netherlands: equal access for equal needs? J Epidemiol Community Health. 2001;55(10):701–7.

30. Sykes S, Wills J, Rowlands G, Popple K. Understanding critical health literacy: a concept analysis. BMC Public Health. 2013;13:150. doi:10.1186/1471-2458-13-150.

31. Tukey JW. Comparing individual means in the analysis of variance. Biometrics. 1949;5(2):99–114.

32. Uiters E, Deville W, Foets M, Spreeuwenberg P, Groenewegen PP. Differences between immigrant and non-immigrant groups in the use of primary medical care; a systematic review. BMC Health Serv Res. 2009;9:76. doi:10.1186/1472-6963-9-76.

33 Uiters E, Deville WL, Foets M, Groenewegen PP. Use of health care services by ethnic minorities in The Netherlands: do patterns differ? Eur J Public Health. 2006;16(4):388–93. doi:10.1093/eurpub/ckl040.

34. van der Heide I, Heijmans M, Schuit AJ, Uiters E, Rademakers J. Functional, interactive and critical health literacy: varying relationships with control over care and number of GP visits. Patient Educ Couns. 2015;98(8):998–1004. doi:10.1016/j.pec.2015.04.006.

35. van der Heide I, Wang J, Droomers M, Spreeuwenberg P, Rademakers J, Uiters E. The relationship between health, education, and health literacy: results from the Dutch adult literacy and life skills survey. J Health Commun. 2013;18 Suppl 1:172–84. doi:10.1080/10810730.2013.825668.

36. Zuvekas SH, Taliaferro GS. Pathways to access: health insurance, the health care delivery system, and racial/ethnic disparities, 1996-1999. Health Aff (Millwood). 2003;22(2):139–53

Chapter 3

The importance of health literacy for self-management: A scoping review of reviews

van der Gaag, M., Heijmans, M., Spoiala, C., & Rademakers, J. (2022). The importance of health literacy for self-management: a scoping review of reviews. Chronic Illness, 18(2), 234-254.

This work was supported by COMPAR-EU, under European Union's Horizon 2020 research and innovation programme: grant agreement No 754936

Abstract

Objectives: Self-management of chronic diseases is rather complex, especially for patients with limited health literacy. In this review, we aim to disentangle the specific difficulties patients with limited health literacy face in relation to self-management and their associated needs with respect to self-management support.

Methods: We performed a literature search in five databases. We used a broad definition of health literacy and self-management was categorized into four types of activities: medical management, changing lifestyle, communicating and navigating through the health care system and coping. Included reviews described the relationship between health literacy and different domains of self-management and were published after 2010.

Results: A total of 28 reviews were included. Some clear difficulties of patients with limited health literacy emerged, predominantly in the area of medical management (especially adherence), communication and knowledge. Other associations between health literacy and self-management were inconclusive. Barriers from the patients' perspective described mainly medical management and the communication and navigation of the health care system.

Discussion: Patients with limited health literacy experience difficulties with specific domains of self-management. For a better understanding of the relationship between health literacy and self-management, a broader conceptualization of health literacy is warranted, including both cognitive and behavioural aspects.

Keywords: Health literacy, self-management, chronic disease

Introduction

Due to ageing populations and changing lifestyles, the prevalence of chronic diseases such as cardiovascular disease, diabetes and chronic obstructive pulmonary disease (COPD) is globally increasing. Additionally, the amount of patients who have to deal with more than one of these chronic conditions is steadily growing. Chronic diseases are the leading cause of death.[1] Moreover, suffering from a chronic disease in many cases limits the patients' quality of life.[2] To counteract, appropriate care can help to control chronic diseases and to increase the quality of life of the patient, yet increasing care for chronic diseases is a major contributor to health care capacity deficiencies and health care costs. Therefore, the challenge to provide appropriate care puts health care services in many countries under additional pressure.

This public health challenge has resulted in a disease management approach where patients have become increasingly more responsible for their own health and health care. The shift from being a passive recipient of care to an active participant in ones' health and health care puts expectations on patients to actively self-manage the day-to-day care of their illness.[3] Today, self-management, defined as 'what individuals, families and communities do with the intention to promote, maintain or restore health and to cope with illness and disability' by patients and their relatives is an essential, yet complex, part of chronic illness care.[4] Self-management can be categorized into four different types of tasks or challenges for patients: medical management, making lifestyle changes, communication and navigation through the health care system, and coping with the long-term physical, emotional and social consequences of the disease.[3,5,6] Medical management may include medication adherence, self-monitoring and managing symptoms. A healthy lifestyle, including a healthy diet, exercising, no smoking and less alcohol are lifestyle recommendations that many chronically ill patients have to deal with. Communication and navigation through the health care system refer to the communication with health care professionals, which also includes shared decision-making. Navigation refers to knowing where to find and when to seek help. With respect to ways of coping with the consequences of living with a chronic disease, a distinction has been made between physical, psychological and social self-management tasks (see Box 1).

Box 1: Self-management activities

Medical management

- Adherence
- Self-monitoring
- Symptom management

Lifestyle

- Diet
- Physical activity
- Smoking

Communication and navigation through the health care system

- Communication with health care provider
- Shared-decision making
- Navigation of the health care system

Coping with consequences of living with a chronic disease

- Physical
- Psychological
- Social

Altogether, self-management is rather complex as it asks for the right motivation, knowledge, skills and confidence to use this knowledge and skills in the daily management of a disease. Moreover, health care systems are increasingly difficult to navigate and further educational systems find it a challenge to provide people with adequate skills to access, understand, assess and use the information to improve their health.[7] It is therefore not remarkable that a lot of patients have difficulties in achieving optimal self-management.[6,8]

One of the most vulnerable patient groups experiencing difficulties in self-management is those with limited health literacy. Patients with limited health literacy often lack the skills and the knowledge to achieve optimal self-management. This group also tends to suffer disproportionally from chronic diseases as they generally have worse health outcomes and consequently use more health care services.[9,10]

In the past decennia, multiple conceptualizations of health literacy have been used. At first, the definitions focused mainly on functional skills, such as reading and writing. Recently, more multidimensional definitions have emerged, in which behavioural and cognitive skills are also included. For this review, the definition by Sørensen is used, in which health literacy entails people's knowledge, motivation and competencies to access, understand, appraise and apply health information to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course.[11] Despite the broad definition by Sørensen, health literacy concepts often focus on cognitive skills or the capacity to think, in which knowledge and the ability to understand information are important factors. However, besides the capacity to think, the capacity to act is just as important in relation to the different aspects of self-management. The capacity to act is related to self-efficacy and motivation and is therefore seen as a major driver of behavioural change and the extent to which people feel able to self-manage.[12] Limited health literacy is often conceptualized as an individual problem. However, the level to which limited health literacy is problematic depends strongly on the difficulty of the context in which the skills are to be used. In this review, we mainly focus on the individual skills of patients with limited health literacy. It is important, though, to acknowledge that the health care environment has a great influence to reduce the potential mismatch between low health literate patients and the system by providing personalized care, easy-to-understand communication and information and tailored support.[13–15]

Understanding the relationship between self-management and health literacy makes it possible to support patients with limited health literacy in a more tailored way and improve their self-management and the associated outcomes. In this review, we aim to disentangle the specific difficulties patients with limited health literacy face in relation to self-management and their associated needs with respect to self-management support. In studying this relationship, we will focus on a broad definition of health literacy, focusing on skills related to the capacity to think (e.g. knowledge and the ability to find information) as well as the capacity to act (e.g. self-efficacy and motivation). To map the existing research in this area, and find gaps in the literature, the research question of this scoping review is:

What is known in the existing literature about the relation between health literacy and self-management behaviour in chronically ill adult patients? More specifically:

1. To what extent and how is self-management behaviour influenced by health literacy?
2. Which challenges do patients with limited health literacy encounter when coping with their different self-management tasks? Do they have specific or different self-management support needs?

Methods

A scoping review of reviews is performed to map the existing literature and to identify gaps in this research. To get a global picture of the available literature, using the broad conceptualizations of health literacy and self-management, the search will include reviews instead of primary studies. The methodological framework developed by Arksey and O'Malley was used for guidance. The framework consists of five stages: identifying research questions and aims, identifying relevant studies, selecting studies, charting the data and collating, summarizing and reporting the results.[16,17]

Search strategy

To answer our research questions, our search strategy focused on Boolean connections (AND, OR) of the terms health literacy, self-management behaviour and chronically ill adult patients. Only reviews, published from 2010 and onwards were included. Searches were conducted in Pubmed, Cinahl, Embase, Scopus and PsycINFO. As an example, Table 1 shows the search string used in Pubmed. This search string was translated for other databases. The last search was performed on 24 June 2020.

Review selection

Titles and abstracts from the searches were screened for inclusion according to the following criteria:

Inclusion criteria

- Study type is a review or meta-analysis.
- Published since 2010.
- Health literacy is at least one of the topics of focus.
- Adult population.
- Chronic disease, for example, asthma, COPD, cardiovascular diseases, diabetes or obesity; studies concerning comorbidity or multi-morbidity are also included.
- Focus is on self-management behaviour, self-management problems or self-management support needs.
- Provides information about the relationship between health literacy and self-management.

Table 1: Search strategy Pubmed

S1	(((((((("Health Literacy"[Mesh] OR "Health Literacy"[tiab] OR "health knowledge"[tiab] OR "medical data interpretation"[tiab] OR "health competence"[tiab]) OR (("Health"[Mesh] OR health[tiab] OR patient*[tiab]) AND (literacy[tiab] OR literate[Tiab] OR "reading skills"[tiab] OR "reading ability"[tiab] OR "reading level"[tiab] OR "writing level"[tiab] OR "writing ability"[tiab] OR "writing skills"[tiab] OR numeracy[tiab] OR analphabetism[tiab]))))
S2	self-management [MeSH Terms] OR self-management [tiab] OR “self management” [tiab]OR selfmanagement [tiab] OR self-care [MeSH Terms] OR self-care [tiab] OR “self care” [tiab] OR selfcare [tiab] OR "empowerment” [tiab] OR self- efficacy [tiab] OR “self efficacy” [tiab] OR selfefficacy [tiab] OR mastery [tiab] OR self-control [tiab] OR “self control” [tiab] OR selfcontrol [tiab] OR self-confidence [tiab] OR “self confidence” [tiab] OR selfconfidence [tiab] OR “perceived control” [tiab] OR competence [tiab] OR self-determination [tiab] OR “self determination” [tiab]OR selfdetermination [tiab]OR “enhanced control” [tiab] OR “locus of control” [tiab] OR self-help [tiab] OR “self-help” [tiab] OR selfhelp [tiab] OR coping [MeSH Terms] OR “shared decision making” [MeSH Terms
S3	“chronic disease” [MeSH Terms] OR “chronic disease” [tiab] OR “chronic diseases” [tiab] OR “chronic illness” [tiab] OR “chronic illnesses” [tiab] OR “chronic condition” [tiab] OR “chronic conditions” [tiab] OR “chronically ill” [tiab] OR disability [tiab] OR disabilities [tiab] OR asthma [tiab] OR copd [tiab] OR “chronic obstructive pulmonary disease” [tiab] OR stroke [tiab] OR “heart failure” [tiab] OR “cardiovascular disease” [tiab] OR hypertension [tiab] OR “high blood pressure” [tiab] OR cancer [tiab] OR “cardiovascular diseases” [MeSH Terms] OR “cardiovascular diseases” [tiab] OR "diabetes mellitus" [MeSH Terms] OR "diabetes mellitus"[tiab] OR diabetes [tiab] OR “pulmonary disease, chronic obstructive” [MeSH Terms] OR stroke [MeSH Terms] OR dementia [MeSH Terms] OR obesity [MeSH Terms] OR adiposis [tiab]
S4	(Meta-Analysis[ptyp] OR Review[ptyp] OR systematic[sb])
S5	("2010"[Date - Publication] : "3000"[Date - Publication])
S6	S1+S2+S3+S4+S5

The search strategy overall focused on the concept of self-management, but the inclusion criteria during the screening included all specific components of self-management. In case of doubts, full texts were screened according to the same criteria. Both the title and abstract screening and full-text screening were done independently by two reviewers (MG and CS), using covidence. The reviewers were trained and calibrated for the screening process in a related research project in which the central concepts of this review (health literacy and self-management) were also included. In case of doubts or discrepancies, a third reviewer (MH) was consulted to make the final decision.

Data collection and analysis

A data charting form was developed and tested by MG, CS and MH on a subset of 10% of the studies and adjusted where needed. The remaining studies were chartered by MG and checked by CS. Doubts were discussed with MH. The following information was chartered if provided: general information about the review (author, year and type of review), the way health literacy was measured, aspect of self-management in four broad categories: medical management, making lifestyle changes, communication with health care providers and navigation through the health care system, coping with consequences of being chronically ill), challenges of self-management encountered, self-management support needs and the information about the relationship between health literacy and self-management. All types of information concerning the relationship between health literacy and self-management were chartered. Some reviews also included primary studies that did not relate to the relationship between health literacy and self-management, and that information was therefore not extracted. The charted data were summarized, and the results of associations were considered conclusive when the majority of the reviews (>50%) found a clear association. In the results section, for each type of self-management, first, the found associations will be described. Subsequently, the information retrieved from other types of studies will be presented.

Results

Overview of reviews

The process of review selection and exclusion is shown in Figure 1. A total of 278 reviews were identified by the search, of which 78 reviews remained for full-text screening. The main reason for exclusion during the full-text screening was that the review did not describe the relationship between health literacy and self-management. Finally, a total of 28 reviews were included in our review of reviews.[18-45] An overview of the 28 reviews is presented in Table 2. The types of reviews were mainly systematic reviews (n= 11)[18,24,28,29,31,34,36,37,39,44,45] or narrative reviews (n=5).[19,22,23,25,26] Diabetes, both type 1 and type 2, were the most studied chronic diseases (n=9),[18,19,26,27,29,36,38,41,45] followed by heart failure (n=5),[21,24,30,31,35] cardiovascular disease (n=2),[20,23] chronic kidney disease (n=2),[22,25] COPD (n=1),[32] asthma (n=1),[43] cancer (n=1),[42] hypertension (n=1)[33] and low back pain (n=1);[34] five reviews included studies on a combination of diseases.[28,37,39,40,44] The number of primary studies in the reviews found varied between 3 and 103; however, most of the time only a subset of these studies was considered relevant for this review of reviews. The vast majority of the reviews and the primary studies of the reviews were published in Northern America. Reviews were conducted between 2010 and 2020 with half of the reviews published between 2018 and 2020.[23,25–30,33,34,37,41,42,44,45] The funding of the included reviews is presented in Table 4.

Table 2: Descriptives of the included reviews

Author year	Disease	Aim	Number of primary studies	Type of review	Type of primary studies	HL def	Health literacy measurement tools
Browne 2010 [22]	CKD	To examine the barriers to adult hemodialysis patient self-management of oral medications.	-	Narrative	Quantitative and Qualitative	Reading and understanding, but it also determines one's capacity to successfully act on health information, including instructions.	-
Evangelista 2010 [35]	HF	To summarize the research on the impact of low health literacy on patients with cardiovascular disease, including heart failure.	-	-	Quantitative	The ability to read written material + understanding the information to actively participate.	-
Disler 2012 [32]	COPD	To identify the determinants which influence the individual's ability to cope and adjust to living with chronic obstructive pulmonary disease in the community.	44	Integrative	Quantitative and Qualitative	The capacity to access, comprehend, and make appropriate decisions about health information.	-

Table 2: Continued

Author year	Disease	Aim	Number of primary studies	Type of review	Type of primary studies	HL def	Health literacy measurement tools
Fransen 2012 [36]	DM	To review studies on the association between health literacy, diabetes self-management and possible mediating variables.	11	Systematic	Quantitative	The capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.	F
Kadirvelu 2012 [38]	DM	To examine the different components impinging on self-care among type II diabetic patients.	-	Review	Quantitative	The capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.	-
Loke 2012 [39]	Cardiovascular, DM	To review the relationship between health literacy and adherence to cardiovascular/diabetes medication.	7	Systematic	Quantitative	The capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.	F

Table 2: Continued

Author year	Disease	Aim	Number of primary studies	Type of review	Type of primary studies	HL def	Health literacy measurement tools
Rosas-Salazar 2012 [43]	Asthma	To summarize the current evidence linking HL and asthma.	13	Review	Quantitative	The capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.	F
Al sayah 2013 [18]	DM	To better understand the relationship between health literacy and numeracy and health outcomes in diabetes.	34	Systematic	Quantitative	HL is a set of skills. Functional, interactive and critical skills, including numeracy.	F + B + C
Bailey 2014 [19]	DM	To critically review the existing literature on the association between health literacy and outcomes among patients with diabetes.	79	Narrative	Quantitative	The capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.	F

Table 2: Continued

Author year	Disease	Aim	Number of primary studies	Type of review	Type of primary studies	HL def	Health literacy measurement tools
Bos-Touwen 2015 [21]	HF	To synthesize the essential literature on patient characteristics associated with self-management capacity and intervention effects.	28	Review	Quantitative	-	-
Cajita 2016 [24]	HF	The specific aims of the systematic review are to discuss the relationship between health literacy and HF self-care and common HF outcomes.	23	Systematic	Quantitative	The capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.	F
Mackey 2016 [40]	Chronic disease	To assess the association between HL and patient characteristics related to self-management behaviours.	31	Review	Quantitative	The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use health information.	F

Table 2: Continued

Author year	Disease	Aim	Number of primary studies	Type of review	Type of primary studies	HL def	Health literacy measurement tools
Barnason 2017 [20]	Cardiovascular	This review of the evidence elucidates the impact of TPE interventions for self-management by patients with CVD.	-	Integrative	Quantitative and Qualitative	The capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.	F
Delgado 2017 [31]	HF	To summarize the research literature related to older Latinos with HF who have limited HL.	8	Systematic	Quantitative	The capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.	F
Cabellos-Garcia 2018 [23]	Cardio vascular	To describe the influence of HL levels in the self-care of cardiovascular pathologies managed with OAC treatment.	10	Narrative systematic	Quantitative	HL is dynamic and refers to the knowledge, motivation, and competencies to act, understand, evaluate and apply health information to care related decisions.	F

Table 2: Continued

Author year	Disease	Aim	Number of primary studies	Type of review	Type of primary studies	HL def	Health literacy measurement tools
Cassidy 2018 [25]	CKD	To review the influencers of RRT decision making in the CKD population.	-	Narrative	Quantitative and Qualitative	HL is the ability of an individual to attain, process, and appreciate basic medical information and risks.	-
Chatterjee 2018 [26]	DM	To examine the effectiveness of diabetes self-management education on biomedical, behavioural, and psychosocial outcomes among adults with type 1 and type 2 diabetes, as well as cost-effectiveness, methods of delivery, and barriers to uptake.	-	Narrative	Qualitative	-	-

Table 2: Continued

Author year	Disease	Aim	Number of primary studies	Type of review	Type of primary studies	HL def	Health literacy measurement tools
Chen 2018 [27]	DM	To determine, through a systematic review and meta-analysis, if health literacy is associated with diabetic foot disease, its risk factors, or foot care.	16	Meta-analysis	Quantitative	The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.	F + B + C
Du 2018 [33]	Hypertension	To summarize the evidence of health literacy and health outcomes in hypertensive patients.	19	Integrative	Quantitative	People with adequate HL have the ability to read and understand (functional), communicate (interactive), make appropriate health decisions (critical) and measure medication doses (numeracy).	F + B + C

Table 2: Continued

Author year	Disease	Aim	Number of primary studies	Type of review	Type of primary studies	HL def	Health literacy measurement tools
Edward 2018 [34]	Chronic low back pain	To examine the importance and implications of health literacy in the treatment and management of LBP.	3	Systematic	Quantitative and Qualitative	The capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions	F
Papadakos 2018 [42]	Cancer	To examine and summarize what is known about the association between HL and self-management behaviours and health service utilization in the cancer setting.	17	Scoping	Quantitative	The degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions. (this review operationalised HL broadly)	F + B + C

Table 2: Continued

Author year	Disease	Aim	Number of primary studies	Type of review	Type of primary studies	HL def	Health literacy measurement tools
Xu 2018 [45]	DM	To investigate the relationship between HL (as a whole) and SE, and the relationships between the different subdomains of HL and SE.	11	Systematic	Quantitative	The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use health information in ways which promote and maintain good health. HL is divided in functional, communicative and critical.	F + B + C
Dahal 2019 [29]	DM	To analyse the existing evidence about the effect of HL on T2DM self-management behaviours by assessing the most current randomised controlled trials.	14	Systematic	Quantitative	The cognitive and social skills which determine the motivation and ability of people to gain access to, understand and use information in ways which promote and maintain good health.	-

Table 2: Continued

Author year	Disease	Aim	Number of primary studies	Type of review	Type of primary studies	HL def	Health literacy measurement tools
Jager 2019 [37]	Multiple	To explore and synthesize evidence on the needs, experiences and preferences of patients with LHL and to inform an existing educational framework.	103	Systematic	Qualitative	People with LHL can be defined as persons who have difficulty in accessing and understanding health information, and in appraising and applying such information in making decisions related to health and healthcare.	-
Marciano 2019 [41]	DM	To shed light on the role of health literacy in diabetes-related knowledge, self-care, and glycaemic control, taking into account variations in functional health literacy assessments.	61	Meta-analysis	Quantitative	The degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions.	F

Table 2: Continued

Author year	Disease	Aim	Number of primary studies	Type of review	Type of primary studies	HL def	Health literacy measurement tools
Shahin 2019 [44]	Chronic disease	To evaluate the consequent effects of personal and cultural beliefs on medication adherence, in patients with chronic conditions such as hypertension, diabetes mellitus, chronic obstructive pulmonary disease and asthma.	25	Systematic	Quantitative	The cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use health information in ways which promote and maintain good health.	F + B + C
Cudjoe 2020 [28]	Multiple	To discuss mechanisms through which HL influences health behavior and/or health outcomes.	20	Systematic	Quantitative	Health literacy is a multidimensional concept that addresses a range of skills people need to effectively and efficiently function in a health care environment.	F

Table 2: Continued

Author year	Disease	Aim	Number of primary studies	Type of review	Type of primary studies	HL def	Health literacy measurement tools
Deek 2020 [30]	HF	This paper explored literacy and health literacy in heart failure and the methods used for its evaluation in this selected group of patients.	-	Scoping	Quantitative	Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.	F + B + C

Heart failure: HF, Chronic kidney disease: CKD, Diabetes: DM
Not specified: -, Functional: F, Behavioural: B, Cognitive: C

Table 3: Associations between health literacy and self-management

Author, year	Disease	Medical management	Lifestyle	Communication and navigation	Coping	Knowledge + self-efficacy	SM in general
Evangelista 2010 [35]	HF	Adherence (+)				Knowledge (+)	Self-care (+)
Fransen 2012 [36]	DM	Self-monitoring (0) Adherence (0)	Nutrition (0) Physical activity (0)			Knowledge (+) Self-efficacy (0)	
Kadirvelu 2012 [38]	DM					Knowledge (+) Understanding of instructions (+)	Self-care (+)
Loke 2012 [39]	Cardiovascular, DM	Adherence (0)					
Rosas-Salazar 2012 [43]	Asthma					Knowledge (+) Self-efficacy (0)	
Al sayah 2013 [18]	DM	Self-monitoring (0) Adherence (0)		SM-support (+) Patient-provider communication (+) Patient trust (0)		Knowledge (+) Self-efficacy (0)	
Bailey 2014 [19]	DM	Adherence (+)		Patient-provider communication (+)		Knowledge (+) Self-efficacy (0)	Self-care (0)

Table 3: Continued

Author, year	Disease	Medical management	Lifestyle	Communication and navigation	Coping	Knowledge + self-efficacy	SM in general
Cajita 2016 [24]	HF	Adherence (+)				HF knowledge (+)	Self-care (0) Self-care confidence (+)
Mackey 2016 [40]	Chronic disease				Fear avoidance (0) Catastrophizing (0) Beliefs (degree of control) +		Knowledge (+) Beliefs (knowledge) (+) Self-efficacy (+)
Barnason 2017 [20]	Cardiovascular	Adherence (+)		SDM (+) Patient-provider communication (+)			Knowledge (+)
Delgado 2017 [31]	HF						Knowledge (+)
Cabellos-Garcia 2018 [23]	Cardiovascular	Adherence (+)					Knowledge (+)
Cassidy 2018 [25]	CKD	Adherence (+)		SDM (+) Screening utilization (+)			

Table 3: Continued

Author, year	Disease	Medical management	Lifestyle	Communication and navigation	Coping	Knowledge + self-efficacy	SM in general
Chatterjee 2018 [26]	DM						
Chen 2018 [27]	DM	Foot-care (0)					
Du 2018 [33]	Hypertension	Adherence (0)		Patient-provider communication (0) SDM (0)		Knowledge (+) Self-efficacy (0)	Self-care (/)
Edward 2018 [34]	Chronic low back pain				Pain beliefs (0) Fear avoidance (0) Catastrophizing (0)	Patient empowerment (/)	
Papadakos 2018 [42]	Cancer	Adherence (+)		Screening utilization (+) SDM (0)		Knowledge (0) Self-efficacy (0) Information needs (0) Information seeking behaviour (+)	
Xu 2018 [45]	DM					Self-efficacy: Critical/ communicative HL (+) Functional HL (0)	

Table 3: Continued

Author year	Disease	Medical management	Lifestyle	Communication and navigation	Coping	Knowledge + self-efficacy	SM in general
Dahal 2019 [29]	DM	Self-monitoring (0) Adherence (0) Foot care (0)	Physical activity (+) Nutrition (+)			Knowledge (+) Self-efficacy (+)	
Marciano 2019 [41]	DM					Knowledge (+)	Self-care activities (0)
Shahin 2019 [44]	Chronic disease	Adherence (0)					
Cudjoe 2020 [28]	Multiple			Patient-provider communication (+)		Knowledge (+) Self-efficacy (+)	Self-care activities (+)
Deek 2020 [30]	HF					Knowledge (+) Self-efficacy (+)	Self-care (0)
Heart failure: HF, Chronic kidney disease: CKD, Diabetes: DM, Self-management: SM Positive association (higher HL = higher outcome): +, no association found: 0							

Table 4: Funding of included reviews

	N
None-sponsored	9
Public-sponsored	9
Industry-sponsored	2
Not reported	8

Measures of health literacy

Multiple measurement tools were used to measure health literacy in the primary studies of the reviews. Some of the tools were developed for screening tests, such as the three screening questions by Chew, others for a more extensive assessment. As stated in the introduction, health literacy can be defined as functional health literacy only (reading, writing and numerical skills), or also including other cognitive and behavioural skills. Most of the tools used were developed to measure functional health literacy, such as reading comprehension and numerical ability. The most tools used were (s)-TOFHLA and REALM. Very few studies measured health literacy from a more multidimensional perspective. Most of the associations between health literacy and outcome measures concerned knowledge (n=17),[18–20,23,24,28–31,33,35,36,38,40–43] self-efficacy (n=12)[18,19,24,28–30,33,34,36,40,42,45] and medical management (n=13).[18-20,23-25,27,29,33,35,36,39,42,44] Fewer reviews were found describing associations between health literacy and communication and navigation of the health care system (n=7),[18–20,25,28,33,42] lifestyle (n=2)[29,36] and coping with long-term consequences (n=2).[35,40] Nine reviews studied the association between health literacy and self-management, with the type of self-management not being specified,[19,21,24,28,30,33,35,38,41] of which four reviews found an association.[21,35,38,41] These nine reviews were specifically focusing on heart failure and diabetes patients.

We will outline our findings from the collected reviews based on the self-management activities shown in Box 1. An association will be described as positive when higher health literacy indicates a better self-management outcome. A summary of the given associations can be found in Table 3.

The influence of health literacy on self-management

Medical management

The vast majority (n=13) of the reviews concerning medical management studied medication adherence, of which the results were mixed.[18–20,23–25,29,33,35,36,39,42,44] Approximately half of the studies found a significant association, showing that patients with limited health literacy have lower levels of adherence.[19,20,23–25,35,42] In contrast, specifically in studies with diabetes patients, no significant associations were found between health literacy and self-monitoring,[18,27,29,36] and no associations were found between health literacy and foot care.[27,29] The reviews that described the difficulties patients experienced during medical management were mainly concerned with adherence, and the information needed for their medication and symptom management. Specifically, during medication adherence, patients with chronic kidney disease experienced difficulties with reading and comprehending small print prescriptions or instructions on pill bottles and medication forms.[22] The length and amount of text in combination with the perceived difficulty prevented patients from reading medical information.[37] Too much information, especially on the internet, was also a barrier for patients with low health literacy. In general, difficulties were experienced accessing and appraising the relevance and reliability of health information.[37] The use of graphic illustrations and images eased readability and understanding for the patient. Further, realistic and practical instructions, such as demonstrations, can also help to translate information into action.[37]

Lifestyle

The association between health literacy and lifestyle factors was assessed in two reviews, with both focusing on diabetes patients.[29,36] The lifestyle factors of physical activity and dietary behaviours were positively associated with health literacy in the review by Dahal and Hosseinzadeh,[29] however, the same relationship was not found by Fransen et al.[36] Motivation is crucial for patients with low health literacy to achieve and maintain positive behaviour change and increased self-management, as shown by qualitative evidence. What is further crucial to sustaining motivation for a longer period is a dedicated support system, consisting of friends, family, peers and health care professionals.[37] Family members are good motivators especially when patients want to set a good example for their children and also when they want to be around to see their grandchildren grow. Health care providers can also contribute positively to the motivation of patients. A true interest and concern from health care providers make patients feel supported, which is a motivating cue and a facilitator of self-management.[37] Motivation here, be it from medical staff or others, is underlined throughout reviews as patients need to know others are connected to them, with other's involvement and feedback being crucial forms of positive reinforcement.

Communication and navigation of the health care system

The association between health literacy and patient–provider communication was assessed by five reviews, with three finding a positive association,[18–20] with another not finding an association,[33] and with one concluding that patient–provider communication is an important mediator between health literacy and self-management.[40] For shared decision-making, two out of four studies reported a negative effect for patients with limited health literacy.[20,25] Additionally, Al Sayah et al.[18] studied the relationship between health literacy and patient trust and self-management support. A positive association was only found between health literacy and self-management support. One example of navigating the health care system is the utilization of services, such as through preventive services and screening utilization.[25] The uptake of cancer screening was found to be at lower levels in patients with limited health literacy.[42] The associations found concerning health literacy and communicating and navigating through the health care system correspond with the problems patients have. In the communication between patients and their health care providers, patients feel that they either lack knowledge, experience or expectations,[37] which is caused by the lack of understanding of written material or caused by the often repetitive and not novel. The use of medical jargon had a further negative impact on patient health, self-management, emotions and mental well-being. A further perceived barrier is the amount of information provided to patients at once. What was beneficial, in counteracting the aforementioned barriers, was the alignment of information with patients' needs and the provision of information separately for diagnosis and treatment.[37]

Additionally, patients experienced barriers when asking their health care providers' questions. Patients perceived time constraints during visits, feeling like they did not know what to ask and feeling embarrassed for their lack of understanding.[37] A perceived facilitator in the communication process was the presence of a family member.[37] In addition, video materials with simple words and sentences, with step-wise changes in behaviour and with clear messages were found to be important for patients in the communication process. In general, videos, as compared to other mediums, increased the involvement of patients with low health literacy and encouraged patients to ask questions.[37]

Navigating the health care system includes more than solely services utilization, other examples including cancer screening services or having reduced access to supportive services for COPD patients.[32] Patients with inadequate health literacy also perceived barriers in the accessibility and availability of health care, which screening utilization can be part of. The perceived lack of availability and long waiting lists led some patients to think that it was faster to see a specialist through emergency care, rather than through primary care.[37] In the transition from primary to secondary care, patients experienced a lack of communication, from providers to patients themselves and also between different health care providers.[37] Throughout, the lack of collaborative communication between primary and secondary care was an important barrier to effective disease management, which further exacerbated patients' perceived barriers.

Coping

Fear avoidance, pain beliefs and pain catastrophizing were assessed in one review concerning patients with chronic low back pain, but no associations with health literacy were found.[34] The association between health literacy and acceptance was not further assessed. One review including chronic diseases in general did find that patients with low health literacy experienced a lower degree of control over their disease.[40]

The feeling of control and autonomy corresponds with qualitative information gathered from patients with limited health literacy. Control and autonomy are important for them because they provide a sense of comfort. To feel in control, patients first need to accept their situation. Religion, spirituality, giving hope and strength, played a big role in accepting their situation, such as through accepting and dealing with their disease. Once again, other patients were found to be beneficial as a source of important support, both emotionally and socially.[37]

Knowledge and self-efficacy

A total of 17 reviews examined the association between health literacy and knowledge. The vast majority reported a positive association between health literacy and knowledge,[18–20,23,24,29–31,33,35,36,38,40,41,43] health literacy and the understanding of instructions,[38] and health literacy and correct disease-specific beliefs.[40] In the review of Rosas-Salazar et al.,[43] patients with asthma and inadequate health literacy had more information needs, yet they displayed less information-seeking behaviour. These results show that inadequate health literacy negatively influences knowledge, independent of the type of chronic disease. Of the 13 reviews that examined the association between health literacy and self-efficacy, five reported a positive association[24,29,30,40,45] and eight did not.[18,19,33,34,36,42,43,45] In the more nuanced review of Xu et al.,[45] functional and critical/communicative health literacy were distinguished, of which only critical/communicative health literacy is associated with self-efficacy in diabetes patients. Additionally, one review on multiple chronic diseases found that both knowledge and self-efficacy are important mediating factors in the relationship between health literacy and self-management.[28] Despite the results that knowledge is worse in patients with limited health literacy, patients do recognize that knowledge about their disease and symptoms is very important. Sufficient knowledge results in feeling more in control and confident about managing their disease.[37] However, possessing only sufficient knowledge is not the full solution. Patients also emphasized the struggle of the gap between knowledge and being able to act.[37] Further, having limited health literacy can result in a limited understanding of the rationale of self-management techniques in patients with COPD.[32]

Discussion

The aim of this scoping review was to gain insights into the relationship between health literacy and self-management behaviour of chronically ill adults, and the problems patients encounter during their self-management. The two main research questions that we aimed to answer were: (1) To what extent and how is self-management behaviour influenced by health literacy? (2) Which challenges do patients with limited health literacy encounter when coping with their different self-management tasks? Do they have specific, or other, self-management support needs?

For answering the research questions, a literature search was performed resulting in 28 reviews. Most of the reviews included studies concerning patients with diabetes, cardiovascular diseases or a combination of these chronic conditions. Half of the reviews were published in the past 2 years, which is indicative of a growing awareness of the importance of this research.

The relationship between health literacy and self-management is described by multiple reviews. However, the operationalization of both health literacy and self-management is often narrow, focusing predominantly on functional health literacy and specific self-management activities, which causes gaps in the literature. Research on the conceptualization of health literacy confirms these findings, but a positive development is that the concept of health literacy is recently evolving to include multiple dimensions.[11] Some clear difficulties of patients with limited health literacy emerged, predominantly in the area of medical management (especially adherence), communication and knowledge. These findings correspond with already known difficulties of patients with limited health literacy.[7] Other associations between health literacy and self-management were inconclusive, where previous research implies a clear relationship between health literacy and for example self-efficacy.[12]

To study the relationship between health literacy and self-management, we divided self-management into four broad areas related to patients' performance on tasks with regard to daily coping with an illness: medical management, making lifestyle changes, coping with consequences of living with a chronic disease, and interacting with health care professionals and the health care system. The amount of evidence found was not equally distributed across these four areas: reviews focused primarily on health literacy in relation to medical management and to communication with the health care system. Proportionately less research focused on the association between health literacy and lifestyle adjustments, and aspects regarding coping with the consequences of a chronic disease. It is notable that most of the reviews focused on knowledge and self-efficacy. Although knowledge and self-efficacy cannot be put in the four categories of self-management activities, they are seen as important prerequisites for self-management.[46]

The reviews focusing on medical management, predominantly on adherence, on patient–provider communication and on knowledge showed that limited health literacy has a negative effect on these outcomes. In most other reviews no association with health literacy was found or the results were inconclusive. On the other hand, none of the reviews reported contradictory, negative associations.

In this review, knowledge and self-efficacy were the most studied variables with respect to health literacy. The results on the association with knowledge showed that health literacy and knowledge are closely related. The relationship between self-efficacy and health literacy was less conclusive. This was in contrast with a recent study that stressed that self-efficacy is an important prerequisite for the capacity to act.[12]

The fact that the evidence concerning the relationship between health literacy and certain self-management activities remains inconclusive can be due to the operationalization of the health literacy concept. In contrast with the broad definition of health literacy intended for this scoping review, the majority of the studies defined and measured health literacy in a much more narrow way, mainly consisting of functional skills, such as reading and writing, and sometimes including other cognitive factors such as understanding information. However, as stated earlier, self-management involves a complex set of activities, such as interpreting information, being motivated for lifestyle changes and making choices about one's health.

A broader operationalization and measurement of health literacy holds the potential to better represent the multiple aspects of health literacy needed for self-management.[12] As self-management has mainly to do with performing specific behaviours, it follows that skills that enable patients to successfully conduct those behaviours are especially important, such as motivation and self-efficacy. Knowledge is an important prerequisite, but the main challenge is the translation of this knowledge to actual behaviour.[12,47] It is only recently that broader definitions of health literacy have begun to be used.[48] While most of the reviews in this scoping review intended to use a broad approach to health literacy, the primary studies of these reviews mainly measured functional skills. Therefore, the relationship between other aspects of health literacy and self-management needs further investigation.

For answering the second research question, we relied mainly on the reviews that contained qualitative data. These reviews showed that patients experienced mainly barriers regarding medical management, especially regarding the way information was provided and communicated. Some barriers with respect to communication were found, for example, time constraints and the opportunity to ask questions, without feeling embarrassed. These reviews provided limited insight into the influence of limited health literacy on coping and motivation to change lifestyle behaviours. Up to now, these self-management outcomes are scarcely studied in patients with limited health literacy. Future research should address the impact of health literacy on these aspects of self-management.

This review provides, besides implications for further research, implications for practice and health care policy. An implication for practice is that medical management is difficult for patients with limited health literacy. The self-management support for this group should be tailored to the skills of the individual, for example, by providing easy-to-understand communication and information. For health care policy, it is important to acknowledge the key roles of organizations to reduce the mismatch between the patients' skills and the health care context. It is important that organizations become health literate by, for example, training health care professionals.[13,14] Since limited information is currently available concerning the influence of health literacy on self-management, the broad scope on all chronic conditions in our review helped to assess as much information as possible. Yet, a limitation of this scoping review is that we only considered English language reviews for inclusion. Besides, the vast majority of the data originates from North America, where research on the topic of health literacy has been most developed. Encouragingly, research on health literacy is increasing noticeably in Europe.[48,49]

In conclusion, health literacy has a negative influence on medical management (especially adherence), patient–provider communication and knowledge. However, either no associations between health literacy and other self-management activities were found or the results were inconclusive. Further research in this area has to focus on both the broad conceptualization of health literacy, including cognitive and behavioural aspects, as well as a comprehensive operationalization of self-management, including lifestyle and coping aspects. Given the small number of reviews found describing the barriers patients with limited health literacy faced during self-management, this area should be further studied to obtain evidence for the development of self-management interventions.

References

1. WHO. Noncommunicable diseases country profiles 2018. https://apps.who.int/iris/handle/10665/274512

2. Megari K. Quality of life in chronic disease patients. Health Psychol Res 2013; 1: e27.

3. Barlow J, Wright C, Sheasby J, et al.Self-management approaches for people with chronic conditions: a review. Patient EducCouns 2002; 48: 177–187.

4. Ballester M, Orrego C, Heijmans M, et al. Comparing the effectiveness and costeffectiveness of self-management interventions in four high-priority chronic conditions in Europe (COMPAR-EU): a research protocol. BMJ open 2020; 10: e034680.

5. Bayliss EA, Steiner JF, Fernald DH, et al. Descriptions of barriers to self-care by persons with comorbid chronic diseases. Ann Family Med 2003; 1: 15–21.

6. van Houtum L, Rijken M, Heijmans M, et al. Patient-perceived self-management tasks and support needs of people with chronic illness:generic or disease specific? Ann Behav Med 2015; 49: 221–229.

7. WHO. Health literacy: The solid facts. 2013. https://apps.who.int/iris/bitstream/handle/10665/128703/e96854.pdf

8. Jerant AF, von Friederichs-Fitzwater MM and Moore M. Patients' perceived barriers to active self-management of chronic conditions. Patient Educ Couns 2005; 57: 300–307.

9. van der Heide I, Heijmans M, Schuit AJ, et al. Functional, interactive and critical health literacy: varying relationships with control over care and number of GP visits. Patient Educ Couns 2015; 98: 998–1004.

10. Berkman ND, Sheridan SL, Donahue KE, et al. Low health literacy and health outcomes: an updated systematic review. Ann Intern Med 2011; 155: 97–107.

11. Sørensen K, Van den Broucke S, Fullam J, et al. Health literacy and public health: a systematic review and integration of definitions and models. BMC Public Health 2012; 12: 1–13.

12. Rademakers J and Heijmans M. Beyond reading and understanding: health literacy as the capacity to act. Int J Environ Res Public Health. 2018; 15: 1676.

13. Brach C and Harris LM. Healthy people 2030 health literacy definition tells organizations: make information and services easy to find, understand, and use. J Gen Intern Med. 2021; 36: 1084–1085.

14. Brach C, Keller D, Hernandez LM, et al. Ten attributes of health literate health care organizations. NAM Perspect 2012. Discussion Paper. Washington, DC: National Academy of Medicine. https://doi.org/10.31478/201206a

15. van der Heide I, Poureslami I, Mitic W, et al. Health literacy in chronic disease management: a matter of interaction. J Clin Epidemiol 2018; 102: 134–138.

16. Arksey H and O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol 2005; 8: 19–32.

17. Levac D, Colquhoun H, and O'Brien KK. Scoping studies: advancing the methodology. Implement Sci 2010; 5: 69.

18. Al Sayah F, Majumdar SR, Williams B, et al.Health literacy and health outcomes in a systematic review. J Gen Intern Med 2013;28: 444–452.

19. Bailey SC, Brega AG, Crutchfield TM, et al. Update on health literacy and diabetes. Diabetes Educ 2014; 40: 581–604.

20. Barnason S, White-Williams C, Rossi LP, et al. Evidence for therapeutic patient education interventions to promote cardiovascular patient self-management: a scientific statement for healthcare professionals from the American Heart Association. Circ: Cardiovasc Qual Outcomes 2017; 10: e00002.

21. Bos-Touwen I, Jonkman N, Westland H, et al. Tailoring of self-management interventions in patients with heart failure. Curr Heart Fail Rep 2015; 12: 223–235.

22. Browne T and Merighi JR. Barriers to adult hemodialysis patients' self-management of oral medications. Am J Kidney Dis 2010; 56: 547–557.

23. Cabellos-Garcia AC, Martinez-Sabater A,Castro-Sanchez E, et al. Relation between health literacy, self-care and adherence to treatment with oral anticoagulants in adults: a narrative systematic review. BMC Public Health. 2018; 18: 1157.

24. Cajita MI, Cajita TR and Hae-Ra H. Health literacy and heart failure. J Cardiovasc Nurs 2016; 31: 121–130.

25. Cassidy BP, Getchell LE, Harwood L, et al. Barriers to education and shared decision making in the chronic kidney disease population: a narrative review. Can J Kidney Health Dis 2018; 5. http://doi.org/2054358118803322

26. Chatterjee S, Davies MJ, Heller S, et al. Diabetes structured self-management education programmes: a narrative review and current innovations. Lancet Diabetes Endocrinol 2018; 6: 130–142.

27. Chen PY, Elmer S, Callisaya M, et al. Associations of health literacy with diabetic foot outcomes: a systematic review and meta-analysis. Diabet ic Med 2018; 35: 1470–1479.

28. Cudjoe J, Delva S, Cajita M, et al. Empirically tested health literacy frameworks. Health Lit Res Pract 2020; 4: e22–e44.

29. Dahal PK and Hosseinzadeh H. Association of health literacy and diabetes self-management: a systematic review. Aust J Prim Health 2019; 25: 526–533.

30. Deek H, Itani L and Davidson PM. Literacy critical to heart failure management: a scoping review. Heart Fail Rev 2020. https://doi.org/10.1007/s10741-020-09964-6

31. Delgado JM and Ruppar TM. Health literacy in Older Latinos with heart failure: a systematic review. J Cardiovasc Nurs 2017; 32: 125–134.

32. Disler RT, Gallagher RD and Davidson PM. Factors influencing self-management in chronic obstructive pulmonary disease: an integrative review. Int J Nurs Stud 2012; 49: 230–242.

33. Du S, Zhou Y, Fu C, et al. Health literacy andhealth outcomes in hypertension: an review. Int J Nurs Sci 2018; 5: 301–309.

34. Edward J, Carreon LY, Williams MV, et al. The importance and impact of patients' health literacy on low back pain management: a systematic review of literature. Spine J 2018; 18: 370–376.

35. Evangelista LS, Rasmusson KD, Laramee AS, et al. Health literacy and the patient with heart failure--implications for patient care and research: a consensus statement of the Heart Failure Society of America. J Card Fail 2010; 16: 9–16.

36. Fransen MP, von Wagner C, and Essink-Bot ML. Diabetes self-management in patients with low health literacy: ordering findings from literature in a health literacy framework. Patient Educ Couns 2012; 88: 44–53.

37. Jager M, de Zeeuw J, Tullius J, et al. Patient perspectives to inform a health literacy educational program: a systematic review and thematic synthesis of qualitative studies. Int J Environ Res Public Health 2019; 16: 4300.

38. Kadirvelu A, Sadasivan S and Ng SH. Social support in type II diabetes care: a case of too little, too late. Diabetes, Metab Syndr Obes: Targets Ther 2012; 5: 407–417.

39. Loke YK, Hinz I, Wang X, et al. Systematic review of consistency between adherence to cardiovascular or diabetes medication and health literacy in older adults. Ann Pharmacother 2012; 46: 863–872.

40. Mackey LM, Doody C, Werner EL, et al. Self-management skills in chronic disease management: what role does health literacy have? Med Decis Making 2016; 36: 741–759.

41. Marciano L, Camerini AL and Schulz PJ. The role of health literacy in diabetes knowledge, self-care, and glycemic control: A meta-analysis. J Gen Intern Med 2019; 34: 1007–1017.

42. Papadakos JK, Hasan SM, Barnsley J, et al. Health literacy and cancer self-management behaviors: a scoping review. Cancer 2018; 124: 4202–4210.

43. Rosas-Salazar C, Apter AJ, Canino G, et al. Health literacy and asthma. J Allergy Clin Immunol 2012; 129: 935–942.

44. Shahin W, Kennedy GA and Stupans I. The impact of personal and cultural beliefs on medication adherence of patients with chronic illnesses: a systematic review. Patient Prefer Adherence 2019; 13: 1019–1035.

45. Xu XY, Leung AYM and Chau PH. Health literacy, self-efficacy, and associated factors among patients with diabetes. Health Lit Res Pract 2018; 2: e67–e77.

46. Heijmans M, Lemmens LC, Otten W, et al. Zelfmanagement door mensen met chronische ziekten: kennissynthese van onderzoek en implementatie in Nederland. Utrecht: Nivel, 2015. https://nivel.nl/sites/default/files/bestanden/Kennissynthese-Zelfmanagement.pdf.

47. Bovens M, Keizer A-G and Tiemeijer W. Weten is nog geen doen: Een realistisch perspectief op redzaamheid. WRR Rapporten aan de Regering. Wetenschappelijke Raad voor het Regeringsbeleid (WRR), 2017. https://www.wrr.nl/publicaties/rapporten/2017/04/24/weten-is-nog-geen-doen.

48. Heijmans M, Uiters E, Rose T, et al. Study on sound evidence for a better understanding of health literacy in the European Union. Brussels: European Commission, 2015. https://op.europa.eu/en/publication-detail/-/publication/cbbbc08e-3a96-4575-8db1-cfe8954b2afd

49. van der Heide I, Heijmans M and Rademakers J. Health literacy policies: European perspectives. Int Handbook Health Literacy 2019; 403–418.

Chapter 4

Preferences regarding self-management intervention outcomes of Dutch chronically ill patients with limited health literacy

van der Gaag, M., Heijmans, M., Ballester, M., Orrego, C., Niño de Guzmán, E., Ninov, L., & Rademakers, J. (2022). Preferences Regarding Self-Management Intervention Outcomes of Dutch Chronically Ill Patients With Limited Health Literacy. Frontiers in Public Health, 1300.

This work was supported by COMPAR-EU, under European Union's Horizon 2020 research and innovation programme: grant agreement No 754936.

Abstract

Background

For many chronically ill patients self-management of their disease is difficult. This may be especially true for people with limited health literacy as they are faced with additional challenges in the day-to-day management of their disease. Research has shown that self-management support is most effective when tailored to the needs and preferences of patients. Therefore, this study explores the preferences regarding self-management outcomes of chronically ill patients with limited health literacy.

Methods

A total of 35 patients with limited health literacy were invited to a concept-mapping procedure consisting of two card sorting tasks. Patients ranked 60 outcomes, which are often found in literature in relation to self-management, to the level that was important for themselves. Means were calculated for each outcome and domain, and differences within the group were analysed.

Results

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, outcomes related to symptom management and improving competences to self-management scored very high. No differences between patient groups for age and sex were found.

Conclusion

Chronically ill patients with limited health literacy prefer a wide variety of outcomes for their self-management. 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.

Background

The general population is getting older and the number of patients with one or more chronic disease(s) is rising [1]. Chronic diseases are the leading cause of morbidity and mortality in Europe [2]. In managing these chronic conditions, chronically ill patients are more often expected to play an active role in their own health care. Their role has shifted from a passive recipient of care to a more active role where patients expected to self-manage their disease [3]. Also, since the last two decades in the Netherlands, a choice has been made for programmatic care for the chronically ill. There is a strong emphasis on self-management and personal responsibility of the patient and their relatives in order to relieve professional care as much as possible [4]. Self-management requires people with chronic illness to undertake a variety of activities, for example, psychologically coping with their illness in daily life, changing eating behaviours, medication adherence, and communicating with their health care providers. It is therefore not surprising that many patients find it difficult to self-manage and instead experience barriers [3, 5–7]. For these patients, self-management support may be needed.

Self-management support is defined as the systematic provision of education and supportive interventions to improve patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support [8]. During the last decades, many self-management interventions (SMIs) have been developed, aimed to equip patients (and caregivers) to actively self-manage their chronic condition(s). Previous research suggests that SMIs may be effective and lead to better patient outcomes and less health care use [9–11]. Literature also shows self-management supporting interventions are more effective when they are tailored to a patient's individual needs and preferences as there is a vast variation in the extent to which patients are able and motivated to self-manage [12–14].

For the tailoring of interventions and to match the needs and opportunities of patients as much as possible, the preferences, needs and capabilities of specific patient groups and individuals should be known. All chronically ill patients would probably benefit from tailored interventions. However, a group of patients that especially may benefit are patients with limited health literacy, who constitute a large group among the general population of patients with chronic conditions [15, 16]. In the Netherlands the group of chronically ill patients with limited health literacy is estimated to be 30% of the general population [17]. Health literacy entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgements and take decisions in everyday life concerning health care, disease prevention and health promotion, and in this way to maintain or improve quality of life during the life course [18]. Research has shown that limited health literacy levels are associated with poorer self-management skills [19], poorer health outcomes, and increased health care use [20, 21]. Patients with limited health literacy often face additional difficulties during the management of their illness, as they may lack the right knowledge and information to make decisions about their health, or the skills to get or apply that information. Also, more than other patients, patients with limited health literacy often lack self-confidence to ask questions to a caregiver, and sometimes lack motivation to live healthier [22–24].

Qualitative research, exploring patients' needs and preferences shows that a variety of outcomes are important for chronically ill patients in the context of or as a result of self-management [3, 25–28]. Often they aim for better medical management of the disease like a reduction in daily symptoms or better adherence to medical advice. However, patients also wish to make lifestyle changes, get more satisfaction from their treatment, have better interaction with their health care providers, and a better quality of life and well-being. In addition, intermediate SMI outcomes are also mentioned as important goals to strive for. These intermediate outcomes can be considered to be prerequisites for successful self-management (support) and may be related to the patient's knowledge, self-efficacy, motivation, behavioral skills or the process of care, such as a trustful relationship with health care providers or more continuity in care offered by different health care professionals.

It is important to know which outcomes are especially important for patients with limited health literacy as this insight may help to better support this vulnerable group in their self-management and may help for the future development and evaluation of self-management interventions directed to this large patient group. Evidence of effectiveness should derive from trials that assess outcomes that are important to patients. Besides, identifying important outcomes from the patient perspective, and taking these as a starting point for intervention development, contributes to uniformity and standardization of outcome reporting [29].

Since preferred outcomes with respect to self-management of patients with limited health literacy have not yet been extensively studied, the aim of this study is to explore which outcomes of self-management are most important for chronically ill patients with limited health literacy and whether these outcomes differ according to patient characteristics such as sex, comorbidity or age.

Methods

To explore which outcomes are most relevant for patients with limited health literacy in the context of or as a result of self-management, we build on experiences and results from an ongoing international study about effective Self-Management Interventions (SMIs) for patients with chronic illnesses. In this study, called COMPAR-EU [30], a general catalogue of SMI outcomes used in self-management interventions for patients with chronic diseases was developed and structured, based on an extensive literature review and expert opinions. In this catalogue, SMI outcomes are categorized in seven domains (see Box 1) [27, 28]. Each domain contains both outcomes that are generic across chronic diseases (e.g., symptom monitoring within the domain of competences and self-monitoring) and disease specific outcomes that can be added when used for a specific diseases (e.g., monitoring blood glucose in case of diabetes). Within COMPAR-EU these seven domains were specified for patients with type 2 diabetes, COPD, heart failure, and obesity. All four diseases together resulted in a catalogue including 145 different SMI outcomes, including both generic and disease-specific outcomes. This catalogue of outcomes was used as the starting point of this study. To explore which outcomes are most relevant for SMIs from the perspective of patients with limited health literacy, we used a concept-mapping approach consisting of two card sorting tasks. The preparation and execution of these tasks is described below.

Box 1

Seven domains of SMI outcomes

- Competences and self-management behaviours
- Health related aspects
- Quality of life of patients
- Caregivers' quality of life and competences
- Satisfaction with care
- Health care use
- Costs

Recruitment

Patients with limited health literacy were recruited using an advertisement distributed by local organizations such as an organization for people with reading and writing difficulties, online peer support groups for patients with diabetes and COPD, and patient organizations in the Netherlands. These organizations contacted there members via their newsletters or social media channels. The advertisement was written in simple Dutch language and invited people to participate in our study who encountered difficulties in their interaction with health care or during the daily management of their disease. Examples were given such as: problems to understand their doctor or medical information, difficulties in following medical advice, or difficulties in finding the right health care. In the advertisement some examples of possible problems were given inspired by the Single Item Literacy Screener [31] and the brief questions of Chew, which are both frequently used and validated to screen for limited health literacy [32]. Patients who felt addressed by this advertisement could sign up as a participant of this study by contacting the researchers by email or phone in February and March 2020. In addition to the experience of problems in using or finding health care, people had to be 18 years or older and reported one or more self-reported diagnoses of a chronic disease.

Outcomes Preparation

To explore which outcomes are most relevant for SMIs for patients with limited health literacy, we used the catalogue of outcomes developed in the COMPAR-EU study for four specific diseases as the starting point. The 145 different outcomes of this catalogue consisted of both generic and disease-specific outcomes. Since this current study explores self-management outcome preferences relevant for patients with limited health literacy suffering from different chronic conditions, we merged and rephrased the disease-specific outcomes in generic terms. This procedure was done independently by two researchers. For example, dietary habits comprising "minimizing water consumption" for heart failure and "adherence to dietary habits" for diabetes and COPD were merged and rephrased in one single outcome "dietary habits."

Furthermore, specific terms which slightly differed were merged. For example terms like "Weight loss," "Bodyweight," and "Stable weight" were merged to "Weight control." Outcomes as "short-term COPD symptoms" and "short term heart failure symptoms" were merged and called "short term symptoms." This process resulted in a list of 60 generic outcomes relevant in the context of chronic disease SMIs. All outcomes were translated to Dutch and formulated in plain language by MG and checked by MH. MH was also involved in the development of the catalogue of outcomes in COMPAR-EU so they knew the meaning of each outcome very well. MH is an expert in health literacy and has vast experience in writing texts for this target group or translating difficult words into plain language.

Concept Mapping

At the start of this study, which took place during the first wave of COVID-19, we planned to hold two face to face group meetings in which we wanted to explore and rank outcomes of SMIs to the extent that they are important for people with limited health literacy. Concept mapping is a frequently used method to discuss complex topics in a structured way. In general concept mapping consists of two rounds of card sorting tasks. During the first task, participants group outcomes in concepts and subsequently rate the outcomes by importance. This method has been often used to explore patient preferences and is a highly valued method to discuss complex topics in a structured way [33–36].

The intention for this study was to use a concept mapping approach consisting of the two card sorting tasks. At first, the participants received instructions to group the cards by concepts. Unfortunately, during the face-to-face sessions, it appeared that the participants were unable to perform this task. It turned out to be too complex for them to sort 60 outcomes according to the similarity of contents. Participants were unable to look at outcomes on a conceptual level and only looked at whether the outcome was relevant for them personally. Therefore, after the face-to-face sessions (n = 6), we decided to only use the prioritization card sorting task, which was easier to perform. During this card sorting task, the participants individually sorted the outcome cards based on the importance they personally attached to an outcome. During the face-to-face sessions it became clear that the participants understood the wording of the outcomes correctly. The main question during the card sorting task was: "What's most important for you? For the self-management of my disease, I would like to…" Outcomes were phrased like "to take my meds properly," or "to be satisfied with my care" or "not feel anxious." For this task, the following rules applied: all outcomes had to be placed in one of five piles, from 5 (most important) to 1 (not important at all); and outcomes had to be distributed equally across the five piles, thus requiring patients to think and set priorities about differences in importance. The card sorting task was carried out in two different ways: initially in face-to-face meetings with participants using an actual pile of cards. The face-to-face meetings took place at a location of choice of the participants and were performed by MG and MH. Later, because of the restrictions by COVID-19, the data was collected digitally using the software of Provenbyusers, which is user-friendly program (https://provenbyusers.com). In the latter, the participants got a link to the online software, where they virtually could divide the pile of cards in the appropriate categories. The participants had the option to contact MG when having difficulties with accessing the online software. For the first five online participants there was a quick telephone follow-up to make sure the card sorting task was understood correctly and to address digital difficulties. All participants filled in a short questionnaire upfront, to collect their demographics, such as: sex, age and chronic disease. The patients who participated face-to-face signed a written informed consent, and the online participants gave their consent via email. Participation was anonymous and participants had the option to withdraw from the study at any time.

For this study no ethical clearance from a recognized medical ethics review committee was necessary. According to the Medical Research Involving Human Subjects Act (WMO), this study does not influence the research participants' health care they receive.

Analyses

Means and standard deviations were calculated for each outcome separately, and for all domains, using STATA version 15.0. Results were grouped and presented per domain and by a top-15 of individual outcomes. Missing values were replaced by the mean value of the outcome. Participants who performed the card sorting task incorrectly, for example by answering almost all outcomes "important" and who did not try to equally divide the outcomes over all answering options were excluded. T-tests were used for the analysis of differences among groups defined by sex and comorbidities. Age was analysed as a continuous variable, using Pearson's correlation coefficient. Differences were considered significant with a p-value <0.05.

Results

Participant Characteristics

In total, 39 patients participated in the card sorting task, of which 35 were included in the analysis. Four participants were excluded due to incorrectly performing the card sorting task. Every participant was diagnosed with one or more chronic diseases. Twenty patients suffered from more than one chronic diseases (n = 20). The diseases reported most were COPD, asthma, diabetes and cardiovascular diseases. Mean participant age was 66 years and 54% of the participants were female. All face-to-face participants were female, but there were no significant differences in mean age or distribution of comorbidities between the online and face-to-face group. A summary of the participant characteristics is described in Table 1.

Table 1: Participant characteristics

		Participants (n=35)
Age, mean (sd), range		65.9 (10.1), [36-89]
Gender	Male, n (%)	16 (46)
	Female, n (%)	19 (54)
Mode of participation	Online, n (%)	29 (83)
	Face to face, n (%)	6 (17)
Comorbidities	No, n(%)	15 (43)
	Yes, n (%)	20 (57)

Preferences at Domain Level

An overview of all scores of the domains and items is presented in Table 2. Patients with limited health literacy rated the domain "satisfaction with care" as most important with a mean (SD) of 3.44 (0.77). This domain describes care satisfaction overall and the relationship between the health care professional and the patient, including trust, communication and getting enough information. Subsequently, "health related aspects," mean 3.25 (0.38), are also important for patients with limited health literacy. In this domain, mainly outcomes related to "seriousness of the disease" and "disease management," score high, but mortality on the contrary, rated low with a mean of 1.89 (1.11). "Symptom control" has the highest mean score with a mean of 4.23 (0.91), followed by "being in good shape." Outcomes in the domain "patients' competence in self-management behaviors" score a mean of 3.10 (0.30). The highest scoring outcome in this domain is medication adherence (mean 4.06), followed by patient activation (mean 3.80) and self-efficacy (mean 3.80). Self-management competences also include two outcomes on health literacy. “How to find health information” scores 2.8 (1.02) and “How to use health information” scores 2.63 (1.17). The mean scores of the domains did not differ significantly by mode of participation.

Table 2: Mean importance scores of the seven outcome domains and their outcomes

	Mean (sd)
Satisfaction with care	3.44 (0.77)
Health care professional trust	3.57 (1.20)
Communication with health care professionals	3.54 (1.20)
To get enough information from health care professional	3.46 (1.22)
Care satisfaction	3.20 (1.16)
Health related aspects	3.25 (0.38)
Seriousness of the disease	3.51 (0.53)
Being in good shape	4.14 (0.91)
Exercise capacity	3.77 (1.26)
Reduce the chance of developing other disease	3.34 (1.41)
General metabolic functions	2.80 (1.32)
Disease-management	3.49 (0.50)
Symptom control	4.23 (0.91)
Symptom recognition	3.74 (1.04)
Sleep quality	3.69 (1.32)
Fatigue	3.69 (1.18)
Prevent progression of symptoms	3.66 (1.43)
Maintaining healthy nutrition	3.57 (1.20)
Maintaining physical activity	3.43 (1.38)
Bloodpressure control	3.06 (1.37)
Weight management	2.94 (1.39)
Pain	2.91 (1.54)
Complications	2.21 (0.99)
Cholesterol	2.40 (1.19)
Hyperglyceamia	2.03 (1.25)
Mortality	1.89 (1.11)
Lower risk of death	1.89 (1.11)

Table 2: Continued

	Mean (sd)
Patients competence in self-management behaviors	3.10 (0.30)
Self-management competences	3.30 (0.47)
Patient activation	3.80 (1.28)
Self-efficacy	3.80 (1.18)
Participation and decision making	3.74 (1.31)
Knowing what care I am entitled to	3.09 (1.36)
Knowledge	3.00 (1.14)
To take my own decisions together with my family	2.86 (1.38)
Health literacy/ how to find health information	2.80 (1.02)
Health literacy/ how to use health information	2.63 (1.17)
Self-management/self-care behaviors	2.96 (0.41)
Medication adherence	4.06 (1.03)
Physical activity	3.74 (1.24)
Dietary habits	3.69 (1.25)
Adherence to program	3.17 (1.25)
Self-monitoring	3.14 (1.29)
Alcohol consumption	1.6 (0.85)
Smoking cessation	1.31 (0.76)
Quality of life	2.92 (0.33)
Psychological functioning	3.21 (0.63)
Positive attitude	3.97 (1.12)
Happiness	3.60 (1.31)
Coping	3.54 (1.22)
Stress	3.28 (1.41)
Participation in social activities	3.17 (1.52)
Depression	2.77 (1.52)
Hostility	2.71 (1.13)
Anxiety	2.60 (1.33)

Table 2: Continued

	Mean (sd)
Treatment burden	2.82 (2.92)
Organize my own care	3.17 (1.40)
Limit treatment side effects	2.94 (1.14)
Medication burden as a perception	2.94 (1.28)
Treatment burden in terms of time	2.23 (1.09)
Social relations and activities	2.66 (0.33)
Family relationships	3.11 (1.35)
Meeting other patients	2.20 (1.16)
Physical functioning	2.64 (0.45)
Being able to do the things I want to	3.86 (1.22)
Mobility	3.60 (1.38)
Being able to do sports	2.37 (1.29)
Being able to work	1.74 (1.09)
Sex life	1.63 (0.97)
Health care use	2.41 (0.88)
Number of visits/contacts with health care provider	2.51 (1.12)
Number of hospital admissions	2.31 (1.37)
Caregiver quality of life and competences	2.34 (0.87)
Caregiver knowledge	2.46 (1.09)
Caregiver burden	2.23 (1.42)
Health care costs	2.17 (0.98)

Preferences at Outcome Level

Table 3 presents the top-15 of highest scoring outcomes. Three outcomes have a mean importance >4, which corresponds to “very important.” “Symptom control” has the highest mean score, followed by “being in good shape,” and “medication adherence.” The table shows that outcomes that were important to chronically ill patients with limited health literacy are diverse and belong to a variety of outcome domains.

Table 3: Top-15 outcome mean scores

Outcome	Mean (sd)	Domain
Symptom control	4.23 (0.91)	Health related
Being in good shape	4.14 (0.81)	Health related
Medication adherence	4.06 (1.03)	Patients' competences
Positive attitude	3.97 (1.12)	Quality of life
Being able to do the things I want to	3.86 (1.22)	Quality of life
Self-efficacy	3.80 (1.18)	Patients' competences
Patient activation	3.80 (1.28)	Patients' competences
Exercise capacity	3.77 (1.26)	Health related
Symptom recognition	3.74 (1.04)	Health related
Participation and decision making	3.74 (1.31)	Patients' competences
Physical activity	3.74 (1.24)	Self-care behaviors
Fatigue	3.69 (1.18)	Health related
Sleep quality	3.69 (1.32)	Health related
Dietary habits	3.69 (1.25)	Self-care behaviors
Prevent progression of symptoms	3.66 (1.43)	Health related

Difference in Outcome Preferences by Background Characteristics

The mean scores of each outcome domain by sex, comorbidity, and age are presented in Table 4. Although no significant differences were found concerning sex and age, there were certain trends in the mean scores. The highest scoring domains for males are subsequently "Health related aspects" (mean 3.33), "Satisfaction with care" (mean 3.28) and "Competences and self-management behaviors" (mean 3.07). The ranking of highest scoring domains slightly differed for females, namely "Satisfaction with care" (mean 3.58), "Health related aspects" (mean 3.19) and "Competences and self-management behaviors" (mean 3.12). A Pearson's correlation was run to assess the relationship between age and the mean scores of outcome preferences. No correlation was found between age and the outcome domains. For participants with comorbidities, the mean score of "Caregivers quality of life and competences" was significantly lower compared to participants with no comorbidities.

Discussion

Until now, information about outcome preferences of patients with limited health literacy regarding SMIs was limited. This study shows that, patients with limited health literacy rated a large number of outcomes as important. These outcomes belonged to a variety of outcome domains. Consistent with the literature on chronically ill patients in general, medical outcomes like indicators of symptom control, being in good shape and medication adherence are among the outcomes that are perceived as most important by patients with limited health literacy. These outcomes are logical consequences of treatment guidelines and often the first goals of professional care in chronic conditions, such as: diabetes, cardiovascular diseases, and lung diseases. This study shows that also for patients with limited health literacy these outcomes are important. However, when asking patients what they think are important outcomes, literature shows that outcomes are often much broader. Although patients also strive for good medical outcomes and a healthy lifestyle, they also strive for a good quality of life for themselves and their network, participation in work, shared decision making, autonomy, and an active role in their own care [26, 37]. This was shown in a recent European study, COMPAR-EU [30], in which the outcome preferences of chronically ill patients with diabetes, heart failure, obesity, and COPD were studied. The catalogue of outcomes for these studies were the same as we used as a starting point for this study [27]. During a Delphi exercise (unpublished data), patients with diabetes, COPD, heart failure, or obesity also ranked the outcomes according to importance. Although the methods are not completely comparable (items were in English, not simplified, and scoring was per item on a 10-point scale), it is interesting to compare their results with the results of this study as both study results are from a patient's perspective. Our highest scoring outcomes, especially adherence and symptom control, correspond with the results of the Delphi study in COMPAR-EU. However, the domain of satisfaction with care scored solely highest in the group of patients with obesity. Patients with heart failure and COPD ranked the domain of competences in self-management the highest, and for patients with diabetes the highest domains were the health-related outcomes.

This is not different for people with limited health literacy as we noticed in this study. Besides the frequently used health related outcomes, also quality of life related outcomes, and outcomes related to the patient-professional relationship were rated as important. Overall, at domain level, the results of this study show that patients with limited health literacy rank the domain of satisfaction with their care as most important. Satisfaction with care includes having trust in on own's health care professional and good communication and information provision. Besides that, outcomes related to the patients competences were seen as essential. Having trust in one's own competences (self-efficacy) and being able to play an active role in their own treatment (patient activation) were on the highest scoring items.

It is not surprising that patients with limited health literacy highly rank communication support for their self-management, as these patients often lack these skills.

Communication skills are crucial for patients to have an active role and for shared-decision making, and to successfully deal with the daily management of a chronic disease. The same goes for self-management competences like self-efficacy and patient activation, which are prerequisites for successful self-management. However, this is often difficult for patients with limited health literacy as they lack the necessary skills for this due to limited knowledge, reading problems, or difficulties in understanding complex information. Self-management often concerns applying advices from health care professionals, independently at home. This requires knowledge and behavioral skills. As patients with limited health literacy often lack these skills, an intermediate step is required. Advices need to be understood first, as well as skills learned. This intermediate step is often automatically successful in patients having adequate health literacy, but not in patients with limited health literacy. A recent scoping review studying patient preferences of self-management, also based on qualitative studies, confirms that patients especially value the relationship with their health care professional. Empathy, emotional support, and compassionate care enhance the adherence to self-management tasks [37].

We did not find significant differences within our group of patients with limited health literacy according to sex, age, or comorbidity. This may be due to the small number of people participating and is in contrast with the findings in other studies. The results seemed to show certain trends, however these are consistent with quantitative studies: for example for participants with comorbidities the mean score of "caregivers quality of life and competences" was significantly lower, but this needs to be further explored with larger sample sizes. It is known that self-management aspects, like motivation and confidence, often differ between patient groups with different background characteristics. For example, literature has shown that men and women differ in self-confidence and motivation to self-manage, and have different preferences regarding patient-provider communication [38, 39] as women often prefer a more active role during consultation than men; the same counts for younger people compared to older [40–42]. Having comorbidities also makes optimal self-management harder to achieve. Patients with comorbidities often get various advices from different health care providers, which also can be contradictory [43–45].

Our work is subject to some limitations. The Dutch study sample may not be entirely representative for the population of patients with limited health literacy in the Netherlands. We know that about 10% of the people with limited health literacy in the Netherlands have problems with reading and some have problems with using a computer. Due to the online card sorting method, patients who lack these skills might have not signed up for this study. However, all participants applied to this study because they experienced difficulties in obtaining or understanding information or in their access to health care to some extent. The online software could also have resulted in invalid results of the card sorting task due to a lack of digital literacy skills. The software, however, was so intuitive that digital errors were unlikely. This was ensured by the telephone follow-up with the first participants. In addition, we had a rather small group of patients as this was an exploratory study and recruiting patients was challenging during the COVID-19 pandemic. It is plausible that the expected differences between patient groups were not found due to limited sample sizes or the heterogeneity of chronic illnesses of the sample. For future research, we suggest larger sample sizes and also to include patients that have difficulties in reading. This would also mean another approach, for example with face-to-face interviews, with the advantage of obtaining qualitative information on why certain outcomes are important for patients.

Implications for Policy and Practice

The most important implication for clinical practice is that since patients with limited health literacy prefer a variety of outcomes for their self-management, it is important for health care professionals to explore these preferences together with the patient in advance. In addition, patients with limited health literacy need specific attention for the prerequisites of self-management, for example knowledge, self-efficacy, and learning self-management competences, before focusing on health related outcomes. A solid relationship between the patient and the health care professional will enhance this process to successful self-management.

During the initially planned concept mapping approach, it became clear that participants were unable to think in an abstract way about the self-management concept, beyond their own experiences. The inability of patients to understand and apply abstract goals is an important implication for clinical practice. Health care professionals should tailor their communication about care and self-management to the specific individual situation of the patient to be fully understood and pay time and effort to explain how outcomes relate to each other.

Conclusion

In summary, chronically ill patients with limited health literacy prefer a wide variety of outcomes for their self-management and differ in this way not from the average patient with a chronic disease. However, patients with limited health literacy prefer more than others 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.

References

1. Anderson G. Responding to the Growing Cost and Prevalence of People With Multiple Chronic Conditions. Johns Hopkins Bloomberg School of Public health (2011).
2. Alwan A. Global Status Report on Noncommunicable Diseases 2010. World Health Organization (2011).
3. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. Patient Educ Couns. (2002) 48:177–87. doi: 10.1016/S0738-3991(02)00032-0.
4. Ministerie Van Volksgezondheid WES. Programmatische Aanpak van Chronisch Zieken. Den Haag (2008).
5. Mead H, Andres E, Ramos C, Siegel B, Regenstein M. Barriers to effective self-management in cardiac patients: the patient's experience. Patient Educ Couns. (2010) 79:69–76. doi: 10.1016/j.pec.2009.08.003.
6. Song M, Lee M, Shim B. Barriers to and facilitators of self-management adherence in Korean older adults with type 2 diabetes. Int J Older People Nurs. (2010) 5:211–18. doi: 10.1111/j.1748-3743.2009.00189.x.
7. Flynn SJ, Ameling JM, Hill-Briggs F, Wolff JL, Bone LR, Levine DM, et al. Facilitators and barriers to hypertension self-management in urban African Americans: perspectives of patients and family members. Patient Prefer Adherence. (2013) 7:741. doi: 10.2147/PPA.S46517.
8. Corrigan JM, Greiner AC, Adams K. The 1st Annual Crossing the Quality Chasm Summit: A Focus on Communities: Report of a Summit. National Academies Press (2004).
9. Newman S, Steed L, Mulligan K. Self-management interventions for chronic illness. Lancet. (2004) 364:1523–37. doi: 10.1016/S0140-6736(04)17277-2.
10. Ruiz S, Brady TJ, Glasgow RE, Birkel R, Spafford M. Chronic condition self-management surveillance: what is and what should be measured? Prev Chronic Dis. (2014) 11:e23. doi: 10.5888/pcd11.130328.
11. Cheng L, Sit JWH, Choi KC, Chair SY, Li X, He XL. Effectiveness of interactive self-management interventions in individuals with poorly controlled type 2 diabetes: a meta-analysis of randomized controlled trials. Worldviews Evid Based Nurs. (2017) 14:65–73. doi: 10.1111/wvn.12191.
12. Lustria MLA, Noar SM, Cortese J, Van Stee SK, Glueckauf RL, Lee J. A meta-analysis of web-delivered tailored health behavior change interventions. J Health Commun. (2013) 18:1039–69. doi: 10.1080/10810730.2013.768727.
13. Trappenburg J, Jonkman N, Jaarsma T, Van Os-Medendorp H, Kort H, De Wit N, et al. Self-management: one size does not fit all. Patient Educ Couns. (2013) 92:134–7. doi: 10.1016/j.pec.2013.02.009.
14. Whatnall MC, Patterson AJ, Ashton LM, Hutchesson MJ. Effectiveness of brief nutrition interventions on dietary behaviours in adults: a systematic review. Appetite. (2018) 120:335–47. doi: 10.1016/j.appet.2017.09.017.
15. Puente-Maestu L, Calle M, Rodríguez-Hermosa JL, Campuzano A, De Miguel Díez J, Álvarez-Sala JL, et al. Health literacy and health outcomes in chronic obstructive pulmonary disease. Respir Med. (2016) 115:78–82. doi: 10.1016/j.rmed.2016.04.016.
16. Abdullah A, Liew SM, Salim H, Ng CJ, Chinna K. Prevalence of limited health literacy among patients with type 2 diabetes mellitus: a systematic review. PLoS ONE. (2019) 14:e0216402. doi: 10.1371/journal.pone.0216402.
17. Sørensen K, Maindal HT, Heijmans M, Rademakers J. Work in Progress: a report on health literacy in denmark and the Netherlands. Stud Health Technol Inform. (2020) 269:202–11. doi: 10.3233/SHTI200033.
18. Sørensen K, Van Den Broucke S, Fullam J, Doyle G, Pelikan J, Slonska Z, et al. Health literacy and public health: a systematic review and integration of definitions and models. BMC Public Health. (2012) 12:80. doi: 10.1186/1471-2458-12-80.

19. Mackey LM, Doody C, Werner EL, Fullen B. Self-management skills in chronic disease management: what role does health literacy have? Med Decis Mak. (2016) 36:741–59. doi: 10.1177/0272989X16638330.

20. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K. Low health literacy and health outcomes: an updated systematic review. Ann Intern Med. (2011) 155:97–107. doi: 10.7326/0003-4819-155-2-201107190-00005.

21. Heijmans M, Uiters E, Rose T, Hofstede J, Devillé W, Van Der Heide I, et al. Study on Sound Evidence for a Better Understanding of Health Literacy in the European Union. European Commission Brussels (2015).

22. Jager M, De Zeeuw J, Tullius J, Papa R, Giammarchi C, Whittal A, et al. Patient Perspectives to inform a health literacy educational program: a systematic review and thematic synthesis of qualitative studies. Int J Environ Res Public Health. (2019) 16:4300. doi: 10.3390/ijerph16214300.

23. Mckenna VB, Sixsmith J, Barry M. Facilitators and barriers to the development of health literacy capacities over time for self-management. HLRP Health Literacy Res Pract. (2020) 4:e104–18. doi: 10.3928/24748307-20200221-01.

24. van Der Gaag M, Heijmans M, Spoiala C, Rademakers J. The importance of health literacy for self-management: a scoping review of reviews. Chronic Illn. (2021) doi: 10.1177/17423953211035472.

25. Heijmans M, Ridder DD, Bensing J. Dissimilarity in patients' and spouses' representations of chronic illness: exploration of relations to patient adaptation. Psychol Health. (1999) 14:451–66. doi: 10.1080/08870449908407340.

26. van Houtum L, Rijken M, Heijmans M, Groenewegen P. Patient-perceived self-management tasks and support needs of people with chronic illness: generic or disease specific? Ann Behav Med. (2015) 49:221–9. doi: 10.1007/s12160-014-9649-0.

27. Camus-García E, González-González AI, Heijmans M, Niño De Guzmán E, Valli C, Beltran J, et al. Self-management interventions for adults living with Chronic Obstructive Pulmonary Disease (COPD): the development of a Core Outcome Set for COMPAR-EU project. PLoS ONE. (2021) 16:e0247522. doi: 10.1371/journal.pone.0247522.

28. Orrego C, Ballester M, Heymans M, Camus E, Groene O, Niño De Guzman E, et al. Talking the same language on patient empowerment: development and content validation of a taxonomy of self-management interventions for chronic conditions. Health Expect. (2021) 24:1626–38. doi: 10.1111/hex.13303.

29. Møller MH. Patient-important outcomes and core outcome sets: increased attention needed! Br J Anaesth. (2019) 122:408–10. doi: 10.1016/j.bja.2019.02.007.

30. Ballester M, Orrego C, Heijmans M, Alonso-Coello P, Versteegh MM, Mavridis D, et al. Comparing the effectiveness and cost-effectiveness of self-management interventions in four high-priority chronic conditions in Europe (COMPAR-EU): a research protocol. BMJ Open. (2020) 10:e034680. doi: 10.1136/bmjopen-2019-034680.

31. Morris NS, Maclean CD, Chew LD, Littenberg B. The single item literacy screener: evaluation of a brief instrument to identify limited reading ability. BMC Fam Pract. (2006) 7:21. doi: 10.1186/1471-2296-7-21.

32. Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. Fam Med. (2004) 36:588–94.

33. Carpenter BD, Van Haitsma K, Ruckdeschel K, Lawton MP. The psychosocial preferences of older adults: a pilot examination of content and structure1. Gerontologist. (2000) 40:335–48. doi: 10.1093/geront/40.3.335.

34. Burke JG, O'campo P, Peak GL, Gielen AC, Mcdonnell KA, Trochim WMK. An introduction to concept mapping as a participatory public health research method. Qual Health Res. (2005) 15:1392–410. doi: 10.1177/1049732305278876.

35. Ammerlaan JW, Van Os-Medendorp H, De Boer-Nijhof N, Maat B, Scholtus L, Kruize AA, et al. Preferences and needs of patients with a rheumatic disease regarding the structure and content of online self-management support. Patient Educ Couns. (2017) 100:501–8. doi: 10.1016/j.pec.2016.10.009.

36. Kool MB, Geenen R, Egberts MR, Wanders H, Van Loey NE. Patients' perspectives on quality of life after burn. Burns. (2017) 43:747–56. doi: 10.1016/j.burns.2016.11.016.

37. de Guzmán Quispe EN, García LM, Villagrán CO, Heijmans M, Sunol R, Fraile-Navarro D, et al. The perspectives of patients with chronic diseases and their caregivers on self-management interventions: a scoping review of reviews. Patient. (2021) 14:719–40. doi: 10.1007/s40271-021-00514-2.

38. Bhaloo T, Juma M, Criscuolo-Higgins C. A solution-focused approach to understanding patient motivation in diabetes self-management: gender differences and implications for primary care. Chronic Illn. (2018) 14:243–55. doi: 10.1177/1742395317736372.

39. Dellafiore F, Arrigoni C, Pittella F, Conte G, Magon A, Caruso R. Paradox of self-care gender differences among Italian patients with chronic heart failure: findings from a real-world cross-sectional study. BMJ Open. (2018) 8:e021966. doi: 10.1136/bmjopen-2018-021966.

40. Street RL Jr, Gordon H, Ward MM, Krupat E, Kravitz RL. Patient participation in medical consultations: why some patients are more involved than others. Med Care. (2005) 43:960–69. doi: 10.1097/01.mlr.0000178172.40344.70.

41. Benbassat J, Pilpel D, Tidhar M. Patients' preferences for participation in clinical decision making: a review of published surveys. Behav Med. (1998) 24:81–88. doi: 10.1080/08964289809596384.

42. Heijmans M, Menting J, Merode TV, Boeije H. Treat Me Like a Woman: A Mixed Studies Review Into Treatement Burden to Develop Gender Sensitive Rheumatic Care. Utrecht: Nivel (2019).

43. Bayliss EA, Ellis JL, Steiner JF. Barriers to self-management and quality-of-life outcomes in seniors with multimorbidities. Ann Fam Med. (2007) 5:395–402. doi: 10.1370/afm.722.

44. Kerr EA, Heisler M, Krein SL, Kabeto M, Langa KM, Weir D, et al. Beyond comorbidity counts: how do comorbidity type and severity influence diabetes patients' treatment priorities and self-management? J Gen Intern Med. (2007) 22:1635–40. doi: 10.1007/s11606-007-0313-2.

45. Fix GM, Cohn ES, Solomon JL, Cortés DE, Mueller N, Kressin NR, et al. The role of comorbidities in patients' hypertension self-management. Chronic Illn. (2013) 10:81–92. doi: 10.1177/1742395313496591.

Chapter 5

Self-management interventions for chronically ill patients with limited health literacy: a descriptive analysis

van der Gaag, M., Heijmans, M., Valli, C., Orrego, C., Ballester, M., & Rademakers, J. (2023). Self-management interventions for chronically ill patients with limited health literacy: A descriptive analysis. Chronic Illness, 17423953231181410.

This work was supported by COMPAR-EU, under European Union's Horizon 2020 research and innovation programme: grant agreement No 754936.

Abstract

Background

To support patients with limited health literacy with the challenges they face in the day-to-day management of their disease(s), numerous self-management interventions (SMIs) have been developed. To date, it is unclear to what extent SMIs have been developed for chronically ill patients with limited health literacy. This study aims to provide a description of these SMIs, and to provide insight in their methodological components.

Methods

A secondary analysis of the COMPAR-EU database, consisting of SMIs addressing patients with type 2 diabetes, COPD, obesity and heart failure, was conducted. The database was searched for SMIs addressing health literacy, including both cognitive aspects and the capacity to act.

Results

Of the 1,681 SMIs in the COMPAR-EU database, 35 studies addressed health literacy, describing 39 SMIs. The overview yields a high variety in interventions given, with overlapping information, but also lacking of specific details.

Discussion

This descriptive analysis shows that there was a large variety in the extensiveness of the description of intervention characteristics and their justification or explanation. A focus on the broad concept of health literacy, including functional skills, cognitive skills, and the capacity to act could improve the effectiveness. This should be taken into account in the future development of SMIs.

Introduction

For patients with limited health literacy, taking decisions about their health and well-being is more difficult. Health literacy entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information. This is used to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion, and in this way to maintain or improve quality of life during one's life course [1]. Patients with limited health literacy often have difficulties finding the right information, understanding the information, and translating that information into the right action. They may lack either functional skills (reading, writing, numeracy) or more advanced interactive skills [2]. During the last decades there has been a growing interest in the concept of health literacy. A number of reviews have pointed to the importance of health literacy as a factor to maintain or improve health, including self-management [3, 4]. Self-management, defined as "what individuals, families and communities do with the intention to promote, maintain, or restore health and to cope with illness and disability", requires a number of skills. For example, following medical advice, being adherent to medication prescriptions, choosing healthier behaviours, interacting with health care professionals, and coping with the physical, psychological and social consequences of a chronic disease [5]. Patients with limited health literacy often lack the necessary skills for optimal self-management of their chronic disease(s) [6, 7]. This is reflected, for example, in the inability to understand written health information and the negative association between health literacy and medication adherence [6, 8]. However, besides these cognitive skills, behavioural aspects or the 'capacity to act' are also an important aspect of health literacy, and important for the extent to which patients are able to take an active role in the management of their health or illness. With the capacity to act, the authors refer to skills, such as goal-setting, making a plan, taking action, persevering and being able to deal with temptations and adverse events or stress. Part of these skills are determined by one's personality structure, but other aspects are learnable [9]. Patients with limited health literacy, more than other patients, often lack confidence to ask questions to healthcare professionals or lack the motivation to change their lifestyle [6, 10]. The capacity to act is generally not incorporated in definitions and measures of health literacy (which are often focused on cognitive skills), but has been captured in the concept of patient activation. For example, the Patient Activation Measure (PAM) is focused on the active role of patients and measures knowledge, skills, and self-confidence in dealing with one's health [11].

To support patients with the challenges they face in the day-to-day management of their disease, numerous self-management interventions (SMIs) have been developed. SMIs can be characterised as supportive interventions that healthcare professionals, peers or laypersons systematically provide to increase patients' skills and confidence in their ability to manage a chronic condition. SMIs aim to equip patients (and, where appropriate, informal caregivers) to actively participate in the management of their conditions. The content of interventions ranges from the provision of information to extensive programmes which promote behavioural change. SMIs have both been associated with the improvement of clinical outcomes and patient reported outcomes, such as quality of life, the reduction of HbA1c in patients with diabetes, dyspnoea in patients with chronic obstructive pulmonary disease (COPD), or mortality in patients with heart failure [12-14]. The group of chronically ill patients with limited health literacy may especially benefit from SMIs, since they often lack the needed skills and confidence [6]. Research has shown, however, that while SMIs could be important instruments to improve self-management in this patient group, most SMIs are developed for 'patients in general' and therefore not tailored to the needs and skills of people with limited health literacy [15]. The interventions are often too complex, and people with limited health literacy either do not start the intervention at all or drop out of SMI programmes. It is therefore important to develop health literacy specific interventions, that are tailored to this patient group and focus on both the cognitive aspects and the behavioural aspects.

To date, it is unclear to what extent specific SMIs have been developed for or evaluated with chronically ill patients with limited health literacy. Available information on these interventions is, so far, fragmented and an overview is lacking. Therefore, this study aims to provide a description of SMIs that are developed for or evaluated with chronically ill patients with limited health literacy living with Type 2 diabetes, COPD, obesity and heart failure, and to provide insight in their methodological components in order to provide cues for future efforts to develop SMIs that match the preferences and needs of people with limited health literacy.

Methods

COMPAR-EU

For the aim of this study, we conducted a secondary analysis of data from the international COMPAR-EU study (www.selfmanagement.eu). COMPAR-EU aimed to identify, compare, and rank the most effective and cost-effective SMIs for adults in Europe living with one of the four high-priority chronic conditions: type 2 diabetes, obesity, COPD, and heart failure [5]. For COMPAR-EU, four large systematic reviews were performed, including randomized controlled trials (RCTs) of SMIs for patients with type 2 diabetes (n=667), COPD (n=235), heart failure (n=282) and obesity (n=497). All studies were published in the period of 2000-2018. The four systematic reviews resulted in a database with 1,681 studies (all RCTs) , including details of SMIs concerning type 2 diabetes (n=667), obesity (n=497), heart failure (n=282) and COPD (n=235). The methods of the development of this database are described in five study protocols (one general and four disease specific), developed following Cochrane guidance [5, 16-19].

Within COMPAR-EU, a taxonomy was developed to identify key characteristics of SMIs and to encourage more uniformity in the reporting of SMIs, and in this way improve comparability across studies [20]. The SMI taxonomy classified 132 components into four domains: intervention characteristics, expected patient (or caregiver) self-management behaviours, type of outcomes for measuring SMIs, and target population characteristics. In addition, to further encourage uniformity of SMI in research, another part of COMPAR-

EU included the development of Core Outcome Sets (COS) to evaluate the effectiveness of SMIs. These COS are four lists of key outcomes recommended to be measured and reported for SMIs for type 2 diabetes, obesity, COPD, and heart failure, respectively [21, 22]. The taxonomy, in combination with the COS for each disease, was also used for the descriptive analysis of SMIs for patients with limited health literacy in this study.

Secondary analysis of SMIs with focus on health literacy

For the secondary analysis, the COMPAR-EU database was searched for studies including interventions that specifically targeted patients with limited health literacy or were evaluated with this patient group, as well as intervention studies that focused on health literacy outcomes. No further inclusion criteria with respect to the definition nor measurement of health literacy were defined. To also include studies that address behavioural aspects of health literacy (the 'capacity to act'), studies that focused on patient activation were also included. A database was created, including all extracted studies for the four diseases focusing either on health or patient activation. Table 1 shows both the inclusion criteria of the COMPAR-EU systematic reviews, as well as the additional criteria for the subset of SMI studies for the aim of this study.

In summary, to find SMIs addressing health literacy, the following three filters in the COMPAR-EU database were used:

- Health literacy or patient activation of the study population was described.
- Subgroups defined by health literacy or patient activation were reported.
- Outcomes for health literacy or patient activation were reported.

Table 1: Inclusion criteria

Inclusion term	Definition	Operational definition
Inclusion criteria COMPAR-EU database		
Self-management	Actions that individuals, families, and communities engage in to promote, maintain, or restore health and cope with illness and disability, with or without the support of health professionals.	We included SMIs including components described in the taxonomy.
Language		English or Spanish
Article type		Journal paper
Study type		RCT
Type of participants		Patients and/or caregivers
Age of participants		18+
Chronic disease	Diagnosed with type 2 diabetes, COPD, heart failure, obesity.	Obesity: BMI >30
Additional criteria for the subset of studies		
Health literacy (HL)	People's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion and in this way to maintain or improve quality of life during the life course.	We included SMIs that: • Measured the HL of the study population using a validated tool, and if >80% had limited HL • Provides outcomes for subgroups defined by HL or patient activation level • Aimed to improve or address HL and/or patient activation

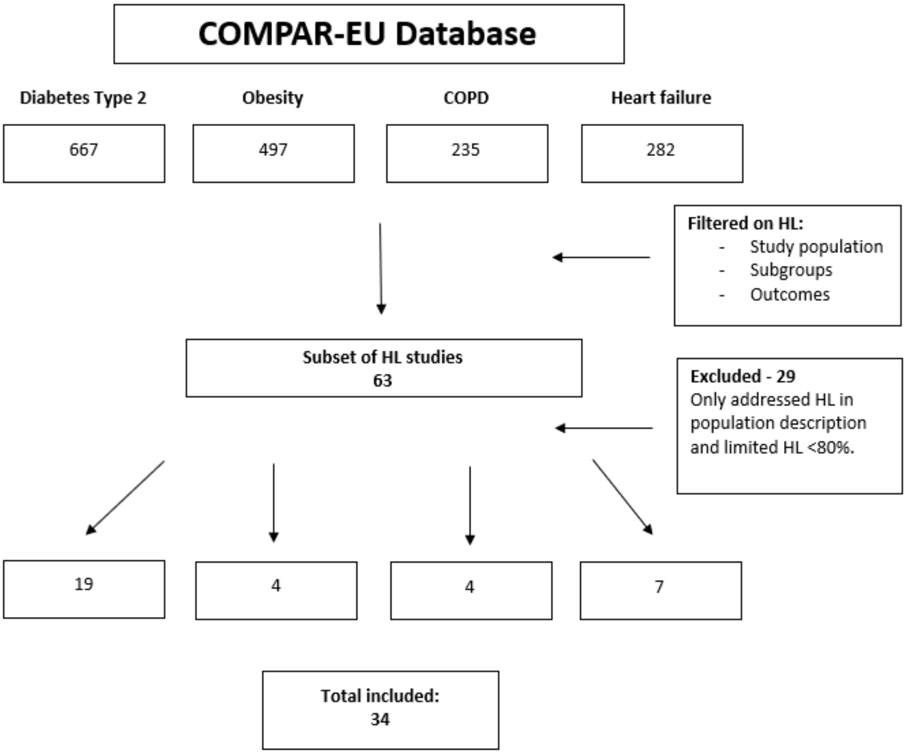
Data synthesis

The COMPAR-EU taxonomy was used to structure these descriptives. *General information* (including information on author, year, disease of interest, country of implementation, and if the intervention was tailored to address health literacy); *intervention characteristics* (including information on mode of delivery, the provider and location of the intervention); *self-management support techniques*, *measured outcomes* and the *effectiveness* of the subset of studies from the COMPAR-EU database were summarized and described by MG and validated by MH.

Results

From the total of 1,681 SMIs in the COMPAR-EU database, the used filters yielded a total of 63 studies. In the end, after excluding studies that only addressed health literacy in describing the study population and did not have >80% participants with limited health literacy, 34 studies of SMIs with a focus on health literacy fitted within the inclusion criteria [23-56]. A flowchart of the study selection process is presented in figure 1. Three studies compared three groups [23, 30, 32], and all others compared two groups [24-29, 31, 33-56]. The majority of the studies compared one SMI to usual care (n=29). The studies described a total of 39 SMIs with a focus on health literacy. Most of the SMIs are included because they are designed to address health literacy (n=22) [24, 26-28, 30-32, 39-42, 44, 45, 49-53], improve health literacy (n=18) [25, 29, 33, 36-38, 47, 48, 54-56], provide outcomes for patients with limited health literacy (n=14) [23, 26, 29, 35, 43, 46, 47, 50-52, 54], or had a study population with >80% participants with limited health literacy (n=3) [25, 30]. The included interventions varied widely in their number of participants, ranging from 20-647; one intervention had a large study population with over 8000 participants included in the intervention [38].

Figure 1: Flowchart of the study selection process



General description

Most of the interventions concerned patients with type 2 diabetes (n=23) [23-41], following heart failure (n=8) [50-56], obesity (n=4) [42-45] and COPD (n=4) [46-49]. The year of publication ranged from 2005-2018, with most of the studies published in the last five years. The 39 SMIs were conducted in 13 different countries, the vast majority in the USA (n=26). Only two interventions, coming from the same study, were implemented in multiple countries [29]. Table 2 presents an overview of general information on the interventions.

Target population

The age of the participants ranged from 24-76 years, with the oldest participants in the SMIs concerning heart failure patients and the youngest in interventions for patients with obesity. Almost all interventions recruited patients from general populations of people with type 2 diabetes, heart failure, obesity or COPD, with some exceptions: a few studied specifically included Latino's/Hispanics [25, 53], black women [43], or targeted on patients with low income [42, 50]. Three interventions, all concerning patients with obesity, only included women [42-44]. Solely one study included only participants with limited health literacy [30]. The study of Protheroe et al. aimed to include only patients with limited health literacy, but the recruitment of this patient group for the trial was highly challenging [31]. The recruitment strategy of the trial was already adapted, from written materials to personal contact with the potential participants. However, the number of patients declining to participate or the failure to make contact with these patients was quite significant.

Tailored to health literacy

Of all interventions, the vast majority (n=34) was tailored to characteristics of the participants and took health literacy (n=17) and/or patient activation (n=10) into account. Three studies adapted the intervention to the culture and language of the participants. For example, an intervention targeting Mexican Americans, which was designed to be congruent with common Mexican-American cultural preferences [34]. The participants were especially satisfied with the intervention because of the tailored content of the intervention. Other examples of tailored interventions are interventions tailored to the participants readiness status [44], to the participants activation level [25], or health literacy and numeracy status [24]. Most of the tailored interventions adapted their communication strategies and/or educational materials to be accessible for patients with limited health literacy or to improve patient activation.

Table 2: General information of the SMIs

Author	Reason for inclusion	Disease	Country	Intervention	Tailored	Effectiveness	Main HL message
Bowen-A 2016 [23]	Outcomes provided for HL subgroups.	T2DM	USA	A diabetes educator delivered self-management education and support intervention with carbohydrate gram counting.	The educational materials were numeracy and literacy sensitive (from the DLNET).	~	Patients with lower numeracy may not be as successful applying carbohydrate Counting.
Bowen-B 2016 [23]	Outcomes provided for HL subgroups.	T2DM	USA	A diabetes educator delivered self-management education and support intervention with The Modified Plate Method, which divides serving plates into sections designated for specific food types and uses cups and bowls to assist with measurement.	The educational materials were numeracy and literacy sensitive (from the DLNET).	~	All patients, regardless of numeracy skill level, may have improvements in HbA1C using the Modified Plate Method.
Cavanaugh 2009 [24]	Designed to address HL	T2DM	USA	Patients received enhanced diabetes care programs that also addressed literacy and numeracy skills. Providers received health communication training and used the interactive DLNET.	The staff used the DLNET toolkit to facilitate literacy and numeracy-sensitive diabetes education and management.	~	A literacy- and numeracy-focused diabetes care program modestly improved self-efficacy and glycemic control compared with standard enhanced diabetes care, but the difference attenuated after conclusion of the intervention.

Table 2: Continued

Author	Reason for inclusion	Disease	Country	Intervention	Tailored	Effectiveness	Main HL message
Calderon 2014 [25]	Designed to improve HL. >80% inadequate HL.	T2DM	USA	A Spanish/English animated video about diabetes to improve diabetes health literacy among Latino/Hispanics.	A culturally appropriate animated video is provided in English and Spanish to improve HL among Latino/Hispanics and African Americans.	+	The results suggest that animation has great potential for improving diabetes health literacy among Latinos having limited functional health literacy.
Graumlich 2016 [26]	Designed to address HL. Outcomes provided for HL subgroups.	T2DM	USA	A medication-planning tool (MedtableTM), implemented via an electronic medical record to improve outcomes among patients with various levels of health literacy.	The intervention was designed to address literacy-related barriers.	~	No differences in effectiveness by HL status.
Koonce 2015 [27]	Designed to address HL.	T2DM	USA	Diabetes educational materials tailored to health literacy levels and learning styles.	Diabetes educational materials are tailored to the HL levels and learning styles of the participants.	+	Diabetes knowledge increased significantly on average after exposure to educational materials targeted to health literacy levels and learning style preferences.

Table 2: Continued

Author	Reason for inclusion	Disease	Country	Intervention	Tailored	Effectiveness	Main HL message
Lee 2017 [28]	Designed to address HL.	T2DM	South-Korea	A health literacy-considered diabetes self-management program.	The intervention is a HL-considered diabetes self-management program.	+	The results indicate that the HL program improved participants' diabetes knowledge, health beliefs, self-efficacy and SM behaviour.
Muller-A 2017 [29]	Designed to improve HL outcomes. Outcomes provided for HL subgroups.	T2DM	Austria, Germany, Ireland, Taiwan, UK	A plain text web-based intervention promoting physical activity among patients with type 2 diabetes.	The intervention content is designed to be accessible for people with lower HL levels.	+	HL outcomes significantly improved in both interventions. The improvements were similar across patients with higher and lower HL levels.
Muller-B 2017 [29]	Designed to improve HL outcomes. Outcomes provided for HL subgroups.	T2DM	Austria, Germany, Ireland, Taiwan, UK	An interactive web-based intervention promoting physical activity among patients with type 2 diabetes. The interactive features of the website consisted of a quiz, a physical activity planner, and tailored advice, feedback, and images based on user responses to questions.	The intervention content is tailored to the participants sex and age and designed to be accessible for people with lower HL levels.	+	

Table 2: Continued

Author	Reason for inclusion	Disease	Country	Intervention	Tailored	Effectiveness	Main HL message
Negarandeh-A 2013 [30]	>80% inadequate HL. Designed to address HL.	T2DM	Iran	An individual educational intervention via illustrated content (pictorial image).	The intervention is designed to communicate diabetes-related health information to low literate patients.	+	Both interventions increased knowledge, medication adherence and diet among patients with low HL.
Negarandeh-B 2013 [30]	>80% inadequate HL. Designed to address HL.	T2DM	Iran	An individual educational intervention based on teach back strategy.	The educational information is tailored to the baseline understanding of the patient.	+	
Protheroe 2016 [31]	Designed to address HL.	T2DM	UK	Lay health trainer improved patient self-management in patients with limited health literacy from a socioeconomically disadvantaged population.	Participants received an information pamphlet designed for individuals with limited HL.	+	The limited HL population is hard to reach. The lay-health trainer intervention was effective.

Table 2: Continued

Author	Reason for inclusion	Disease	Country	Intervention	Tailored	Effectiveness	Main HL message
Schillinger-A-2009[32]	Designed to address HL.	T2DM	USA	Automated telephone self-management support with nurse follow-up (ATSM) uses technology to provide surveillance, education and patient activation.	The SMS models were delivered in English, Spanish and Cantonese and were literacy-sensitive.	+	Both interventions were effective in a population with a range of literacy skills.
Schillinger-B 2009[32]	Designed to address HL.	T2DM	USA	SMS strategy in combination with group medical visits (GMV) uses a group process to provide support, education and patient activation.	The SMS models were delivered in English, Spanish and Cantonese and were literacy-sensitive.	+	
Sugita 2017[33]	Designed to improve HL.	T2DM	Japan	A text message-based health literacy intervention to promote medication adherence.	Participants received HL-related text messages.	-	The results suggest that the intervention did not improve medication adherence. Functional HL scores were likely to increase, but no other HL scores showed a tendency to increase and stayed at near-constant levels.

Table 2: Continued

Author	Reason for inclusion	Disease	Country	Intervention	Tailored	Effectiveness	Main HL message
Garcia 2015 [34]	Designed to improve HL.	T2DM	USA	A home-based diabetes symptom self-management education intervention for Mexican Americans.	The intervention components were designed to be congruent with common Mexican American cultural preferences. The intervention is offered in both English and Spanish.	+	The participants significantly improved in diabetes literacy.
Rothman 2005 [35]	Outcomes provided for HL subgroups.	T2DM	USA	A primary care-based disease management program.	All communication was individualized and delivered to enhance comprehension among patients with low HL.	+	Among patients with low HL, the intervention was effective. The results show that literacy may be an important factor for predicting who will benefit from an intervention.
Drake 2018 [36]	Designed to improve HL (patient activation).	T2DM	USA	A personalized health planning (PHP) intervention within shared medical appointments (SMAs).	The intervention was designed to improve patient activation.	+	The intervention improved patient activation.

Table 2: Continued

Author	Reason for inclusion	Disease	Country	Intervention	Tailored	Effectiveness	Main HL message
Lorig 2009 [37]	Designed to improve HL (patient activation).	T2DM	USA	A community-based, peer led diabetes self-management program.	-	+	The intervention improved patient activation.
Gillani 2015 [38]	Designed to improve HL (patient activation).	T2DM	UK	The WICKED project: A structured information booklet to promote patient activation.	The intervention was designed to improve patient activation.	+	The intervention can positively influence the level of patient activation, promote better engagement and open the potential to improve other crucial diabetes outcomes.
Thoolen 2009 [39]	Designed to address HL (patient activation).	T2DM	NL	A brief self-management intervention to support patients recently diagnosed with type-2 diabetes, based on proactive coping.	The intervention is based on proactive coping.	+	The intervention was effective in improving proximal outcomes and behaviour.

Table 2: Continued

Author	Reason for inclusion	Disease	Country	Intervention	Tailored	Effectiveness	Main HL message
Williams 2005 [40]	Designed to address HL (patient activation).	T2DM	USA	An activation intervention designed to encourage patients to become more involved in the management of their diabetes, and specifically, to help them generate and ask 3 to 5 care-related questions.	The activation intervention was designed to become more involved in the management of their diabetes, specifically to help participants to generate care-related questions.	~	The intervention increased patient activation, but the intervention had no effect on HbA1c.
Wolever 2010 [41]	Designed to address HL (patient activation).	T2DM	USA	An integrative health coaching intervention by telephone.	The intervention was designed to improve patient activation.	+	The intervention increased patient activation.

Table 2: Continued

Author	Reason for inclusion	Disease	Country	Intervention	Tailored	Effectiveness	Main HL message
Herring 2014 [42]	Designed to address HL.	Obesity	USA	A novel technology-based behavioral weight control program (using text messaging, Facebook, and telephonic counseling sessions with a health coach) to promote postpartum weight loss among predominately obese, socioeconomically disadvantaged, ethnic minority women.	The intervention included HL sensitive communication.	+	The participants of the intervention had significantly greater weight loss than usual care.
Steinberg 2014 [43]	Outcomes provided for HL subgroups.	Obesity	USA	The Shape Program: A behavioral treatment for weight gain prevention among black women in primary care practice.	-	+	Low HL did not serve as a barrier to the successful prevention of weight through the Shape Program intervention.
Karintrakul 2017 [44]	Designed to address HL (patient activation).	Obesity	Thailand	An individualized nutrition counseling program matched with a transtheoretical model for overweight and obese females in Thailand.	The program comprised individualized counseling matched with the subjects' activation level.	+	The intervention increased HL (patient activation).

Table 2: Continued

Author	Reason for inclusion	Disease	Country	Intervention	Tailored	Effectiveness	Main HL message
Oddone 2018 [45]	Designed to address HL (patient activation).	Obesity	USA	A coaching by telephone intervention on engaging patients to address modifiable cardiovascular risk factors.	The intervention was designed to improve patient activation.	+	The intervention increased patient activation.
Haesum-2017 [46]	Outcomes provided for HL subgroups.	COPD	Denmark	An educational telehomecare intervention; The Telekit.	-	~	The functional HL was increased in both the intervention and control group.
Kiser 2012 [47]	Designed to improve HL outcomes. Outcomes provided for HL subgroups.	COPD	USA	A randomized controlled trial of a literacy-sensitive self-management intervention for chronic obstructive pulmonary disease patients.	The intervention included a one-on-one education session which utilized a literacy-sensitive handout.	+	The literacy sensitive SM intervention can lead to improvements in inhaler technique, for patients with both lower and higher HL.
Collinsworth 2018 [48]	Designed to improve HL (patient activation).	COPD	USA	A pragmatic COPD Chronic Care education program led by registered respiratory therapists.	-	-	Patients.experienced improvements in patient activation in both the intervention as the usual care group
Titova 2017 [49]	Designed to address HL (patient activation).	COPD	Norway	The COPD-Home integrated disease management intervention.	-	-	The intervention increased patient activation.

Table 2: Continued

Author	Reason for inclusion	Disease	Country	Intervention	Tailored	Effectiveness	Main HL message
Morrow 2007 [50]	Designed to address HL. Outcomes provided for HL subgroups.	HF	USA	Pharmacist intervention to improve medication adherence in heart failure patients.	Written and verbal instructions were aimed at patients with low HL.	~	The results of this study show that HL level was an independent predictor of drug adherence.
Dewalt 2006 [52]	Designed to address HL. Outcomes provided for HL subgroups.	HF	USA	A disease management program for low literacy patients with heart failure.	An educational booklet was developed for low literacy patients.	+	Patients in the intervention group (vs usual care) had a lower rate of hospitalization or death. The difference was larger for patients with low HL.
Dewalt Darren-A 2012 [51]	Designed to address HL. Outcomes provided for HL subgroups.	HF	USA	A single-session literacy-sensitive self-care intervention for patients with heart failure.	The intervention was literacy-sensitive.	+	An intensive multisession intervention did not change the clinical outcomes compared with a single-session intervention. However, people with low HL appear to benefit more from the multisession intervention.
Dewalt Darren-B 2012 [51]	Designed to address HL. Outcomes provided for HL subgroups.	HF	USA	A multi-session literacy-sensitive self-care intervention for patients with heart failure.	The intervention was literacy-sensitive.	+	
Howie-Esquivel 2014 [53]	Designed to address HL.	HF	USA	A culturally appropriate educational self-care intervention.	The intervention was culturally appropriate and education was provided in Spanish.	+	The intervention was an effective method to improve self-care and HF literacy among Spanish-speaking HF patients.

Table 2: Continued

Author	Reason for inclusion	Disease	Country	Intervention	Tailored	Effectiveness	Main HL message
Shively 2013 [54]	Designed to improve HL (patient activation). Outcomes provided for HL subgroups.	HF	USA	Heart Pact: A patient activation intervention.	The intervention used activation theory and was tailored to each participants' activation level.	+	The intervention increased patient activation.
Young 2017 [55]	Designed to improve HL (patient activation).	HF	USA	The PATCH RCT: A home-based activation intervention delivered by telephone on self-management adherence and readmission in rural heart failure patients.	The self-management and coaching program was tailored on subjects' activation levels.	~	Significantly higher patient-reported self-management adherence was not accompanied by lower clinical biomarkers or readmission rates.
Shearer 2007 [56]	Designed to improve HL (patient activation).	HF	USA	A telephone delivered empowerment intervention.	The intervention was designed to improve patient activation.	-	No differences in patient activation was noted between the groups.

Abbreviations: HL: Health literacy, HF: Heart failure, COPD: Chronic obstructive pulmonary disease, DLNET: Diabetes Literacy and Numeracy Education Toolkit, USA: United States of America, UK: United Kingdom, NL: Netherlands

Intervention characteristics

Table 3 shows a summary of the characteristics of the SMIs. Most of the interventions are delivered face-to-face (n=27), and the others remote (n=12), for example via internet or by phone. Almost all interventions are performed in groups (n=32). The advantage of group sessions is, for example, that besides health information and discussion of self-management activities, patients are able to share their emotions, beliefs and experiences and get stimulated [39]. The accountability and social support of the groups are key advantages for patients [36].

Nurses are the most common providers (n=13), followed by educators (n=9). The studies mainly reported that providers are trained (n=29). The details of the training are described in varying degrees, from solely trained to more specific information, for example health communication training [24] or the fact that the pharmacist was experienced in communication with patients with limited health literacy [35].

A coaching intervention for patients with diabetes puts emphasis on the role of the provider. The experienced coached gained specific coaching skills, to facilitate behaviour change, adapted to the needs and pace of the patient [41]. Another example is an intervention, which was a diabetes self-management program led by peers from the same community as the participants. They received four days of training and feedback from experienced healthcare providers [37]. For the satisfaction of the intervention, Garcia et al. found that the experience of the nurse, which was expressed through their non-judgemental approach and the flexibility, was key for the participants [34].

The location of the intervention was mostly outpatient care (n=18) or home care (n=10). Little detail was given about the location of the interventions in the context of accessibility, except for interventions in the community setting [28, 31, 37]. For one intervention for patients with heart failure, the location was dependent on the preferences of the participant [53].

Self-management support techniques and outcomes measured

An overview of the used self-management support techniques, and the combination of support techniques, is provided in table 4. Sharing information and goal-setting are the techniques mostly used. Shared-decision making and emotional support are seldom used. Some of the support techniques are often used in combination with other techniques, for example sharing information and goal-setting, goal-setting and self-monitoring, and sharing information and self-monitoring. Table 4 also shows which outcomes are measured for each intervention. Four interventions measured health literacy as an outcome, and patient activation was measured as an outcome in 12 interventions.

Table 3: Intervention characteristics

Location	**N (N=39 interventions)**
Outpatient care	18
Homecare	10
Virtual	8
Primary care	5
Community care	3
Hospital	2
Unclear	1
Recipient	
Individual	2
Group	32
Individual + Group	5
Provider	
Nurse	13
Educator	9
Service	6
Pharmacist	5
Physician	5
Other	5
Nutritionist	4
Unclear	3
Lay person	1
Healthcare assistant	1
Peers	1
Social worker	1
Psychologist	1
Mode of delivery	
Face to face	27
Remote	12
Tailored	
Yes	34
No	5

Table 4: Self-management techniques and outcomes of the SMIs

Author	Disease	Self-management techniques	Outcomes
Bowen-A-2016	T2DM	Sharing information; Goal setting	HbA1c; Experience of care; Self-management; Weight
Bowen-B-2016	T2DM	Sharing information; Goal setting; Coaching; Provision of equipment	HbA1c; Experience of care; Self-management; Weight
Cavanaugh -2009	T2DM	Sharing information; Self-monitoring; Skills training	HbA1c
Calderon-2014	T2DM	Sharing information	HL
Graumlich-2016	T2DM	Sharing information; Goal setting; Self-monitoring; Skills training; Shared decision making;	HbA1c; Experience of care; Knowledge; Adherence;
Koonce-2015	T2DM	Sharing information	Knowledge;
Lee-2017	T2DM	Sharing information; Goal setting; Self-monitoring; Skills training; Provision of equipment	HbA1c; Self-management; Knowledge; Self-efficacy; BP; PA; Dietary habits; Lipid profile; Self-monitoring
Muller-A-2017	T2DM	Sharing information	Experience of care; Knowledge; Dietary habits
Muller-B-2017	T2DM	Sharing information	Experience of care; Knowledge; Dietary habits
Negarandeh-A-2013	T2DM	Sharing information	Knowledge; Adherence
Negarandeh-B-2013	T2DM	Sharing information; Problem solving; Emotional management;	Knowledge; Adherence
Protheroe-2016	T2DM	Sharing information; Goal setting; Coaching; Skills training	Self-management; QoL; (un)scheduled care
Schillinger-A-2009	T2DM	Sharing information; Goal setting; Self-monitoring; Encourage service use;	HbA1c; Experience of care; Self-management; Weight; Self-efficacy; BP; QoL; PA

Table 4: Continued

Author	Disease	Self-management techniques	Outcomes
Schillinger-B-2009	T2DM	Sharing information; Goal setting; Problem solving; Emotional management; Social support;	HbA1c; Experience of care; Self-management; Weight; Self-efficacy; BP; QoL; PA
Sugita-2017	T2DM	Sharing information; Prompts and reminders; Encourage service use;	HbA1c; Self-efficacy; Adherence; HL
Garcia-2015	T2DM	Sharing information; Goal setting; Self-monitoring; Coaching; Skills training; Provision of equipment; Problem solving; Emotional management; Social support;	HbA1c; Self-management; BP; Lipid profile; HL
Rothman-2005	T2DM	Sharing information; Goal setting; Self-monitoring; Skills training; Prompts and reminders; Encourage service use;	HbA1c; Experience of care; Knowledge; Weight; BP; Lipid profile; (un)scheduled care; Hyper/hypoglycemia
Drake-2018	T2DM	Sharing information; Goal setting; Self-monitoring	HbA1c; Experience of care; Weight; Self-efficacy; BP; QoL; Patient activation; Lipid profile
Lorig-2009	T2DM	Sharing information; Goal setting; Skills training; Problem solving;	HbA1c; Weight; Patient activation; PA; (un)scheduled care; Hyper/hypoglycemia
Gillani-2015	T2DM	Sharing information	Patient activation
Thoolen-2009	T2DM	Sharing information; Goal setting; Self-Monitoring; Coaching; Problem solving; Emotional management;	Self-management; Weight; Self-efficacy; Patient activation; Adherence; PA; Dietary habits
Williams-2005	T2DM	Coaching;	Patient activation
Wolever-2010	T2DM	Sharing information; Goal setting; Coaching;	HbA1c; QoL; Patient activation; Adherence

Table 4: Continued

Author	**Disease**	**Self-management techniques**	**Outcomes**
Herring-2014	Obesity	Sharing information; Goal setting; Self-monitoring; Skills training; Provision of equipment; Problem solving; Prompts and reminders; Social support;	Weight
Steinberg-2014	Obesity	Sharing information; Goal setting; Self-monitoring; Coaching; Skills training; Problem solving; Encourage service use;	Weight; Mortality; QoL
Karintrakul-2017	Obesity	Sharing information; Goal setting; Self-monitoring; Coaching; Problem solving	Weight; Patient activation; PA; Dietary habits
Oddone-2018	Obesity	Sharing information; Goal setting; Coaching;	Patient Activation
Haesum-2017	COPD	Sharing information; Self-monitoring; Provision of equipment	Emergency visits and admissions; QoL
Kiser-2012	COPD	Sharing information; Skills training	Knowledge
Collinsworth-2018	COPD	Sharing information; Goal setting; Coaching; Emotional management;	Emergency visits and admissions; QoL
Titova-2017	COPD	Sharing information; Goal setting; Self-monitoring; Coaching; Skills training; Encourage service use;	Emergency visits and admissions; QoL; Coping; Patient activation
Morrow-2007	HF	Sharing information	Hospital admissions; QoL; Adherence
Dewalt-2006	HF	Sharing information; Goal setting; Self-monitoring; Coaching; Provision of equipment	Hospital admissions; Mortality
Dewalt Darren-A-2012	HF	Sharing information; Goal setting; Provision of equipment	Hospital admissions; Mortality

Table 4: Continued

Author	Disease	Self-management techniques	Outcomes
Dewalt Darren-B-2012	HF	Sharing information; Goal setting; Self-monitoring; Coaching; Provision of equipment	Hospital admissions; Mortality
Howie-Esquivel-2014	HF	Sharing information; Goal setting; Self-monitoring; Skills training; Provision of equipment; Problem solving; Prompts and reminders; Social support;	Self-efficacy; HL
Shively-2013	HF	Sharing information; Goal setting; Self-monitoring; Coaching; Provision of equipment; Problem solving	Hospital admissions; Patient activation
Young-2017	HF	Sharing information; Goal setting; Self-monitoring; Coaching; Provision of equipment; Prompts and reminders;	Hospital admissions; Self-efficacy; Patient activation; PA; Self-monitoring
Shearer-2007	HF	Sharing information; Goal setting; Self-monitoring; Coaching;	Self-efficacy; Patient activation; QoL
Abbreviations: HL: Health literacy, HF: Heart failure, COPD: Chronic obstructive pulmonary disease, BP: Blood pressure, PA: Physical activity, QoL: Quality of Life			

Effectiveness of the SMIs

Of the 39 interventions, 27 were reported as being effective by the authors [25, 27-32, 34-39, 41-45, 47, 51-54], 4 as not effective [33, 48, 49, 56] and the results of 8 interventions were inconclusive or partially effective [23, 24, 26, 40, 46, 50, 55]. Some of the studies explicitly investigated the role of health literacy for the effectiveness of the interventions. The study of Steinberg et al. concluded that limited health literacy was not a barrier to the successful prevention of weight gain trough the effective Shape Program intervention [43]. The same counts for a literacy-sensitive intervention, which was designed for patients with limited health literacy, but included patients with all literacy levels. Patients with limited literacy benefited as much from the intervention as the patients with higher literacy [52]. On the other hand, a comprehensive diabetes disease management plan benefited patients with limited literacy to a greater degree than it did patients with higher literacy [35].

Few studies measured the effect of health literacy as an outcome. A tele-homecare intervention for patients with COPD has no effect on functional health literacy. The authors suggested that further research is needed to explore if digital literacy or resistance to technology might influence the effectiveness [46]. However, using animations or health literacy-sensitive text messages during the intervention might be promising in improving functional health literacy [25, 33]. Disease-specific health literacy also improved by adapting the intervention language [34, 53].

Specific techniques were mentioned to increase the success of SMIs. Tailoring of communication strategies to the participants' health literacy, specifically decreasing the complexity of information and concrete examples, may help overcome barriers to successfully implementing the intervention. Using simple strategies, for example "the teach back method", to ensure that patients have learned what is taught can have a great influence on maintaining outcomes [30, 35].

Discussion

This study aimed to provide a description of the available SMIs that are developed for or evaluated with chronically ill patients with limited health literacy, and to provide insight in their methodological components. A total of 39 interventions with a focus on health literacy were derived from the COMPAR-EU database. The overview yields a high variety in interventions given, with overlapping information, but also lacking of specific details.

Only a few of the interventions solely included patients with limited health literacy, or aimed to include this patient group. It appears that the recruitment of patients with limited health literacy is more challenging than recruiting patients who are more health literate and asks for extra effort. It is possible though, for example by using recruitment strategies that keep written information to a minimum and tailored to participants with limited health literacy[31,57]. It requires high flexibility from researchers, for example using personal contact by someone known to the potential participant [31,58]. However, some of the interventions targeted this patient group by recruiting for example patients low-income or ethnic minorities from which it is known that many suffer from limited health literacy [59,60].

A large variety of sample sizes was found in the included interventions. The advantages of a large sample size are that it allows a more precise estimate of the treatment effect and it usually is easier to assess the representativeness of the sample and to generalize the results. Given the small sample sizes of some of the studies found, the difficulty in recruitment and the heterogeneity across samples we should be cautious to generalize the findings to other groups. Larger samples are needed to draw more firm conclusions.

However, the strategy of developing interventions that are accessible for patients with all levels of health literacy appears promising. Most of the studies took the health literacy levels of their participants into account, mainly by adapting their intervention materials or their communication strategies to the health literacy levels of their patients. These adaptations were appreciated and, for example, by patients with limited health literacy and participants with limited health literacy were more likely to recommend the intervention to others [29]. This strategy, called organizational health literacy, corresponds with global health literacy policies to strengthen health literacy-friendly settings, especially in healthcare settings, instead of increasing the patients' health literacy levels [58,61]. This is depending on the organization-wide effort to make it easier for patients to navigate, understand and use information and services to take care of their health.

Functional health literacy was the measure of effectiveness in four of the interventions, and patient activation was measured and improved in twelve of the interventions. Overall, the goal of SMIs for patients with limited health literacy appears not to improve functional health literacy, but it underlines the importance of the capacity to act, measured as patient activation. The effectiveness of the interventions shows that focussing on the capacity to act is promising. However, none of the interventions measured both health literacy and patient activation. For future development of interventions, tailoring to the broad concept of health literacy, including functional skills, cognitive skills, and the capacity to act could improve the effectiveness of interventions.

There was a large variety in the extensiveness of the description of intervention characteristics and their justification or explanation. The reasons for choosing a specific location for the intervention or a specific provider are almost never explained. Since travelling can be a possible barrier, the location can have a great effect on the engagement of participants. Intervention providers were often described in general, for example as certified nurses or dieticians. More extensive descriptions were mostly about the training of the providers and whether the training was communication-based or intervention-specific.

This current overview is subject to some limitations. The majority of the interventions are developed in the USA, but there is a growing interest in interventions addressing health literacy in Europe [3]. Secondly, the data for this overview of interventions is derived from the COMPAR-EU database, which is updated until 2018. In all probability, more recent interventions are developed. Besides, the database consists of studies describing RCTs. For further research, qualitative studies describing intervention characteristics could gain more insights. On the other hand, the COMPAR-EU database is a strength of this study, because it consists of an abundance of RCTs and contains a vast amount of details about these studies. Another strength of this study is that a broad definition of health literacy was used, including the capacity to act, measured as patient activation. This overview shows the effectiveness and importance of patient activation for self-management. This corresponds to previous research showing that the capacity to act is critical for the readiness to self-management [9].

References

1. Sørensen K, Van den Broucke S, Fullam J, et al. Health literacy and public health: a systematic review and integration of definitions and models. BMC public health 2012; 12: 80. 2012/01/27. DOI: 10.1186/1471-2458-12-80.
2. Nutbeam D. Defining, measuring and improving health literacy. 総合健診 2015; 42: 450-456.
3. Visscher BB, Steunenberg B, Heijmans M, et al. Evidence on the effectiveness of health literacy interventions in the EU: a systematic review. BMC public health 2018; 18: 1414. 2018/12/31. DOI: 10.1186/s12889-018-6331-7.
4. Berkman ND, Sheridan SL, Donahue KE, et al. Low health literacy and health outcomes: an updated systematic review. Annals of internal medicine 2011; 155: 97-107.
5. Ballester M, Orrego C, Heijmans M, et al. Comparing the effectiveness and cost-effectiveness of self-management interventions in four high-priority chronic conditions in Europe (COMPAR-EU): a research protocol. BMJ open 2020; 10: e034680. 2020/01/22. DOI: 10.1136/bmjopen-2019-034680.
6. van der Gaag M, Heijmans M, Spoiala C, et al. The importance of health literacy for self-management: A scoping review of reviews. Chronic Illness 2021: 17423953211035472. DOI: 10.1177/17423953211035472.
7. van der Heide I, Heijmans M and Rademakers J. Health literacy policies: European perspectives. INTERNATIONAL HANDBOOK OF HEALTH LITERACY. 2019, pp.403.
8. Mackey LM, Doody C, Werner EL, et al. Self-Management Skills in Chronic Disease Management: What Role Does Health Literacy Have? Medical Decision Making 2016; 36: 741-759. 2016/04/08. DOI: 10.1177/0272989X16638330.
9. Rademakers J and Heijmans M. Beyond Reading and Understanding: Health Literacy as the Capacity to Act. International journal of environmental research and public health 2018; 15: 1676.
10. Jager M, de Zeeuw J, Tullius J, et al. Patient Perspectives to Inform a Health Literacy Educational Program: A Systematic Review and Thematic Synthesis of Qualitative Studies. Int J Environ Res Public Health 2019; 16 2019/11/07. DOI: 10.3390/ijerph16214300.
11. Hibbard JH, Stockard J, Mahoney ER, et al. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health services research 2004; 39: 1005-1026.
12. Umpierre D, Ribeiro PA, Kramer CK, et al. Physical activity advice only or structured exercise training and association with HbA1c levels in type 2 diabetes: a systematic review and meta-analysis. Jama 2011; 305: 1790-1799.
13. McLean S, Nurmatov U, Liu JL, et al. Telehealthcare for chronic obstructive pulmonary disease. Cochrane Database of Systematic Reviews 2011.
14. Inglis SC, Clark RA, Dierckx R, et al. Structured telephone support or non-invasive telemonitoring for patients with heart failure. Cochrane Database of Systematic Reviews 2015.
15. Bos-Touwen I, Jonkman N, Westland H, et al. Tailoring of self-management interventions in patients with heart failure. Curr Heart Fail Rep 2015; 12: 223-235. DOI: 10.1007/s11897-015-0259-3.
16. A. VA. Comparative effectiveness of self-management interventions for type 2 diabetes: a protocol for a systematic review and network meta-analysis. . OSF 2019. DOI: https://doi.org/10.17605/OSF.IO/65ZGR.
17. Beltran J, Alonso-Coello P, Canelo-Aybar C, et al. Comparative effectiveness of self-management interventions for Chronic Obstructive Pulmonary Disease (COPD): a systematic review and network meta-analysis. PROSPERO 2020. DOI: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020177238.

18. Heijmans M, Orrego C, Ballester M, et al. Comparative effectiveness of self-management interventions for health failure: a systematic review and network meta-analysis. PROSPERO 2020. DOI: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020167916.

19. Orrego C, Ballester M, Heijmans M, et al. Comparative effectiveness of self-management interventions for obesity: a systematic review and network meta-analysis. PROSPERO 2020. DOI: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020155441.

20. Orrego C, Ballester M, Heijmans M, et al. Talking the same language on patient empowerment: development and content validation of a taxonomy of self-management interventions for chronic conditions (in press). Health Expect 2021.

21. Camus-García E, González-González AI, Heijmans M, et al. Self-management interventions for adults living with Chronic Obstructive Pulmonary Disease (COPD): The development of a Core Outcome Set for COMPAR-EU project. PloS one 2021; 16: e0247522. 2021/03/02. DOI: 10.1371/journal.pone.0247522.

22. Valli C, Suñol R, Orrego C, et al. The development of a Core Outcome Set for self-management interventions for patients living with obesity (submitted). 2021.

23. Bowen ME, Cavanaugh KL, Wolff K, et al. The diabetes nutrition education study randomized controlled trial: A comparative effectiveness study of approaches to nutrition in diabetes self-management education. Patient Educ Couns 2016; 99: 1368-1376. DOI: 10.1016/j.pec.2016.03.017.

24. Cavanaugh K, Wallston KA, Gebretsadik T, et al. Addressing literacy and numeracy to improve diabetes care: Two randomized controlled trials. Diabetes Care 2009; 32: 2149-2155. DOI: 10.2337/dc09-0563.

25. Calderon JL, Shaheen M, Hays RD, et al. Improving Diabetes Health Literacy by Animation. Diabetes Educ 2014; 40: 361-372. DOI: 10.1177/0145721714527518.

26. Graumlich JF, Wang H, Madison A, et al. Effects of a Patient-Provider, Collaborative, Medication-Planning Tool: A Randomized, Controlled Trial. J Diabetes Res 2016; 2016: 2129838. DOI: 10.1155/2016/2129838.

27. Koonce TY, Giuse NB, Kusnoor SV, et al. A personalized approach to deliver health care information to diabetic patients in community care clinics. J Med Libr Assoc 2015; 103: 123-130. DOI: 10.3163/1536-5050.103.3.004.

28. Lee SJ, Song M and Im EO. Effect of a Health Literacy-Considered Diabetes Self-Management Program for Older Adults in South Korea. Res Gerontol Nurs 2017; 10: 215-225. DOI: 10.3928/19404921-20170831-03.

29. Muller I, Rowsell A, Stuart B, et al. Effects on Engagement and Health Literacy Outcomes of Web-Based Materials Promoting Physical Activity in People With Diabetes: An International Randomized Trial. J Med Internet Res 2017; 19: e21. DOI: 10.2196/jmir.6601.

30. Negarandeh R, Mahmoodi H, Noktehdan H, et al. Teach back and pictorial image educational strategies on knowledge about diabetes and medication/dietary adherence among low health literate patients with type 2 diabetes. Primary care diabetes 2013; 7: 111-118. DOI: 10.1016/j.pcd.2012.11.001.

31. Protheroe J, Rathod T, Bartlam B, et al. The Feasibility of Health Trainer Improved Patient Self-Management in Patients with Low Health Literacy and Poorly Controlled Diabetes: A Pilot Randomised Controlled Trial. J Diabetes Res 2016; 2016: 6903245. DOI: 10.1155/2016/6903245.

32. Schillinger D, Handley M, Wang F, et al. Effects of self-management support on structure, process, and outcomes among vulnerable patients with diabetes: a three-arm practical clinical trial. Diabetes Care 2009; 32: 559-566. DOI: 10.2337/dc08-0787.

33. Sugita H, Shinohara R, Yokomichi H, et al. Effect of text messages to improve health literacy on medication adherence in patients with type 2 diabetes mellitus: A randomized controlled pilot trial. Nagoya J Med Sci 2017; 79: 313-321. DOI: 10.18999/nagjms.79.3.313.

34. Garcia AA, Brown SA, Horner SD, et al. Home-based diabetes symptom self-management education for Mexican Americans with type 2 diabetes. Health Educ Res 2015; 30: 484-496. DOI: 10.1093/her/cyv018.

35. Rothman RL, DeWalt DA, Malone R, et al. Influence of patient literacy on the effectiveness of a primary care-based diabetes disease management program. JAMA : the journal of the American Medical Association 2004; 292: 1711-1716. DOI: 10.1001/jama.292.14.1711.

36. Drake C, Meade C, Hull SK, et al. Integration of Personalized Health Planning and Shared Medical Appointments for Patients with Type 2 Diabetes Mellitus. South Med J 2018; 111: 674-682. DOI: 10.14423/smj.0000000000000892.

37. Lorig K, Ritter PL, Villa FJ, et al. Community-based peer-led diabetes self-management: a randomized trial. The Diabetes educator 2009; 35: 641-651. DOI: 10.1177/0145721709335006.

38. Gillani SM, Nevill A and Singh BM. Provision of structured diabetes information encourages activation amongst people with diabetes as measured by diabetes care process attainment: the WICKED Project. Diabet Med 2015; 32: 865-871. DOI: 10.1111/dme.12737.

39. Thoolen BJ, de Ridder D, Bensing J, et al. Beyond good intentions: The role of proactive coping in achieving sustained behavioural change in the context of diabetes management. Psychology & health 2009; 24: 237-254. DOI: 10.1080/08870440701864504.

40. Williams GC, McGregor H, Zeldman A, et al. Promoting glycemic control through diabetes self-management: evaluating a patient activation intervention. Patient Education and Counseling 2005; 56: 28-34.

41. Wolever RQ, Dreusicke M, Fikkan J, et al. Integrative health coaching for patients with type 2 diabetes: a randomized clinical trial. The Diabetes educator 2010; 36: 629-639. DOI: 10.1177/0145721710371523.

42. Herring SJ, Cruice JF, Bennett GG, et al. Using Technology to Promote Postpartum Weight Loss in Urban, Low-Income Mothers: A Pilot Randomized Controlled Trial. Journal of Nutrition Education and Behavior 2014; 46: 610-615. DOI: 10.1016/j.jneb.2014.06.002.

43. Steinberg DM, Levine EL, Lane I, et al. Adherence to self-monitoring via interactive voice response technology in an eHealth intervention targeting weight gain prevention among Black women: randomized controlled trial. J Med Internet Res 2014; 16: e114. DOI: 10.2196/jmir.2996.

44. Karintrakul S and Angkatavanich J. A randomized controlled trial of an individualized nutrition counseling program matched with a transtheoretical model for overweight and obese females in Thailand. Nutr Res Pract 2017; 11: 319-326. DOI: 10.4162/nrp.2017.11.4.319.

45. Oddone EZ, Gierisch JM, Sanders LL, et al. A Coaching by Telephone Intervention on Engaging Patients to Address Modifiable Cardiovascular Risk Factors: a Randomized Controlled Trial. J Gen Intern Med 2018; 33: 1487-1494. DOI: 10.1007/s11606-018-4398-6.

46. Haesum LKE, Ehlers LH and Hejlesen OK. The long-term effects of using telehomecare technology on functional health literacy: results from a randomized trial. Public Health 2017; 150: 43-50. DOI: 10.1016/j.puhe.2017.05.002.

47. Kiser K, Jonas D, Warner Z, et al. A randomized controlled trial of a literacy-sensitive self-management intervention for chronic obstructive pulmonary disease patients. J Gen Intern Med 2012; 27: 190-195. DOI: 10.1007/s11606-011-1867-6.

48. Collinsworth AW, Brown RM, James CS, et al. The impact of patient education and shared decision making on hospital readmissions for COPD. Int J Chron Obstruct Pulmon Dis 2018; 13: 1325-1332. DOI: 10.2147/copd.S154414.

49. Titova E, Salvesen O, Bentsen SB, et al. Does an integrated care intervention for COPD patients have long-term effects on quality of life and patient activation? A prospective, open, controlled single-center intervention study. PLoS One 2017; 12: e0167887. DOI: 10.1371/journal.pone.0167887.

50. Morrow DG, Weiner M, Steinley D, et al. Patients' health literacy and experience with instructions: Influence preferences for heart failure medication instructions. Journal of Aging and Health 2007; 19: 575-593. DOI: 10.1177/0898264307304448.

51. DeWalt Darren A, Schillinger D, Ruo B, et al. Multisite Randomized Trial of a Single-Session Versus Multisession Literacy-Sensitive Self-Care Intervention for Patients With Heart Failure. Circulation 2012; 125: 2854-2862. DOI: 10.1161/CIRCULATIONAHA.111.081745.

52. DeWalt DA, Malone RM, Bryant ME, et al. A heart failure self-management program for patients of all literacy levels: a randomized, controlled trial [ISRCTN11535170]. BMC Health Serv Res 2006; 6: 30. DOI: 10.1186/1472-6963-6-30.

53. Howie-Esquivel J, Bibbins-Domingo K, Clark R, et al. A Culturally Appropriate Educational Intervention Can Improve Self-Care in Hispanic Patients With Heart Failure: A Pilot Randomized Controlled Trial. Cardiol Res 2014; 5: 91-100. DOI: 10.14740/cr346w.

54. Shively MJ, Gardetto NJ, Kodiath MF, et al. Effect of patient activation on self-management in patients with heart failure. Journal of Cardiovascular Nursing 2013; 28: 20-34. DOI: 10.1097/JCN.0b013e318239f9f9.

55. Young L, Hertzog M and Barnason S. Effects of a home-based activation intervention on self-management adherence and readmission in rural heart failure patients: the PATCH randomized controlled trial. BMC Cardiovasc Disord 2016; 16: 176. DOI: 10.1186/s12872-016-0339-7.

56. Shearer NBC, Cisar N and Greenberg EA. A telephone-delivered empowerment intervention with patients diagnosed with heart failure. Heart & Lung: The Journal of Acute and Critical Care 2007; 36: 159-169. DOI: 10.1016/j.hrtlng.2006.08.006.

57. Taani MH, Zabler B, Fendrich M, et al. Lessons learned for recruitment and retention of low-income African Americans. Contemporary Clinical Trials Communications 2020; 17: 100533. DOI: 10.1016/j.conctc.2020.100533.

58. Perrins G, Ferdous T, Hay D, et al. Conducting Health Literacy Research With Hard-to-Reach Regional Culturally and Linguistically Diverse Populations: Evaluation Study of Recruitment and Retention Methods Before and During COVID-19. JMIR Form Res 2021; 5: e26136. DOI: 10.2196/26136.

59. Svendsen MT, Bak CK, Sørensen K, et al. Associations of health literacy with socioeconomic position, health risk behavior, and health status: a large national population-based survey among Danish adults. BMC public health 2020; 20: 1-12.

60. World Health Organization. Health literacy: The solid facts. 2013.

Chapter 6

General discussion

This thesis focused on the self-management of patients with limited health literacy, the problems they encounter, and their needs regarding self-management support. The following research questions were examined:

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. Based on the findings from research question 1 through 3, what recommendations can we make regarding development, design, and implementation of SMIs for chronically ill patients with limited health literacy?

The following paragraphs address and reflect upon the main findings of this thesis. Further, implications for practice and research are formulated.

Reflection on main findings

Which patient groups are vulnerable regarding health literacy in the Netherlands?

To answer the first research question, a questionnaire was sent to members of the Dutch Health Care Consumer panel **(chapter 2).** This panel consisted of the indigenous Dutch population and the four largest ethnic minority groups in the Netherlands, which are Turks, Moroccans, Netherlands Antilleans and Surinamese. Health literacy levels were measured in this sample with the Health Literacy Questionnaire (HLQ). In general, there were no differences in health literacy between most of the ethnic minority groups in the Netherlands and the indigenous Dutch population. Only the Turkish population scored significantly lower on several health literacy domains, such as finding and understanding sufficient health information, navigating the health care system and active engagement. It must be noted that the expected differences of health literacy levels between ethnic minorities and the indigenous Dutch population were larger. This might be due to the small sample size of the study, as well as possible selection bias. The sample of this study was a representation of the Dutch population, and not solely chronically ill patients. A recent study in the same Dutch Health Care Consumer panel shows, however, that people with a low perceived health status are more likely to have limited health literacy [1]. This is further confirmed by research studying health literacy in a representative sample of Dutch people with one or more medically diagnosed chronic illnesses: limited health literacy often goes together with a worse health and more complex health problems for example due to comorbidities [2]. Therefore, chronically ill patients are considered a vulnerable patient group.

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?

To answer the second research question, a scoping review was conducted from the scientific literature published between 2010 and 2020 **(chapter 3).** This review of reviews addressed the specific difficulties patients with limited health literacy face in relation to self-management of their chronic disease and their associated needs with respect to self-management support. Most of the reviews included studies concerning patients with diabetes, cardiovascular diseases or a combination of chronic conditions. Half of the reviews were published between 2018 and 2020, which is indicative of a growing awareness of the importance of this research. The SMIs for these patients are nowadays predominantly focused on medical management, communication and knowledge. The 28 included reviews described the relationship between health literacy and different types of self-management activities: such as medical management, changing lifestyle, communicating and navigating through the health care system and coping with the physical, psychological and social consequences of having a chronic diseases. This will be elaborated upon in the following paragraphs.

Medical management

The scoping review showed that the vast majority of research on health literacy in relation to medical management concerned medication adherence, of which the results regarding the interrelationship between health literacy and adherence were mixed and depended on the type of adherence being measured. Approximately half of the studies showed that patients with limited health literacy show lower levels of adherence then patient with sufficient levels of health literacy. Adherence in these studies was mainly related to adherence to medication advice. Studies looking at adherence to self-monitoring of HbA1C in diabetes patients showed no significant associations however.

Qualitative studies also showed that patients with limited health literacy primarily experience difficulties with adherence to medication prescriptions: they encountered problems in finding and understanding information needed for their medication and symptom management. In addition, they experienced difficulties with reading small print prescriptions and/or instructions, long texts or difficult wordings and with appraising the reliability of health information, especially information found on the internet. The use of graphic illustrations and images eased readability and understanding for the patient. Further, realistic and practical instructions, such as demonstrations, helped to translate information into action.

Changing lifestyle

The scoping review included few reviews concerning the association between self-management in terms of lifestyle changes and health literacy. A common finding was that motivation is crucial for patients with limited health literacy to achieve and maintain positive behaviour change and increased self-management. Sustainment of motivation is dependent on a dedicated support system, consisting of friends, family, peers and health care professionals. Motivational cues and therefore also facilitators of self-management for people with limited health literacy are wanting to set a good example for their children and feeling supported by true interest and concern from health care providers [3]. These results align with other research on facilitators for self-management for people with limited health literacy, which states that the relationship with the health care professional is key [4]. The importance of a support system is also recognized in a meta-review concerning people with prediabetes [4].

Communicating and navigating the health care system

Patients with limited health literacy experience problems in communicating and navigating through the health care system. In the communication with health care professionals, patients feel that they either lack knowledge or experience, which is partly caused by the lack of understanding of written materials. The use of jargon has a significant negative impact on their capacity for self-management, their emotions and mental well-being. In addition, during medical visits, patients can feel embarrassed of perceive time constraints to ask additional questions. Finally, in navigating the health care system, the lack of collaborative communication between primary and secondary care was an important barrier for patients with limited health literacy to effective disease management, which further exacerbated patients' perceived barriers.

Coping

In the scoping review, the association between coping with the long term consequences of having a chronic disease and health literacy was hardly assessed. Instead, in qualitative studies we found that the feeling of control and autonomy is very important for patients because it provides a sense of comfort. For example, religion, spirituality and the support of other patient play a big role in accepting and dealing with the disease. For patients with limited health literacy at risk for chronic diseases, research suggests that patients exhibit fewer coping behaviours their selves [5] and need help or motivation from others in taking an active role in coping with the consequences of a chronic disease.

Which SMIs are available for chronically ill patients with limited health literacy, and do they match the needs of these patients?

We used two different methods to answer the third research question. To get insight into the needs of patients with limited health literacy regarding self-management support, first, a concept-mapping procedure was conducted, consisting of a card sorting task **(chapter 4).** With this method we aimed to explore the preferences regarding self-management outcomes of chronically ill patients with limited health literacy, which is an often used proxy of patients' needs in research on self-management [6]. Also other research has shown that self-management support is most effective when tailored to the needs and preferences of patients and therefore it was important to know the preferences of this patient group with respect to the preferred outcomes of SMIs [7, 8].

Subsequently, we provided a description of available SMIs, focussed on the challenges chronically ill patients with limited health literacy face during the day-to-day management of their disease(s) **(chapter 5).**

Preferences regarding self-management intervention outcomes

Research has shown that self-management support is most effective when tailored to the needs and preferences of patients [7-9]. Therefore, we study the preferences of this patient group with respect to the preferred outcomes of self-management interventions **(Chapter 4).**

For chronically ill patients with limited health literacy, satisfaction with care is the most important outcome domain to measure the effect of SMIs. This domain includes overall satisfaction with care provided by professionals, the communication with health care providers, the provision of information and trust. This means that building a solid patient-provider relationship will enhance successful self-management. Also, outcomes related to symptom management and improving intermediate competences to self-management such as patient activation and self-efficacy scored very high. Overall, patients with limited health literacy prefer a wide variety of outcomes for their self-management, which does not differ in this respect to people with chronic disease that are more health literate [10, 11]. However, as shown in our research **(chapter 4)** the type of outcomes differed to some extent. Since patients with limited health literacy rated the outcome domain related to satisfaction with care as most important, special attention is needed for the relationship between the patient and the health care professional.

Description of available SMIs for patients with limited health literacy

In **chapter 5**, a secondary analysis of the COMPAR-EU database was conducted. COMPAR-EU was an international research project focusing on the effectiveness of SMIs for chronically ill patients. The database consisted of 1,681 interventions to improve self-management in patients with type 2 diabetes, chronic obstructive pulmonary disease (COPD), obesity and heart failure. From this broad database we searched SMIs related to health literacy in which we used a broad definition of health literacy, including both cognitive aspects as well as behaviour related aspects. This resulted in a description of 35 studies addressing health literacy, which are describing a total of 39 SMIs. The overview yields a high variety in interventions given, varying in sample(size), operationalization of health literacy, methods, self-management techniques and outcomes. These findings correspond with a recent review studying health literacy interventions, where the researchers found the same heterogeneity [12].

Do they match the needs of patients with limited health literacy?

As shown in **chapter 5,** only a few of the interventions solely included patients with limited health literacy, due to the challenging recruitment of this target group, but rather had a mixed study sample of both people with limited and more high health literacy skills. However, the strategy of developing interventions that are accessible for patients with all levels of health literacy appears promising, for example by adapting intervention materials or communication strategies to limited health literacy. This matches the needs of this patient group, while easy to comprehend information also profits patients in general.

Overall, the goal of SMIs for patients with limited health literacy appears not to improve functional health literacy, as this was not often an outcome of the studies. The interventions were largely targeted on improving, for example, patient activation and self-efficacy, which underlines the importance of the intermediate outcomes as found in **chapter 4**. Therefore, on outcome basis, the interventions partly match with the preferences of patients, when focusing on self-management competences.

What recommendations can we make regarding development, design, and implementation of SMIs for chronically ill patients with limited health literacy?

To answer the last research question, multiple chapters **(3-5)** gave insight into this. The difficulties patients with limited health literacy face and their supported needs **(chapter 3),** patient preferences regarding outcomes **(chapter 4)**, and the descriptive analysis **(chapter 5)** provide the necessary information to make recommendations regarding the development, design and implementation of SMIs. Based on the gathered insights in this thesis, we provide the following recommendations:

1. Patient participation
   When taking the findings of this thesis into account, 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. Our findings confirm earlier studies that it is important to include patients with limited health literacy in the development of SMIs. During the implementation the involvement of patients is most important, with both interventions on patient as organizational level. The co-creation of researchers, organisations and patients is likely to improve SMIs and the health outcomes, especially for patients with limited health literacy [13]. Involving users of the intervention promotes acceptability and feasibility of the intervention [14]. A possible approach, called Ophelia, was developed to both optimise individual health literacy levels as the organizational health literacy. The Ophelia Protocol builds on the needs of patients with limited health literacy and subsequently works in co-creation during the development of interventions for these patients [15, 16].
2. Tailoring of SMIs
   A recommendation considering the development of SMIs is to tailor the SMI to the needs and preferences of patients with limited health literacy. This confirms earlier studies [8, 9]. 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 (e.g. medical management, changing lifestyle, communicating and navigating through the health care system and coping). 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. When developing a SMI for patients with limited health literacy, a broad conceptualization of health literacy, including both cognitive and behavioural aspects, holds the potential to better represent the multiple aspects of health literacy needed for self-management. **Chapter 4** showed that the preferred outcomes of patients with limited health literacy include a wide variety of outcomes. Besides clinical outcomes, patients prefer to work on the competences needed for effective self-management. In the development of SMIs, these different preferences should be acknowledged and taken into consideration during development.

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. These findings correspond with previous research [17]. In the development of interventions for patients with limited health literacy, attention has been given to these functional health literacy skills [18, 19].
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. It is important that health care organizations become more health literate, by for example, training health care professionals, providing extra consultation time, and integrating health literacy in organizational vision and strategic planning [20, 21]. 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. This means that people with limited health literacy would profit from a continuity in the health care professionals who are aware of their limited health literacy so that they do not have to explain themselves repeatedly.
5. Uniformity in the description of SMIs
   Chapter 5 gives insight in the description of SMI designs and how they are described. In the description of the intervention characteristics, there was a large variety in the extensiveness of the description and their justification or explanation is often lacking. These results were also found in a systematic review on health literacy interventions in chronic conditions [22]. 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 heterogeneity in outcomes interferes the comparison of effectiveness of different SMIs. Besides, 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. The quality of research on SMIs for patients with limited health literacy would largely improve if interventions are uniformly described [22, 23]. In a uniform way, studies can be compared, evaluated and replicated. The descriptive analysis of **chapter 5** used the taxonomy which was developed for SMIs, within the COMPAR-EU project [24]. Taxonomies such as the COMPAR-EU SMI taxonomy provide in a common language and definitions to describe SMIs.

Methodological considerations

The concept of health literacy

In this thesis, the conceptualization of health literacy is discussed repeatedly. In the chapters of this thesis, we intended to apply a broad concept of health literacy, including functional skills, cognitive skills and the capacity to act [25]. The capacity to act is generally not incorporated in health literacy conceptualizations and measurements. However, when reflecting on health literacy in relation to self-management, the behavioural aspects such as described in concepts like patient activation or measured in broad instruments like the Health literacy questionnaire (HLQ) are just as important. The capacity to act refers to skills such as goal-setting, making a plan, taking action, persevering and being able to deal with temptations and adverse events. These skills are important for the extent to which patients are able to take an active role in the management of their health and illness. The way in which health literacy is conceptualized and measured in the included research differed to a huge extent. Despite the necessity of a broad conceptualization, a large part of previous research concerning health literacy and self-management uses a narrow concept of health literacy, mainly focussing on cognitive aspects of health literacy. In **chapter 5**, this limitation has been overcome by adding patient activation in the search for SMIs.

The narrow approach is largely due to the available measurement tools to measure the broad concept of health literacy. The measurement of health literacy across all studies is heterogeneous, varying from different questionnaires and proxies like education or income of individuals. Very few studies measured health literacy from a multidimensional perspective. In chapter 2, health literacy was measured with the Health Literacy Questionnaire (HLQ). The HLQ is an extensive multidimensional instrument, which distinguishes cognitive, psychosocial and social aspects that may affect health behaviour. The nine domains of the HLQ provide in-depth insight in the health literacy levels of populations. Most studies, however, use instruments that cover a limited concept of health literacy. The different approaches of the concept of health literacy is, however, a problem for the generalizability of study results. This heterogeneity complicates the comparison of people in different countries or ethnic groups, or with different diseases.

During the recruitment of participants of **chapter 3** we intended to include patients using the broad concept of health literacy. Patients were invited who encountered difficulties in the interaction with their health care providers or during the daily management of their disease, for example: understanding the health care provider or other information, following medical advice, or finding the right care. In this way, patients were recruited multidimensionally, and not with lacking functional skills such as reading and understanding information solely.

The concept of self-management

Chronically ill patients have to deal with various challenges and self-management tasks on a daily basis. In this thesis, self-management is defined as "what individuals, families and communities do with the intention to promote, maintain, or restore health and to cope with illness and disability with or without the support of health professionals" [26]. To study the many divergent self-management tasks independently, four types of self-management were distinguished: medical management, making lifestyle changes, communication and navigation through the health care system, and coping with the long-term physical, and emotional and social consequences of the disease. Medical management may include medication adherence, self-monitoring and managing symptoms. A healthy lifestyle, including a healthy diet, exercising, no smoking and less alcohol are lifestyle recommendations that many chronically ill patients have to deal with. Communication and navigation through the health care system refer to the communication with health care professionals, which also includes shared decision-making. Navigation refers to knowing where to find and when to seek help. With respect to ways of coping with the consequences of living with a chronic disease, a distinction has been made between physical, psychological and social self-management tasks. In previous research, the focus lies mainly on restricted parts of the concept of self-management, including medical management and communication with the health care provider, as shown in **chapter 3**. For future research, also including other aspects of self-management as lifestyle and coping is recommended.

Strengths and limitations

An important strength of this thesis is that it is the first systematic exploration of the match between the available SMIs and the needs of patients with limited health literacy. Besides, **Chapter 2** of this thesis is the first study in the Netherlands that describes the health literacy levels of different ethnic minorities in the Netherlands. A third strength is the use of methods (**Chapter 3 and 4**) and data (**Chapter 5**) of the COMPAR-EU project. There was never such a large study before that described all SMIs for patients with type 2 diabetes, chronic obstructive pulmonary disease (COPD), obesity and heart failure.

The studies described in this thesis are also subject to limitations. The study samples used in **chapter 2 and 4** are relatively small and may be subject to selection bias. Despite the small sample size, the data on health literacy levels of different ethnic minority groups in the Netherlands that is provided in **chapter 2,** are the first data that provides this information. The sample size in **chapter 4** was insufficient to perform significant subgroup analysis, although it was sufficient to calculate mean scores of preferences amongst the whole sample.

The relatively small study samples are likely due to the challenges of recruiting people with limited health literacy. Difficulties with the recruitment of people with limited health literacy are generally acknowledged [27, 28], and the recruitment of the participants in **chapter 4** during the Covid-19 pandemic made the challenge even bigger. Therefore, studies concerning patients with limited health literacy are often subject to selection bias. Patients with limited health literacy are not likely to participate in studies, especially when the study is designed in written form, such as questionnaires. Online questionnaire are an even bigger hurdle for people with limited health literacy who often also lack digital skills [29]. It is plausible that study samples miss the people with insufficient literacy skills and consequently lower health literacy levels and recruit mostly relatively higher levels. However, in **chapter 2,** the health literacy levels are extensively measured for an adequate comparison and the possible selection bias was equal across the sample. During the concept mapping approach of **chapter 4**, we attempted to take any possible barriers away, by using very user-friendly software, pilot testing, and the possibility to receive technical help by phone. Despite these attempts, innovative ways to include people with limited health literacy on an equal basis in research and enabling methods and tools are highly needed. Another limitation of this thesis is that the studied associations and SMIs mostly concern studies originated from North America, where research on the topic of health literacy is most developed. Encouragingly, research on health literacy is increasing noticeably in Europe [9].

Implications

Based on the findings presented in this thesis, and in light of the current knowledge base concerning the relationship between self-management and health literacy, implications were formulated with respect to practice and future research.

Implications for practice

Future development of tailored SMIs

For future development of interventions for patients with limited health literacy, it is recommended to tailor SMIs on multiple levels. Progress is made in some of the interventions, but structural attention is needed. Firstly, tailoring to the broad concept of health literacy, including functional skills, cognitive skills and the capacity to act may improve the effectiveness of interventions. Secondly, by tailoring the self-management, support should be tailored to the skills of the patient. Communication and provision of information that is easily accessible and easy to understand is key. In addition, patients with limited health literacy need specific attention tailored to the prerequisites of self-management, for example knowledge, self-efficacy, and learning self-management competences. These prerequisites are needed before focusing on health related outcomes. Having the right information is a good start, but knowing what to do with the information is just as important. Lastly, SMIs tailored to the needs and preferences of patients are more effective [7, 8]. Since patients with limited health literacy prefer a variety of outcomes for their self-management, it is important for health care professionals to explore these preferences together with the patient in advance.

Another recommendation for practice concerns the process of reporting the interventions and their characteristics. The findings of the descriptive analysis of **chapter 5** show that an accurate and complete description of the intervention is often lacking. The description of certain details of previously designed and implemented interventions is needed to learn from them and to improve, for example the provider and the duration of the SMI. The description of interventions characteristics is needed for every SMI, but specifically for SMIs that are developed for patients with limited health literacy, since these factors have great influence on the effectiveness of the intervention.

Health care providers

The findings of this thesis underline the importance of the interaction and the relationship between the health care provider and patients with limited health literacy. The most important outcomes for this patient group are in the domain of 'satisfaction with care'. This domain describes satisfaction with care overall and the relationship between the health care provider and the patient, including trust and communication. During the initially planned concept mapping approach of **chapter 4,** where participants had to group outcomes according to similarity of content, it became clear that participants were unable to think in an abstract way about the self-management concept, beyond their own experiences. The challenge patients experience to understand and apply abstract goals is an important implication for clinical practice. Health care professionals should tailor their communication about care and self-management to the specific individual situation of the patient to be fully understood and pay time and effort to explain how outcomes relate to each other. The investment of time and effort of the health care provider will help to create a solid relationship with the patient, which will enhance the process to successful self-management.

The health literate organisation

The approach of enhancing the individual health literacy levels of patients to improve self-management behaviours, is one way to improve health outcomes. On the contrary, healthcare system factors have a major influence on the fact that health literacy levels are sufficient enough to obtain optimal self-management behaviours. For health care policy, it is important to acknowledge the key roles of organisations to reduce the mismatch between the patients' skills and the health care context. This concept is called organizational health literacy: the degree to which health care organizations implement strategies to make it easier for patients to understand health information, navigate the health care system, engage in the health care process, and manage their health [30, 31]. It is important that organizations become health literate by, for example, training health care professionals, simplifying the process to make an appointment and the 'Teach back method' [31-33].

Implications for research

Enhancing a broader operationalization of health literacy and self-management

In the context of research concerning health literacy in the light of self-management, a broader operationalization and measurement of health literacy holds the potential to better represent the multiple aspects of health literacy needed for self-management. It is only recently that broader definitions of health literacy have begun to be used, but it is not represented in the literature yet, which focusses mainly on functional health literacy. Besides, the same implication for self-management is applicable. The findings of this thesis provide limited insight into the influence of limited health literacy on coping and motivation to change lifestyle behaviours. Up to now, these types of self-management activities are scarcely studied in patients with limited health literacy. Future research should address the impact of health literacy on these aspects of self-management. Therefore, the relationship between other aspects of health literacy and self-management activities require further investigation.

Health literacy-friendly research methods

Recruiting patients with limited health literacy for your research is difficult [27, 28]. However, a representative sample is very important to avoid under- or overestimation of results, small sample sizes and selection bias. One part of enhancing the participation of patients with limited health literacy has to do with recruitment methods. Creative and efficient ways to recruit people with the lowest health literacy levels will also reduce the plausible selection bias of current methods. Avoiding written information as much as possible, and using personal contact to recruit patients might help [27, 34]. To further enhance the participation of people with limited health literacy in SMIs, effective recruitment methods should be studied, so that lessons can be learned [27]. On the other hand, a diversity of research methods is needed to keep all participants with limited health literacy involved in research and avoid selective dropouts.

References

1. Willems A, Heijmans M, Brabers A, et al. Gezondheidsvaardigheden in Nederland: factsheet cijfers 2021. 2022.
2. Heijmans M, Willems, A., Scherpenzeel, A. Eigen regie over ziekte en zorg: ervaringen van mensen met een chronische longziekte. 2022. Utrecht: Nivel.
3. Jager M, de Zeeuw J, Tullius J, et al. Patient Perspectives to Inform a Health Literacy Educational Program: A Systematic Review and Thematic Synthesis of Qualitative Studies. Int J Environ Res Public Health 2019; 16 2019/11/07. DOI: 10.3390/ijerph16214300.
4. Skoglund G, Nilsson BB, Olsen CF, et al. Facilitators and barriers for lifestyle change in people with prediabetes: A meta-synthesis of qualitative studies. BMC public health 2022; 22: 1-27.
5. Peltzer S, Hellstern M, Genske A, et al. Health literacy in persons at risk of and patients with coronary heart disease: A systematic review. Social science & medicine 2020; 245: 112711.
6. de Guzmán Quispe EN, García LM, Villagrán CO, et al. The perspectives of patients with chronic diseases and their caregivers on self-management interventions: A scoping review of reviews. The Patient-Patient-Centered Outcomes Research 2021: 1-22. DOI: 10.1007/s40271-021-00514-2
7. Trappenburg J, Jonkman N, Jaarsma T, et al. Self-management: one size does not fit all. Patient education and counseling 2013; 92: 134-137. DOI: https://doi.org/10.1016/j.pec.2013.02.009.
8. Bos-Touwen I, Jonkman N, Westland H, et al. Tailoring of self-management interventions in patients with heart failure. Curr Heart Fail Rep 2015; 12: 223-235. DOI: 10.1007/s11897-015-0259-3.
9. Visscher BB, Steunenberg B, Heijmans M, et al. Evidence on the effectiveness of health literacy interventions in the EU: a systematic review. BMC public health 2018; 18: 1414. DOI: 10.1186/s12889-018-6331-7.
10. Valli C, Sunol R, Orrego C, et al. The development of a core outcomes set for self-management interventions for patients living with obesity. Clin Obes 2021; n/a: e12489. 2021/10/08. DOI: 10.1111/cob.12489.
11. Camus-García E, González-González AI, Heijmans M, et al. Self-management interventions for adults living with Chronic Obstructive Pulmonary Disease (COPD): The development of a Core Outcome Set for COMPAR-EU project. PloS one 2021; 16: e0247522. 2021/03/02. DOI: 10.1371/journal.pone.0247522.
12. Larsen MH, Mengshoel AM, Andersen MH, et al. "A bit of everything": Health literacy interventions in chronic conditions – a systematic review. Patient Education and Counseling 2022; 105: 2999-3016. DOI: https://doi.org/10.1016/j.pec.2022.05.008.
13. Loignon C, Dupéré S, Fortin M, et al. Health literacy – engaging the community in the co-creation of meaningful health navigation services: a study protocol. BMC Health Services Research 2018; 18: 505. DOI: 10.1186/s12913-018-3315-3.
14. Leask CF, Sandlund M, Skelton DA, et al. Framework, principles and recommendations for utilising participatory methodologies in the co-creation and evaluation of public health interventions. Research involvement and engagement 2019; 5: 1-16.
15. Batterham RW, Buchbinder R, Beauchamp A, et al. The OPtimising HEalth LIterAcy (Ophelia) process: study protocol for using health literacy profiling and community engagement to create and implement health reform. BMC public health 2014; 14: 1-10.
16. Beauchamp A, Batterham RW, Dodson S, et al. Systematic development and implementation of interventions to OPtimise Health Literacy and Access (Ophelia). BMC public health 2017; 17: 1-18.
17. Nutbeam D and Lloyd JE. Understanding and responding to health literacy as a social determinant of health. Annu Rev Public Health 2021; 42: 159-173.

18. Stormacq C, Wosinski J, Boillat E, et al. Effects of health literacy interventions on health-related outcomes in socioeconomically disadvantaged adults living in the community: a systematic review. JBI Evidence Synthesis 2020; 18.

19. Visscher BB, Heerdink ER and Rademakers J. Usability of an animated diabetes information tool for patients with different health literacy levels: a qualitative study. International Journal of Pharmacy Practice 2022.

20. Baumeister A, Chakraverty D, Aldin A, et al. "The system has to be health literate, too"-perspectives among healthcare professionals on health literacy in transcultural treatment settings. BMC health services research 2021; 21: 1-16.

21. Charoghchian Khorasani E, Tavakoly Sany SB, Tehrani H, et al. Review of organizational health literacy practice at health care centers: outcomes, barriers and facilitators. International journal of environmental research and public health 2020; 17: 7544.

22. Larsen MH, Mengshoel AM, Andersen MH, et al. "A bit of everything": Health literacy interventions in chronic conditions–a systematic review. Patient Education and Counseling 2022.

23. Okan O, Bauer U, Levin-Zamir D, et al. International Handbook of Health Literacy: Research, practice and policy across the lifespan. Policy Press, 2019.

24. Orrego C, Ballester M, Heymans M, et al. Talking the same language on patient empowerment: Development and content validation of a taxonomy of self-management interventions for chronic conditions. Health Expectations 2021; 24: 1626-1638. DOI: https://doi.org/10.1111/hex.13303.

25. Rademakers J and Heijmans M. Beyond Reading and Understanding: Health Literacy as the Capacity to Act. International journal of environmental research and public health 2018; 15: 1676.

26. Barlow J, Wright C, Sheasby J, et al. Self-management approaches for people with chronic conditions: a review. Patient Education and Counseling 2002; 48: 177-187. 2002/10/29. DOI: https://doi.org/10.1016/S0738-3991(02)00032-0.

27. Blanch DC, Rudd RE, Wright E, et al. Predictors of refusal during a multi-step recruitment process for a randomized controlled trial of arthritis education. Patient Educ Couns 2008; 73: 280-285. 2008/08/22. DOI: 10.1016/j.pec.2008.06.017.

28. Livaudais-Toman J, Burke NJ, Napoles A, et al. Health literate organizations: are clinical trial sites equipped to recruit minority and limited health literacy patients? Journal of health disparities research and practice 2014; 7: 1.

29. Neter E and Brainin E. Association between health literacy, ehealth literacy, and health outcomes among patients with long-term conditions. European Psychologist 2019.

30. Brach C and Harris LM. Healthy People 2030 Health Literacy Definition Tells Organizations: Make Information and Services Easy to Find, Understand, and Use. Journal of General Internal Medicine 2021; 36: 1084-1085. DOI: 10.1007/s11606-020-06384-y.

31. Brega AG, Hamer MK, Albright K, et al. Organizational health literacy: Quality improvement measures with expert consensus. HLRP: Health Literacy Research and Practice 2019; 3: e127-e146.

32. Yen PH and Leasure AR. Use and effectiveness of the teach-back method in patient education and health outcomes. Federal practitioner 2019; 36: 284.

33. Dinh TTH, Bonner A, Clark R, et al. The effectiveness of the teach-back method on adherence and self-management in health education for people with chronic disease: a systematic review. JBI Evidence Synthesis 2016; 14: 210-247.

34. Protheroe J, Rathod T, Bartlam B, et al. The Feasibility of Health Trainer Improved Patient Self-Management in Patients with Low Health Literacy and Poorly Controlled Diabetes: A Pilot Randomised Controlled Trial. J Diabetes Res 2016; 2016: 6903245. DOI: 10.1155/2016/6903245.

Impact paragraph

Living with a chronic disease is challenging, especially for patients with limited health literacy. Limited health literacy is an important barrier for adequately dealing with a chronic disease. The self-management of patients with limited health literacy, the problems they encounter and research on self-management support were addressed in this thesis. This chapter reflects on the scientific and societal impact of this thesis.

Scientific impact

This thesis has scientific relevance, as it adds knowledge to an important field which have received increasing attention in the past decades. First, it demonstrates that the current scientific evidence base would benefit from a broader operationalization of both the concept of health literacy as the concept of self-management. It holds the potential to better represent the multiple aspects of health literacy needed for different self-management activities. Second, this thesis shows that research on this subject needs uniformity. The heterogeneity of the conceptualization of concepts as well as die heterogeneity in the description of the design of SMIs hinders the ability to learn from and thereby also improve interventions. Third, it was already known that tailoring interventions increases the effectiveness. This thesis provides the additional information to tailor SMIs to the outcome preferences of patients with limited health literacy. Third, this thesis adds the first insights in the health literacy levels of different ethnic groups in the Netherlands, which were previously unknown.

Societal impact

This thesis underlines the importance of special attention to the health literacy levels of patients. Patient with limited health literacy struggle with specific elements of self-management, which can be supported by health care professionals. As specifically shown in chapter 3 and 4, the relationship and the interaction between the health care professional and patients with limited health literacy has great impact. Besides, chapter 4 shows that patients with limited health literacy need special attention for the prerequisites of self-management before focusing on health related outcomes. Summarized, these findings call for an investment in time and effort in the self-management of patients with limited health literacy. Therewith, health care professionals can explore patient preferences, invest in communication, trust and the self-management skills the patient needs.

Dissemination of findings

Various channels were used to disseminate the findings of this thesis to researchers, policy makers, health care providers and other stakeholders. Since this thesis is partly funded by COMPAR-EU, the results are also disseminated through the channels of COMPAR-EU. The dissemination includes presentations and poster presentations on conferences, newsletters and dissemination through social media. All the articles in this thesis were published in international, peer-reviewed journals. All of the articles are accessible free of charge, since they are published open access. All articles are also available through the Nivel repository.

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.

Nederlandse samenvatting

Hoofdstuk 1 van dit proefschrift beschrijft de concepten gezondheidsvaardigheden, zelfmanagement en zelfmanagementondersteuning en de achtergrond daarvan. Momenteel is er te weinig aandacht voor zelfmanagementondersteuning voor personen met beperkte gezondheidsvaardigheden, terwijl beperkte gezondheidsvaardigheden een belangrijke barrière vormen voor het adequaat omgaan met chronische ziekten. Dit proefschrift richt zich op zelfmanagement van patiënten met beperkte gezondheidsvaardigheden, de problemen die zij tegenkomen en hun behoeften op het gebied van zelfmanagementondersteuning. Om te onderzoeken hoe patiënten met beperkte gezondheidsvaardigheden optimaal ondersteund kunnen worden, hebben we de volgende onderzoeksvragen gedefinieerd:

1. Welke patiëntengroepen zijn kwetsbaar met betrekking tot gezondheidsvaardigheden in Nederland?
2. Welke moeilijkheden ondervinden patiënten met beperkte gezondheidsvaardigheden met betrekking tot zelfmanagement en wat zijn hun behoeften met betrekking tot zelfmanagementondersteuning?
3. Welke zelfmanagement interventies zijn beschikbaar voor chronisch zieke patiënten met beperkte gezondheidsvaardigheden en sluiten deze aan bij de behoeften van deze patiënten?
4. Welke aanbevelingen kunnen we doen met betrekking tot de ontwikkeling, het ontwerp en de implementatie van zelfmanagement interventies voor chronisch zieke patiënten met beperkte gezondheidsvaardigheden?

Belangrijkste bevindingen

Om onderzoeksvraag 1 te beantwoorden, wordt in **hoofdstuk 2** inzicht verkregen in het niveau van gezondheidsvaardigheden van etnische minderheidsgroepen in Nederland. Er is een vragenlijst afgenomen bij een steekproef van 2.116 leden van het Nederlands Consumentenpanel Gezondheidszorg. Gezondheidsvaardigheden werden gemeten met de Health Literacy Questionnaire (HLQ), die negen verschillende domeinen omvat. De niveaus van gezondheidsvaardigheden van etnische minderheidsgroepen werden vergeleken met die van de autochtone bevolking. Significante verschillen in niveaus van gezondheidsvaardigheden werden alleen gevonden tussen de Turkse bevolking en de autochtone Nederlandse bevolking op verschillende domeinen, zoals het vinden en begrijpen van voldoende gezondheidsinformatie, het navigeren door het gezondheidszorgsysteem en actieve betrokkenheid. Deze resultaten kunnen te wijten zijn aan de kleine steekproefgrootte van de etnische minderheidsgroepen en aan de representativiteit van de steekproef. De verwachte verschillen in gezondheidsvaardigheden tussen etnische minderheden en de autochtone Nederlandse bevolking waren immers groter.

Voor de tweede onderzoeksvraag beschrijft **hoofdstuk 3** het belang van gezondheidsvaardigheden voor zelfmanagement. De *scoping review of reviews* in **hoofdstuk 3** is gericht op het ontrafelen van specifieke moeilijkheden die patiënten met beperkte gezondheidsvaardigheden ondervinden met betrekking tot zelfmanagement en hun bijbehorende behoeften met betrekking tot zelfmanagementondersteuning. In totaal werden 28 reviews geïncludeerd. Er kwamen enkele duidelijke problemen naar voren, voornamelijk op het gebied van medisch management (vooral therapietrouw), communicatie en kennis, maar andere verbanden tussen gezondheidsvaardigheden en zelfmanagement waren niet overtuigend. De overgrote meerderheid van het onderzoek naar gezondheidsvaardigheden en zelfmanagement richtte zich op medisch management en communicatie, en slechts enkele reviews gingen in op leefstijlverandering en coping. Om de relatie tussen gezondheidsvaardigheden en zelfmanagement beter te kunnen begrijpen is een bredere conceptualisering van zowel gezondheidsvaardigheden als zelfmanagement nodig.

Hoofdstuk 4 beschrijft een onderzoek naar de voorkeuren met betrekking tot zelfmanagement uitkomsten van chronisch zieke patiënten met beperkte gezondheidsvaardigheden. Een groep van 35 patiënten met beperkte gezondheidsvaardigheden voerde een *concept-mapping* procedure uit die bestond uit het sorteren van kaarten. Patiënten rangschikten 60 kaarten met uitkomsten, die vaak voorkomen in de literatuur met betrekking tot zelfmanagement, op volgorde van belangrijkheid voor henzelf. De gemiddelden werden berekend voor elke uitkomst en elk domein. Voor patiënten met beperkte gezondheidsvaardigheden is tevredenheid met de zorg het belangrijkste uitkomstdomein. Dit domein omvat algemene tevredenheid, de communicatie met zorgverleners, informatievoorziening en vertrouwen. Op het niveau van uitkomsten, naast gezondheid gerelateerde uitkomsten, hebben patiënten de voorkeur om te werken aan hun competenties voor zelfmanagement. Voor zorgverleners geldt dat inspelen op deze voorkeuren van patiënten en het opbouwen van een goede relatie het succes van zelfmanagement zal vergroten.

Hoofdstuk 5 geeft een beschrijvende analyse van zelfmanagement interventies voor chronisch zieke patiënten met beperkte gezondheidsvaardigheden. Dit onderzoek is een secundaire analyse van de COMPAR-EU database, die bestaat uit zelfmanagement interventies voor patiënten met diabetes type 2, COPD, obesitas en hartfalen. De database werd doorzocht op interventies die betrekking hebben op een brede definitie van gezondheidsvaardigheden, waaronder zowel cognitieve aspecten (denken) als het vermogen om te handelen (doen). Uit de beschrijving van 35 studies, die 39 zelfmanagement interventies bevatten, bleek dat er een grote variëteit zit in hoe uitgebreid de designs van de verschillende interventies beschreven zijn. Daarnaast varieerden de interventies in steekproef(grootte), methoden, zelfmanagement technieken, uitkomsten en operationalisering van gezondheidsvaardigheden. Om de derde onderzoeksvraag te beantwoorden, combineren we de resultaten van **hoofdstuk 4** en **hoofdstuk 5**. De interventies waren grotendeels gericht op het verbeteren van bijvoorbeeld activering en zelfredzaamheid van patiënten. Dit onderstreept het belang van het vermogen om te kunnen handelen (doen). Op basis van uitkomsten sluiten de interventies dus gedeeltelijk aan bij de voorkeuren van patiënten, vooral wanneer ze zich richten op zelfmanagement competenties.

Discussie

Hoofdstuk 6 is het afsluitende hoofdstuk, waarin de belangrijkste bevindingen worden behandeld inclusief een reflectie daarop. Het beschrijft ook de methodologische overwegingen en de implicaties voor de praktijk en de implicaties voor onderzoek.

De belangrijkste bevindingen en reflecties van dit proefschrift gaven inzichten om de vierde onderzoeksvraag te beantwoorden. De volgende aanbevelingen worden geformuleerd met betrekking tot de ontwikkeling, het ontwerp en de implementatie van zelfmanagement interventies voor chronisch zieke patiënten met beperkte gezondheidsvaardigheden:

1. Patiëntenparticipatie
   Onze aanbeveling is om patiënten met beperkte gezondheidsvaardigheden te betrekken tijdens, of zelfs voorafgaand aan, de ontwikkeling, het ontwerp en de implementatie van zelfmanagement interventies, en zo te werken in co-creatie. Wanneer patiëntenparticipatie wordt toegepast bij de ontwikkeling van interventies, worden hun behoeften, voorkeuren en mogelijkheden erkend en afgestemd op de inhoud en de uitkomsten van de interventie. Tijdens de implementatie is de betrokkenheid van patiënten het belangrijkst, met interventies op zowel patiënt- als organisatieniveau.
2. Zelfmanagement interventies op maat
   Voor de ontwikkeling van zelfmanagement interventies wordt aanbevolen om de interventie af te stemmen op de behoeften en voorkeuren van patiënten met beperkte gezondheidsvaardigheden. De benodigde afstemming betreft zowel afstemming op cognitieve aspecten (denken), het vermogen om te handelen (doen), als de afstemming op voorkeursuitkomsten. De scoping review van reviews in **hoofdstuk 3** wees erop dat bij de ontwikkeling van zelfmanagement interventies alle vier de typen zelfmanagement activiteiten als belangrijk moeten worden beschouwd. Patiënten met beperkte gezondheidsvaardigheden ondervinden moeilijkheden bij alle vier de soorten zelfmanagement activiteiten en interventies voor deze patiënten zijn tegenwoordig voornamelijk gericht op medisch management, communicatie en kennis.
3. Makkelijk te begrijpen informatie
   Om de begrijpelijkheid van informatie voor patiënten met beperkte gezondheidsvaardigheden te vergroten, moet het design van de zelfmanagement interventie kleine lettertjes in voorschriften en/of instructies en lange teksten vermijden. Deze worden namelijk als ingewikkeld ervaren. Het gebruik van grafische illustraties en plaatjes daarentegen, verbetert de leesbaarheid en daarmee begrip van de patiënt. Daarnaast kunnen realistische en praktische instructies, zoals demonstraties, helpen om informatie om te zetten in actie.
4. De rol van de zorgverlener
   Voor de implementatie van zelfmanagementondersteuning voor patiënten met beperkte gezondheidsvaardigheden is het belangrijk om de grote rol van het

gezondheidszorgsysteem en de zorgverlener te erkennen. Een eerste stap is het verminderen van de mismatch tussen de vaardigheden van de patiënt en de context van de gezondheidszorg. Ten tweede laten de voorkeuren van patiënten met betrekking tot de uitkomsten in **hoofdstuk 4** het belang zien van een vertrouwensrelatie tussen de patiënten en de zorgverlener en ook de noodzaak om in een dergelijke relatie te investeren.

5 Uniformiteit in de beschrijving van zelfmanagement interventies
De verschillen van de designs en het gebrek aan voldoende details in de beschrijvingen van interventies bemoeilijken de onderlinge vergelijking en evaluatie van zelfmanagement interventies. Hetzelfde geldt voor uitkomsten en de manier waarop ze gemeten worden. Het gebrek aan informatie maakt het zeer uitdagend om te leren van eerder ontwikkelde of geïmplementeerde interventies en ze te gebruiken in de praktijk. Om het beschikbare onderzoek en de implementatie van zelfmanagement interventies met betrekking tot patiënten met beperkte gezondheidsvaardigheden te verrijken, is de aanbeveling om de keuzes met betrekking tot studiekenmerken te beschrijven en toe te lichten. Daarnaast zou de kwaliteit van het onderzoek naar zelfmanagement interventies voor patiënten met beperkte gezondheidsvaardigheden sterk verbeteren als interventies uniform worden beschreven, zodat ze kunnen worden vergeleken, geëvalueerd en herhaald.

List of publications

Articles

van der Gaag, M., Heijmans, M., Valli, C., Orrego, C., Ballester, M., & Rademakers, J. (2023). Self-management interventions for chronically ill patients with limited health literacy: A descriptive analysis. Chronic Illness, 17423953231181410

van der Gaag, M., Heijmans, M., Ballester, M., Orrego, C., Niño de Guzmán, E., Ninov, L., & Rademakers, J. (2022). Preferences Regarding Self-Management Intervention Outcomes of Dutch Chronically Ill Patients With Limited Health Literacy. Frontiers in Public Health, 1300

Claudia Valli, Rosa Suñol, Carola Orrego, Ena Niño de Guzmán, Valentina Strammiello, Nina Adrion, Kaisa Immonen, Lyudmil Ninov, Marieke van der Gaag, Marta Ballester, Pablo Alonso-Coello (2021). The development of a Core Outcome Set for self-management interventions for patients living with obesity. Clinical Obesity: 2021, e12489

van der Gaag, M., Heijmans, M., Spoiala, C., & Rademakers, J. (2021). The importance of health literacy for self-management: A scoping review of reviews. Chronic illness, 17423953211035472. doi:10.1177/17423953211035472

van der Gaag, M., van der Heide, I., Spreeuwenberg, P. M. M., Brabers, A. E. M., & Rademakers, J. J. D. J. M. (2017). Health literacy and primary health care use of ethnic minorities in the Netherlands. BMC Health Serv Res, 17(1), 350. doi:10.1186/s12913-017-2276-2

Reports

Gaag, M. van der, Bos, N., Hendriks, M., Boer, D. de. Beter gebruik van personenalarmering. www.nivel.nl: Nivel, 2018

Flinterman, L., van der Gaag, M., Opstelten, W., Nielen, M., Korevaar, J. Kleine kwalen in de huisartsenpraktijk: contacten en medicatiebeleid voor de jaren 2011, 2013 en 2015. Utrecht, NIVEL, 2017, 79 p

Garritsen, H., Boer, D. de, Gaag, M. van der, Rademakers, J. De toegankelijkheid en bruikbaarheid van patiëntenportalen voor mensen met lage gezondheidsvaardigheden: inzichten voor het Versnellingsprogramma Informatie-uitwisseling Patiënten en Professional. Utrecht: NIVEL, 2017

Congresses

ICIC 2021. Ballester M, Heijmans M, Orrego C, Ninov L, Beltran J, González A, van der Gaag M, Sunol R. Are we measuring what matters to people? A review of PROMs and PREMs used to evaluate self-management interventions

EHLC 2019, Dublin. Posterpresentatie: van der Gaag M, Heijmans M, Rademakers J. Towards optimal self-management support for chronically ill with low health literacy levels

Others

Gaag, M. van der, Bos, N., Hendriks, M., Boer, D. de. Infografic: samenwerking bij personenalarmering. www.nivel.nl: Nivel, 2018

Gaag, M. van der, Bos, N., Hendriks, M., Boer, D. de. Video: Samenwerking bij personenalarmering: een inventarisatie van de spoedzorgketen. www.nivel.nl: Nivel, 2018

Prospero/OSF registrations

Veroniki, A. A. (2019, December 22). Comparative effectiveness of self-management interventions for type 2 diabetes: a protocol for a systematic review and network meta-analysis. Retrieved from osf.io/65zgr

Carola Orrego, Marta Ballester, Monique Heijmans, Pablo Alonso-Coello, Carlos Canelo-Aybar, Marieke van der Gaag, Rune Poortvliet, Claudia Valli, Claudio Rocha, Jessica Beltran, Montserrat Leon, Karla Salas, Ana Isabel González-González, Kevin Pacheco-Barrios, Jessica Zafra-Tanaka, Stella Zevgiti, Areti Angeliki Veroniki, Giorgos Seitidis, Dimitris Mavridis, Rosa Suñol. Comparative effectiveness of self-management interventions for obesity: a systematic review and network meta-analysis. PROSPERO 2020 CRD42020155441 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020155441

Monique Heijmans, Carola Orrego, Marta Ballester, Dimitris Mavridis, Pablo Alonso-Coello, Carlos Canelo-Aybar, Rune Poortvliet, Marieke van der Gaag, Cristina Spoiala, Pema Gurung, Saida Moaddine, Fabienne Willemen, Iza Cools, Julia Bleeker, Angelina Kancheva, Julia Ertl, Tajde Laure, Ivana Kancheva, Areti Angeliki Veroniki, Stella Zevgiti, Giorgos Seitidis, Claudia Valli, Claudio Rocha, Leon Montserrat, Karla Salas, Marilina Santero, Chrysoula Kaloteraki, Jesica Beltran, Ena Niño de Guzman, Ana Isabel González-González, Kevin Pacheco-Barrios, Jessica Zafra-Tanaka, Rosa Sunol. Comparative effectiveness of self-management interventions for heart failure: a systematic review and network meta-analysis. PROSPERO 2020 CRD42020167916 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020167916

Jessica Beltran, Pablo Alonso-Coello, Carlos Canelo-Aybar, Monique Heijmans, Carola Orrego, Marta Ballester, Dimitris Mavridis, Claudia Valli, Claudio Rocha, Montserrat Leon, Karla Salas, Ena Niño de Guzman, Crysoula Kaloteraki, Marilina Santero, Areti Angeliki Veroniki, Stella Zevgiti, Giorgos Stetidis, Stavros Nikalakopoulos, Rune Poortvliet, Marieke van der Gaag, Ana Isabel Gonzalez-Gonzalez, Kevin Pacheco-Barrios, Jessica Zafra, Cristina Spoiala, Pema Gurung, Saida Moaddine, Fabienne Willemen, Iza Cools, Julia Bleeker, Angelina Kancheva, Julia Ertl, Tajda Laure, Ivana Kancheva, Rosa Sunol. Comparative effectiveness of self-management interventions for Chronic Obstructive Pulmonary Disease (COPD): a systematic review and network meta-analysis. PROSPERO 2020 CRD42020177238 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020177238

About the author

Marieke van der Gaag was born on the 5th of June 1993 in Gouda, the Netherlands. She completed secondary school at GSG Leo Vroman. During this period, her interest in health research arose trough a final research assignment on leukemia. In 2015, she obtained a bachelor's degree in Health Sciences at VU Amsterdam, with a minor in Biomedical Health Topics. Inspired by her interest in the influence of the health care systems and behavioural factors on health outcomes, she chose to enrol in the Master Health Sciences at VU Amsterdam, with a specialization in Public Health and Prevention. In 2016, Marieke initially joined Nivel, the Netherlands Institute for Health Services Research, for her internship on health literacy of ethnic minority groups, from which the contours of her research originated. After the internship, Marieke worked as a researcher at Nivel on various projects, mostly concerning research from the patient perspective. From 2018-2022, she was part of the Nivel team in the COMPAR-EU consortium. COMPAR-EU is a multimethod project, that focuses on the effectiveness of self-management interventions for patients with chronic illnesses. During this period at Nivel, she was attached as an external PhD candidate to the department of Family Medicine of Maastricht University. From 2022, Marieke continued her career at Q-Consult Zorg as a health care consultant.

Dankwoord

En dan tot slot… het meest gelezen hoofdstuk van elk proefschrift. Om zelf 'in control' te blijven heb ik nogal wat mensen nodig gehad in de afgelopen jaren. Ik wil iedereen graag bedanken die heeft meegewerkt of meegedacht aan dit proefschrift. Daarnaast bedank ik ook iedereen die heeft gezorgd voor advies, motivatie of juist voor de nodige afleiding.

Allereerst bedank ik graag de beoordelingscommissie die de tijd heeft genomen om mijn proefschrift te lezen te beoordelen: prof. dr. J.D. de Jong, prof. dr. J.S. Burgers, prof. dr. A.E.R.C.H. Boonen, prof. dr. J.C.M van Weert en dr. A.F. de Winter.

Dan mijn promotor Jany Rademakers en copromotor Monique Heijmans. Wat een reis was het! Monique, wat heb ik veel van je geleerd in de COMPAR-EU jaren. Dank voor je creativiteit, werkspirit en enorme motivatie. Door jou is zowel COMPAR-EU als mijn proefschrift naar een hoger niveau getild. En Jany, wat een geluk dat ik op mijn 22e als student bij jou terecht kwam om mijn masterscriptie te schrijven. Bedankt voor alle kennis en kunde die je me de afgelopen jaren bijgebracht hebt. En daarmee bedoel ik niet alleen de vakinhoudelijke vaardigheden. In mijn eerste week als 'jouw' nieuwe junior kreeg ik tijdens de lunch gelijk een paar belangrijke tips mee voor als ik later een succesvolle onderzoeker zou zijn: hou altijd je eigen achternaam én je eigen bankrekening! Wat ik ook bijzonder vind is dat we tijdens de buitenlandse tripjes veel de tijd hadden om te sparren over dingen binnen en buiten werk, wat ik belangrijk vond en waar ik heen wilde. Dit heeft me in de afgelopen jaren veel geholpen, want dit proefschrift is er zeker niet vanzelf gekomen. Daarom nogmaals dank voor de inspiratie, motivatie en vooral ook de incidentele schop onder m'n kont als ik die nodig had. Het zal gek voelen als ik straks, 8 jaar later, echt 'los' van je ben. Jij, Monique en ik hebben nogal wat meegemaakt in de afgelopen jaren, zeker als we op pad waren. De nodige anekdotes zullen nog wel voorbij komen de komende weken, zoals de dag dat Ajax de Champions League finale nét misliep en jij echt niet meer wist wat je met me aan moest. En uiteraard Corfu, waar ik strompelend op krukken dat eiland (en de rest van Griekenland) over ging en we uiteindelijk noodgedwongen de laatste nacht met z'n drieën op een kamer sliepen. Slaapfeestje met je promotor en copromotor, dat kunnen er niet veel zeggen!

Dit proefschrift schreef ik bij het Nivel. Wat heb ik hier veel leuke en lieve collega's ontmoet! Om te beginnen mijn kamergenootjes van 1.13 en de buren van 1.12. De koffierondjes om 10.00 en 15.00 uur waren vaste prik en mijn houvast van de dag. Femke en Kim in het bijzonder, ik ben trots op jullie hoe jullie het promoveren aangepakt hebben en ook mij door het traject heen gesleept hebben. Alle feestmomentjes én tegenslagen in het traject hebben we gedeeld en vaak genoeg met wijn gevierd. Het wordt trouwens wel weer tijd voor zo'n wijnmomentje… En Kim, naast kamergenoot en collega was jij nog veel meer: verpleegkundige, psycholoog, personal coach, noem maar op. Jij was daar met pleisters, een dikke knuffel, wijn of chocolade wanneer ik dat nodig had. Je keek zelfs de samenvattingen van Ajax zodat je de volgende dag wist in welke status ik op kantoor zou zijn. Vanaf het begin was het duidelijk dat wij elkaars paranimf zouden worden en ik ben trots op hoe we het allemaal gedaan hebben. Ik ben blij dat we elkaar na het Nivel blijven zien en dat moeten we ook zeker zo houden! Naast deze shout-out bedank ik ook nog graag Marion voor de opmaak van mijn proefschrift, Laura voor de (altijd zeer snelle) Engels checks, Elsie voor de koekjes en bijpraatsessies, Hille en Laurens voor de altijd gezellige juniorenborrels en de Nivel ORries voor de fijne tijd in de OR.

Naast mijn Nivel collega's bedank ik ook graag alle collega's van het COMPAR-EU consortium, met Marta, Carola, Rosa, Ena en Claudia in het bijzonder als co-auteurs van mijn artikelen. Na COMPAR-EU wilde ik de opgedane kennis in de praktijk gaan inzetten en zo ben ik bij Q-Consult Zorg terecht gekomen. Bij deze wil ik ook graag mijn Qollega's bedanken voor het warme welkom en ook voor de aanmoediging en flexibiliteit bij het afronden van dit proefschrift.

Heel veel dank ook aan alle vriendinnen en vrienden die voor me klaar stonden en voor de nodige afleiding hebben gezorgd. Het begin van dit proefschrift is ontstaan toen ik nog op de Vismarkt woonde, omringd door mijn lieve Vissies: Hes, Stef, Myr en Anne. Jullie hebben deze tijd tot een feestje gemaakt en dat doen jullie nog steeds! Myr, van brugpiepers naar 30ers en eigenlijk zijn we niks veranderd. En Anne, m'n blondie, wat ben ik trots op jou met lieve Yara. Hes, wat ben ik blij dat je de Vismarkt binnen kwam wandelen. Nadat ik (heel letterlijk) voor je gevallen ben, ben je inmiddels ruim 8 jaar later onmisbaar geworden. En nog bedankt dat je me altijd voorzag van eten en wijn als ik weer eens achter mijn laptop zat. En last but not least, Stef, Steffie, Musa, Stefner, m'n gekke lieve stuiterbal. Soms kijk ik naar ons en denk ik: hoe kunnen twee mensen zo verschillen en tegelijk zo goed samen gaan!? Toch een beetje ying en yang denk ik ;). Oh en ik hoop dat je in dit stuk geen spelfouten vindtdt, want anders hoor ik dat de rest van mijn leven vrees ik.

En dan mijn lieve familie. Papa en mama, wat ben ik blij dat ik altijd bij jullie terecht kan. Voor de serieuze zaken, maar vooral ook voor 'zomaar' even een bakkie of een biertje. Het is fijn dat jullie altijd apetrots zijn en alle overwinningen en tegenslagen met me meeleven. Mama, ik ga door de jaren heen steeds meer op jou (en daarmee stiekem ook op oma) lijken, en daar ben ik trots op! Veel van de kwaliteiten die ik nodig had om dit proefschrift te schrijven heb ik toch wel van jou! Pap, toen jij nog de trainert was ben ik eraan gewend geraakt om wekelijks een (aantal) biertje(s) te doen en de week te evalueren. Deze afleiding was altijd zeer welkom! Gelukkig vinden we nog steeds genoeg momenten om dit erin te houden.

Porkie! Wat zijn we volwassen geworden hè. Bedankt dat je me altijd blijft uitdagen om het beste uit mezelf te halen. Eigenlijk heb jij me al die tijd al voorbereid op de verdediging. Je kritische vragen over mijn onderzoek hebben me in ieder geval goed scherp gehouden de afgelopen tijd! Ik ben trots op jou en trots op ons, samen met dat gekke zusje van ons. Lieve Fleur, zusje en mijn beste maat. En dan nu ook nog eens paranimf! Toen je had opgezocht wat dat was vatte je het samen als; dus ik moet er tijdens de verdediging gewoon naast zitten van 'I've got your back!'? Tijdens het promoveren heeft deze rol een fancy naam, maar eigenlijk vervul je deze rol altijd al. Wat er ook is, ik weet dat jij altijd achter me staat!

Tot slot mijn lieve Karel. Het is gelukt, hij is af! Bedankt voor je support, vooral bij de laatste loodjes. Zelfs als ik bijna met mijn laptop ging gooien, toverde jij een glimlach op mijn gezicht. Eigenlijk maak jij alles leuker. Op naar nieuwe avonturen!