
Health
Literacy
An asset for public health
Iris van der Heide

Health literacy: an asset for public health

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The research described in this thesis was conducted at the Centre for Nutrition, Prevention and Health Services, National Institute for Public Health and the Environment (RIVM), Bilthoven, the Netherlands and at the Netherlands Institute for Health Services Research (NIVEL), Utrecht, the Netherlands. NIVEL participates in the Netherlands School of Primary Care Research (CaRe), acknowledged by the Royal Dutch Academy of Science (KNAW). The Dutch Ministry of Education, Culture and Science provided financial support for this thesis. NIVEL and RIVM provided financial support for the printing of this thesis.

ISBN: 978-94-6122-300-5

Cover design: Désirée Staarman
Lay-out: Christel van Well, Désirée Staarman
Printed by: Gildeprint

VRIJE UNIVERSITEIT

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ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad Doctor aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof.dr. F.A. van der Duyn Schouten,
in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de Faculteit der Aard- en Levenswetenschappen
op donderdag 28 mei 2015 om 13.45 uur
in de aula van de universiteit,
De Boelelaan 110

door

Iris van der Heide

geboren te Leusden

promotor:	prof.dr.ir. A.J. Schuit
copromotoren:	dr. E. Uiters
	dr. J.J.D.J.M. Rademakers

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Chapter 1

Introduction

Background

In the past decennia, in the Netherlands and other Western countries, citizens have increasingly been expected to fulfil an autonomous and responsible role when it comes to their health and healthcare.[1] This has been motivated by various societal developments:

1. A number of legal reforms were introduced in the 1990's that were directed at strengthening a patient's position in healthcare (e.g. the Dutch Law of Agreement to Medical Treatment (WGBO)).[2] Simultaneously, 'patient-centred care' became an important perspective as increased attention was given to patient preferences in healthcare practices and the involvement of patients. For example, whereas in the past, healthcare providers predominantly made treatment decisions, shared decision-making has increasingly become the point of departure.
2. Another development is the aging population in the Netherlands, which leads to a growing number of elderly citizens with one or more chronic health conditions. This leads to an increase in healthcare needs as well as a decrease in potential labour force in the healthcare sector.[3] Therefore, changes in the healthcare system are needed to meet the healthcare needs of individuals with a chronic condition.[4] In this respect a strong call for patient self-management has been made.[5] Self-management is directed at enabling patients to take care for their disease independently, for instance by stimulating healthy behaviours and monitoring the symptoms of a condition.[4] This requires that patients fulfil an active role in the care for their disease.
3. In 2006, reforms directed at transforming the Dutch healthcare system from a supply to a demand regulation have also contributed to the increased focus on citizens' autonomy and responsibility with respect to health and healthcare. This includes the introduction of the Health Insurance Act (Zvw) and the Act on Market Regulation in Healthcare (WMG).[6] These reforms were intended to reorganize healthcare on a regulated-market basis and thus, Dutch citizens became more important as stakeholders in the system. As a result, individual Dutch citizens now need to make personal choices among insurance companies and healthcare providers.

More room for autonomy and individual responsibility with respect to health and healthcare can be considered a positive development, since it meets the human value that individuals should be free to decide what is best for his or her health. On the other hand, the focus on individual responsibility for health has raised some concerns. For example, some question whether every individual is

able to make well-considered decisions and whether those who are already disadvantaged when it comes to their health become even more disadvantaged, since they may be less equipped to manage their disease and organize their care.

In order for patients and citizens to fulfil an active and responsible role regarding their health and healthcare, people need various competences. Competences encompass characteristics such as knowledge, skills, mind sets and thought patterns.[7] Individuals with more or better developed competences may have a higher opportunity of obtaining or maintaining the best possible state of health and receiving the care they need compared to those with less or less developed competences. For instance, individuals who are more knowledgeable about the benefits of taking medication correctly may be advanced with respect to their health compared to those who are less knowledgeable in this regard.[8]

The same applies to skills, including the skills to obtain and use health- and healthcare-related information. Those who have the skills to obtain relevant information and to understand and judge it, have a greater opportunity to find the care they might need or to learn about their health and hazards for their health than those who are less skilled. However, not everyone is able to obtain the right information, understand or judge it, or use it to the benefit of their health or the health of others. This specific set of skills is referred to by the term 'health literacy'. The World Health Organization (WHO) stresses the importance of increased attention for health literacy in research, policy and practice, since it is the right of individuals to have access to health information and health systems that they can understand and navigate.[9] The importance of health literacy for health and health-related behaviour among the Dutch population will be the central theme of this thesis.

Health literacy

Health literacy skills reflect the ability to access, understand, appraise and use health-related information in various domains.[10] Important domains in this regard are healthcare and prevention. In general prevention refers to the prevention of disease (e.g., vaccination and screening), the promotion of health (e.g., stimulation of a healthy lifestyle) and the protection of health (e.g., quality control of drinking-water).[11] In the current thesis, the term prevention will refer to the prevention of disease by vaccination or screening.

Health literacy skills are relevant when it comes to understanding information from healthcare providers, as well as information in print from

newspapers or medication leaflets and digital information from websites. In part, interest in health literacy is driven by its potential contribution to individuals' ability to exert control and make personal decisions with respect to their health and healthcare.[12] Individuals who have better access to information sources and who are better able to understand information are more likely to internalize the information.[8] This could contribute to better health outcomes and/or to lower healthcare use, since health education may have a larger effect on the health-related behaviour of individuals with higher health literacy skills.

A systematic review shows that individuals' health literacy skills can contribute to the explanation of the variation in health-related behaviour and health outcomes, such as perceived health status, hospitalizations, glycaemic control and vaccination or screening, in addition to other factors like education, sex, age and ethnicity.[13] However, health literacy is relatively infrequently addressed in studies that address variation in health-related behaviour and health outcomes. Factors that are often addressed in this regard include individual characteristics such as ethnicity, sex, socio-economic position and age[14,15] as well as psychosocial factors such as social support, motivation, beliefs/attitude, self-efficacy and knowledge.[16-18] Therefore, health literacy seems to have an added value to other factors that are generally addressed when researchers attempt to explain variation in health-related behaviour and health.

Interest in health literacy is also prompted by its potential role in explaining health disparities.[13] Health disparities are an important public health concern, even in countries with strong welfare systems such as the Netherlands.[14,15,19-22] Studies indicate that health literacy can be considered as an underlying mechanism driving the relation between socio-economic position and health outcomes.[23-26] Therefore, the WHO considers health literacy to be a central determinant of health inequalities and emphasizes the importance of research and initiatives to tackle the negative influence of lower health literacy on health outcomes.[9]

Conceptualization of health literacy

Research on health literacy has emerged partly from the field of education in North America. Nationwide surveys of adult literacy conducted in the United States in the 1990s triggered interest in investigating literacy in the context of healthcare.[27] Literacy encompasses the ability to read and write (basic literacy skills), but is also more broadly defined as the ability to use printed and written information in order to function in society, reach one's goals and develop knowledge and opportunities.[28] These nationwide literacy surveys have revealed

that those with the lowest literacy levels were also most likely to have the highest risk for health problems.[29] During this period, the term health literacy became broadly adopted by public health theorists, originally defined as reading, writing and numeracy skills in the context of health and healthcare.[30]

As the health literacy paradigm developed, it was noted that greater emphasis should be placed on health literacy beyond the medical setting, since health is constituted in daily life outside the consultation room or hospital.[31] Furthermore, some commentators stated that the focus on reading and writing was too narrow and that individuals needed a wide range of cognitive and social skills to make best use of health systems.[12] In this respect, Nutbeam's typology of health literacy became influential since it conceptualized health literacy as advancing through levels of cognitive, inter-personal and social skills.[12] This typology describes health literacy as consisting of three types: functional or basic health literacy, communicative or interactive health literacy and critical health literacy.[41-43] According to Nutbeam, these three types of health literacy characterize the application of necessary skills for functioning effectively in everyday situations (functional health literacy), to more advanced literacy and cognitive skills that can be used to actively participate in everyday activities and apply new information to changing circumstances (interactive or communicative health literacy). At the top, health literacy extends to the even more advanced cognitive and social skills needed to critically analyse information, and use information to exert greater control over life events and situations (critical health literacy).[32,33,42] In this typology, health literacy encompasses more than the ability to read information in print in a medical context, but also the ability to understand and react to verbal information, for example.

In addition to the three types of health literacy, Nutbeam also drew a distinction between two ways of approaching health literacy in research and practice, namely the 'risk approach' and the 'asset approach'. The risk approach emerged from the perceived risk of low literacy for health outcomes. Research has implied that low literacy is associated with poorer health outcomes and higher healthcare costs, which has called attention to low literacy as a deficiency in the context of healthcare.[12] The risk approach reflects the way health literacy is currently most often conceptualized in research stemming from clinical practice. Another perception of health literacy is as an asset—a means to exert greater control over health and over personal, social and environmental determinants of health. In this respect, health literacy is seen as an asset that can be developed instead of a deficiency. This 'asset approach' is more often adopted by public health researchers.[12] Yet to date, most studies on health literacy have

focused on health literacy as a risk factor rather than an asset for health, although the latter approach to health literacy is gaining momentum.[32,33]

Defining health literacy

As already indicated by the foregoing, the conceptualization of health literacy is not univocal and it is also subject to change.[34] Over time, more than 17 definitions of health literacy have been suggested[10] and the best way to define health literacy is still a topic of debate. For example, there is no agreement upon whether to include psychological factors such as knowledge and motivation as part of health literacy. Some scholars state that health literacy reflects skills, which can be learned and practiced and should not be entangled with psychological factors. Others find motivation a critical part of people's ability to handle health-related information. Additionally, the discussion surrounding the conceptualization of health literacy is currently engaged with the question of whether or not context-specific literacies should be (further) distinguished (such as diabetes health literacy or media literacy) or whether a robust measurement of a general set of skills applicable in various health-related contexts should be the goal. Furthermore, there are deliberations on whether health literacy extends beyond individual skills and reflects the capacities of institutions or societies as well. This has led to terms such as 'health-literate organizations', which refers to organizations that make it easier for people to navigate, understand and use their services and information.[35]

Measuring health literacy

Similar to the conceptualization of health literacy, the most appropriate way to measure health literacy is subject for discussion. Instruments that stem from a 'risk' perspective on health literacy were initially developed as screening instruments to be used by healthcare providers in clinical practice. These instruments are often applied to differentiate people with lower health literacy from those with higher health literacy. Such instruments are relatively short and focus on a quick identification of those who are likely to have lower health literacy skills. Examples are the Rapid Estimate of Adult Literacy, the Wide Range Achievement Test and the Test of Functional Health Literacy in Adults (see Table 1.1). Outcomes are often presented in quantitative terms (e.g., a certain number of people with low health literacy). Some of these instruments have also been validated and applied in questionnaire-based studies that aim to relate health literacy to health outcomes, such as the Set of Brief Screening Questions and the Newest Vital Sign (see Table 1.1). Instruments that stem from

an 'asset' point of view on health literacy have been developed to gain insight into the distribution and development of health literacy in the general population and appear to be more useful for application in public health. These types of instruments are extensive and generally provide a relative indication of health literacy (higher or lower scores). Examples are the European Health Literacy Survey Questionnaire, the Health Activities and Literacy Scale and the Health Literacy Questionnaire (see Table 1.1).

Table 1.1 Health literacy instruments

Author (year)	*Instrument*	*What does it measure and how?*	*Context*
Jastak et al. (1984)[37]	Wide Range Achievement Test – Revised (WRAT-R)	Word recognition based on 57 items which requires pronouncing letters and words.	Clinical practice
Davis et al. (1991, 1993)[38,39]	Rapid Estimate of Adult Literacy in Medicine (REALM)	Reading skills based on 125 words (long version) or 66 words (short version). Subjects are asked to read the words aloud and receive a score of one point per correctly pronounced word. Scores below 18 indicate that patients might not be able to read most low-literacy materials, scores between 19 and 44 indicate that patients need low-literacy materials, scores between 45 and 60 indicate that patients may have problems in reading most patient education materials, and scores above 60 indicate that patients are probably able to read most patient education materials.	Clinical practice
Parker et al. (1995)[40]	Test of Functional Health Literacy in Adults (TOFHLA)	Reading comprehension, based on 50 items and numerical ability based on 17 items.	Clinical practice
Schwartz et al. (1997)[41]	3-item numeracy measure	Health numeracy in the context of breast cancer screening, based on 3-items assessing familiarity with probabilities, converting percentages to proportions and proportions to percentages.	General population

- table 1.1 continues -

- table 1.1 continued -

Author (year)	*Instrument*	*What does it measure and how?*	*Context*
Lipkus et al. (2001)[42]	10-item expanded numeracy scale	Health numeracy based on the 3 items as proposed by Schwartz and colleagues (1997) extended with 7 additional items assessing the extent to which people can differentiate and use percentages and proportions, convert percentages to proportions and proportions to percentages and convert probabilities to proportions.	General population
Chew et al. (2004)[43]	Set of Brief Screening Questions (SBSQ)	Perceived difficulties with health information based on three 5-point Likert scale statements ranging from 0-4. An average score of ≤ 2 indicates inadequate health literacy, and a score of>2 adequate health literacy.	Clinical practice
Rudd et al. (2004)[24,36]	Health Activities and Literacy Scale (HALS)	Prose-, document and problem solving skills based on tasks that differ in complexity. Points ranges from 0 to 500 and are given for correctly fulfilling the task. More points were given for more complex tasks and less points for more simple tasks. An average score (ranging between 0 and 500) was calculated, with a cut-of scores for very poor health literacy, poor health literacy, adequate health literacy, high health literacy and very high health literacy.	General population
Weiss et al. (2005)[44]	Newest Vital Sign (NVS)	Reading skills, numeracy skills and the ability to apply information based on six items concerning a nutrition label from an ice cream container. For each correctly answered one point is granted. A score between 0 and 1 suggests a likelihood of 50% of limited literacy, 2-3 indicates the possibility of limited literacy, and 4-6 almost always indicates adequate literacy.	Clinical practice

- table 1.1 continues –

- table 1.1 continued -

Author (year)	*Instrument*	*What does it measure and how?*	*Context*
Ishikawa et al. (2008)[45]	Functional Communicative and Critical Health Literacy measure (FCCHL)	Perceived functional, communicative and critical health literacy based on 14 statements using 4-point Likert scales from 1-4. Total scores are obtained by summing item scores and dividing by the total number of items.	Clinical practice
Lee et al. (2010)[46]	Short Assessment of Health Literacy (SAHL)	18 items that reflect a word recognition test combined with a comprehension test with multiple-choice questions.	Clinical practice
Fullam et al. (2011)[47]	European Health Literacy Survey Questionnaire (HLS-EU-Q)	Perceived difficulties with accessing, understanding, appraising and applying health related information concerning healthcare, disease prevention and health promotion. Based on 47 items (long version) or 16 items (short version) and 4-point Likert scale from 1-4.	General population
Osborne et al. (2013)[48]	Health Literacy Questionnaire (HLQ)	Perceived functional, communicative and critical health literacy based on 44-items with 4-point or 5-point Likert scale options covering nine areas of health literacy.	General population and Clinical practice

Instruments to measure health literacy can thus be categorized according to the perspective of health literacy that they are most closely serving. In addition, a distinction can be made between instruments that measure health literacy objectively and subjectively. Subjective measures provide an indication of the extent to which people feel they can understand and use health-related information. These instruments may also provide information on the demands of health systems, although, to date no instrument has been developed for this purpose. In addition to subjective measures, objective health literacy measures provide an indication of an individual's literacy capability in the context of health derived by a careful examination of their ability to accomplish certain reading and problem-solving tasks. These are more closely related to the field of literacy research.[36] Table 1.1 provides an overview of frequently applied health literacy measures, including the measures that were used in the present thesis

(i.e., the Set of Brief Screening Questions; the Functional, Communicative and Critical Health Literacy measure; the Health Activities and Literacy Scale; the European Health Literacy Questionnaire).

Conceptual model of health literacy

The association between the performance on health literacy measures and health outcomes is indicated by a number of studies, but relatively little is known on processes through which health literacy affects health. In order to guide research on the relation between health literacy and health, Von Wagner and colleagues developed a conceptual model, see Figure 1.1, including key-elements of established psychological health-behaviour models.[49] This model expands on the model developed by Paasche-Orlow and Wolf in 2007 [50] and proposes that the association between health and health outcomes could be mediated by a range of health actions. The model makes explicit what factors are expected to constitute health literacy and via which routes health literacy is expected to affect health actions, which may subsequently determine health outcomes. Determinants of health literacy included in Von Wagners' model are:

- Basic skills in reading and arithmetic. Being able to decode written text is considered a requirement for health literacy.
- Internal influences, which are thought to influence both the development as well as the maintenance of health literacy. Internal influences include cognitive abilities, age-related cognitive decline and pre-existing knowledge.[51]
- External influences, which are also thought to influence both the development and the maintenance of health literacy. External influences include the social environment (in particular parents), which plays an important role in acquiring language skills[52], formal educational opportunities[24,25] and experiential learning. Experiential learning includes life events that increase exposure to (health-related) information, which can maintain or strengthen health literacy. This may include work, family or health-related events. However, little is known with respect to experiential learning throughout the life-course in relation to health literacy.

The model also focuses on the impact of health literacy on psychological determinants of health actions. To a large extent, the selection of these determinants is based on established theories and psychosocial models of health behaviour such as the Theory of Planned Behaviour and the Health Belief Model.[53,54] These types of models share the idea that health actions result from a combination of motivational factors (e.g., knowledge and attitude) as well as

volitional factors (e.g., self-efficacy and planning skills). Various studies have underlined the association between health literacy and motivational factors, as well as self-efficacy.[55] According to Von Wagner's framework, these factors can be influenced by practical barriers (e.g., system characteristics or financial costs).[49] In their paper, Von Wagner and colleagues further specify the psychological processes that are included in their model, describing that for instance preferences for emotional versus analytical information processing can also be placed under the denominator 'attitudes'.[49]

Furthermore, they specify the volitional phase, by describing that this may include decision-making skills as well.[49] Von Wagner and colleagues propose that health literacy can influence individuals' decision-making process when deciding whether or not to perform a certain health action, like participation in cancer screening or vaccination. Furthermore, the researchers describe that in addition to these psychological factors, socio-economic and demographic determinants like gender and wealth are likely to be associated with both health actions and health literacy.[49] These types of determinants were however not included in their conceptual model.

Last, the model outlines three types of health actions that can indirectly be influenced by health literacy. The first is the access and utilization of healthcare, the second is patient-provider interaction and the third is management of health and illness. Health literacy as a determinant of the utilization of healthcare is based on the finding that people with lower health literacy make more use of emergency care and hospital care, and make less use of preventive services (for instance, cancer screening).[13] For example, less knowledge of screening possibilities or the severity of cancer, or a negative attitude towards screening could be a pathway between lower health literacy and lower cancer screening uptake. With respect to the second type of health action, patient-provider interaction, health literacy can have an important influence on the ability to interact with health-care providers. For instance, patients with lower health literacy may have more difficulty completing medical forms and asking relevant questions.[56-58] The third type of action, management of health and illness, may include lifestyle-related behaviours as well as the performance of self-care tasks. Several studies indicate that lower health literacy is associated with a lower understanding of disease and treatment, lower adherence to medical instructions and lower self-managements skills.[59]

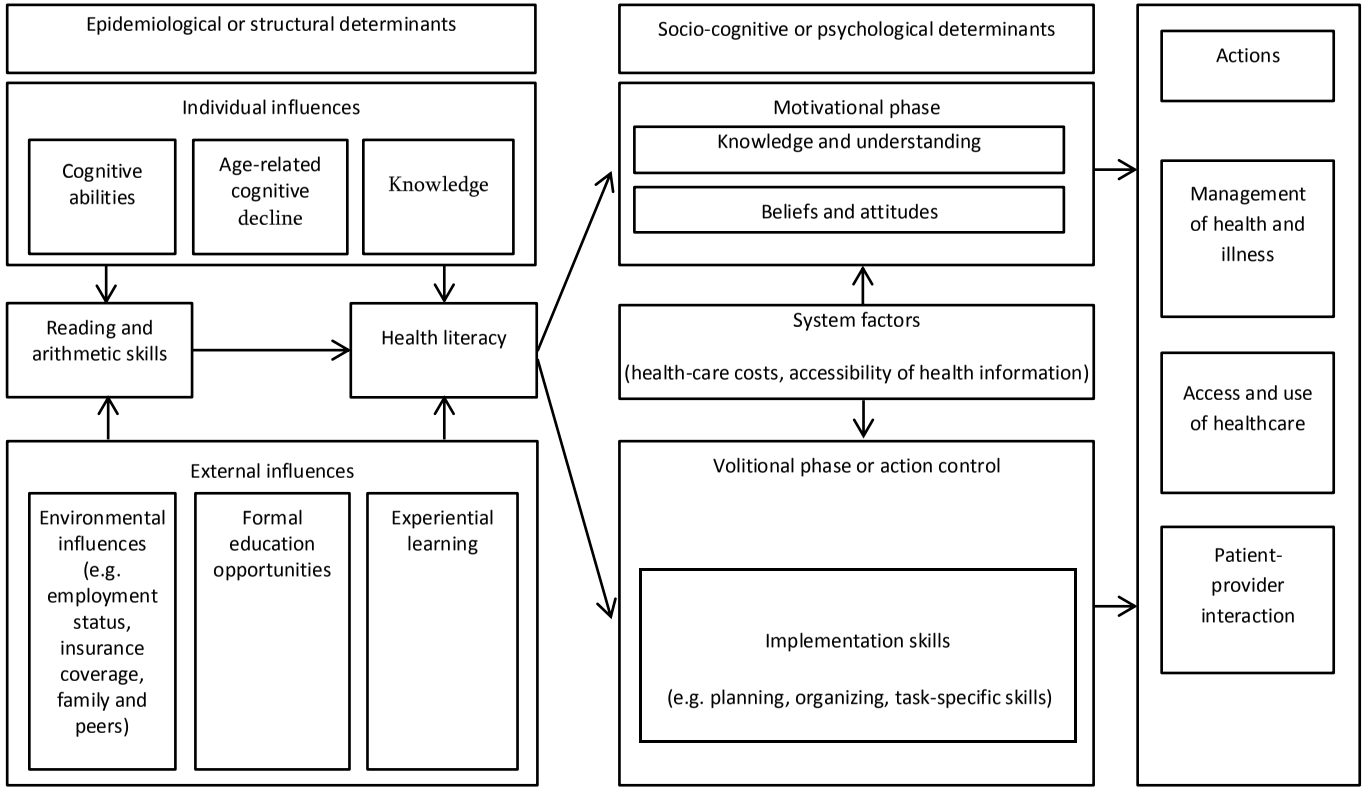

Figure 1.1 Conceptual model of determinants and consequences of health literacy by Von Wagner et al., 2009

Aim and research questions

To date, most studies on health literacy stem from North America and until recently, insights from European countries were lacking to a large extent.[60] However, the importance of health literacy for public health is gradually being recognized in Europe.[9] Little is known on the health literacy skills of general populations in relation to socio-economic and demographic characteristics, health actions and health-outcomes. Furthermore, most studies on health literacy have been conducted in the context of clinical practice, mainly among patients. An increased attempt is being made to foster individuals' responsibility and autonomy, particularly with respect to chronic care and prevention. This makes it especially relevant to study the role of health literacy in the context of chronic care and prevention. Therefore, this thesis aims to provide insight into the health literacy skills of the Dutch adult population in relation to socio-economic and demographic characteristics, psychological factors, health actions and health. Three research questions were formulated that could be placed in the conceptual framework of Von Wagner and colleauges.[49] More specifically, the following three research questions were formulated:

1 *To what extent is health literacy associated with socio-economic and demographic characteristics and with health status?*

2 *To what extent is health literacy associated with (psychological determinants of) use of primary care, patient-provider interaction and self-management in the context of chronic care?*

3 *To what extent is health literacy associated with psychological determinants of participation in prevention programs?*

Outline of this thesis

In line with the three research questions, this thesis will be structured in three parts. Figure 1.2 illustrates the specific routes between health literacy and possible determinants, psychological factors, and health actions, that are presented in the present thesis. The numbers accompanying the arrows in this figure represent the chapter numbers in which the specific pathway will be the

focus of research.

Part I – Health literacy in the Dutch adult population

The objective of the first part of this thesis is to examine to what extent health literacy is related to socio-economic and demographic characteristics and health status in the Dutch adult population. The studies as described in this part of the thesis are driven by literature that suggests that health literacy relates to socio-economic and demographic characteristics as well as to health outcomes, rather than the conceptual model of Von Wagner and colleagues.[49] Ch*apter 2* provides insight into the perceived health literacy skills of Dutch adults and the extent to which perceived health literacy skills relate to socio-economic position (indicated by level of education, income and perceived social status), age and gender. The findings as described in this chapter, are based on data from the European Health Literacy Survey (HLS-EU). Subsequently, ***Chapter 3*** provides insight into the health literacy skills of the Dutch adult population based on an objective health literacy measure, namely the Health Activities and Literacy Scale (HALS). This chapter describes the extent to which health literacy relates to perceived general, mental and physical health and whether health literacy mediates the association between attained level of education and perceived general, mental and physical health.

Part II – Health literacy in the context of chronic care

The aim of the second part of this thesis is to obtain insight into the relation between health literacy and (psychological determinants of) use of primary care, patient-provider interaction and self-management in the context of chronic care. In this respect, ***Chapter 4*** focusses on the relation between health literacy and diabetes self-management among patients with diabetes and explores the role of knowledge in this relation. The study described in this chapter is based on data that was obtained for the purpose of a larger observational study performed between January 2008 and June 2010 that focused on disease management programs and related bundled payments. Then, in ***Chapter 5*** the relation between health literacy and perceived ability to exert control in healthcare is addressed, as indicated by perceived ability to exert control over the organization of care, interaction with health-care providers and self-care. Additionally, the relation between health literacy and the number of GP visits on a yearly basis is described. In this respect, attention is given to three types of health literacy: functional, interactive and critical health literacy. This study is based on data

form the 'National Panel of people with Chronic illness or 107 Disability' (NPCD), a Dutch nationwide prospective panel-study on the consequences of chronic illness or a long term disability.

Part III – Health literacy in the context of prevention

The aim of the third part of this thesis is to obtain insight into the relation between health literacy and psychological determinants of participation in prevention programs. More specifically, the chapters in this part of the thesis focus on decision-making with respect to cancer screening and preferences towards childhood vaccination. As expounded in the first paragraph of this general introduction, citizens are increasingly expected to be autonomous and responsible, including when it comes to the decision to participate in prevention programs. Whereas Dutch cancer screening campaigns used to be based on persuasive communication techniques, a shift has been made to an informed decision-making approach.[61] This approach is based on the idea that in order to facilitate well-considered decisions, information on pros and cons should be provided. In the Netherlands, this approach is currently manifested with respect to the national colorectal cancer (CRC) screening program, which was introduced in 2014. In order to support the development of education materials on CRC screening, we aimed to provide insight into the current knowledge base on health literacy and informed decision-making on CRC screening. In this context, ***Chapter 6*** describes a systematic review of literature on the relation between health literacy and informed decision-making with respect to CRC screening. In this review it is examined in which aspects of the informed decision-making process individuals with lower health literacy differ from those with higher health literacy. Subsequently, this review examines whether health literacy is associated with the extent to which informed decisions are made. Then the last chapter of this thesis, ***Chapter 7***, describes how health literacy relates to parents' decisions to vaccinate their new-born against the rotavirus. By the use of a discrete choice experiment, whether parents with lower health literacy skills differ from parents with higher health literacy skills in their preferences for vaccine characteristics is explored. This study is part of a larger study investigating parental preferences for rotavirus vaccination.

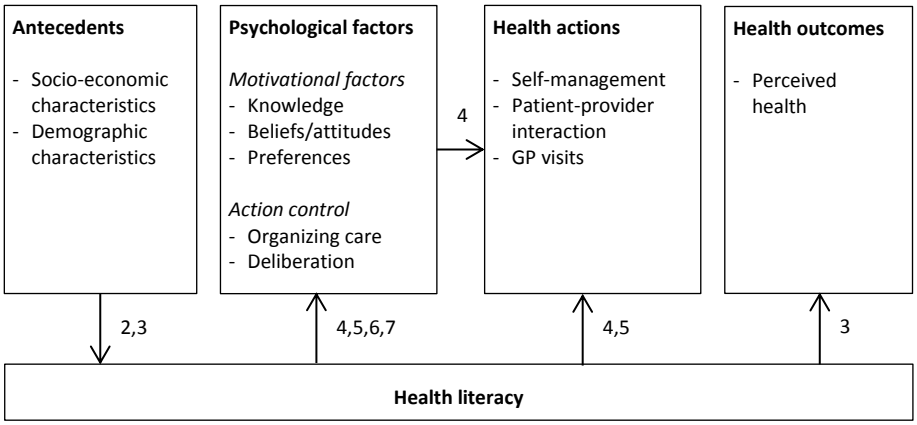

Figure 1.2 *Studied associations based on the conceptual framework of Von Wagner et al., 2009, including the chapter numbers in which the studied associations are described.*

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Part I

Health Literacy in the Dutch adult population

Chapter 2

Health literacy of Dutch adults: a cross sectional survey

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BMC Public Health, 2013, 13:179

Abstract

Background Relatively little knowledge is available to date about health literacy among the general population in Europe. It is important to gain insights into health literacy competences among the general population, as this might contribute to more effective health promotion and help clarify socio-economic disparities in health. This paper is part of the European Health Literacy Survey (HLS-EU). It aims to add to the body of theoretical knowledge about health literacy by measuring perceived difficulties with health information in various domains of health, looking at a number of competences. The definition and measure of health literacy is still topic of debate and hardly any instruments are available that are applicable for the general population. The objectives were to obtain an initial measure of health literacy in a sample of the general population in the Netherlands and to relate this measure to education, income, perceived social status, age, and sex.

Method The HLS-EU questionnaire was administered face-to-face in a sample of 925 Dutch adults, during July 2011. Perceived difficulties with the health literacy competences for accessing, understanding, appraising and applying information were measured within the domains of healthcare, disease prevention and health promotion. Multiple linear regression analyses were applied to explore the associations between health literacy competences and education, income, perceived social status, age, and sex.

Results Perceived difficulties with health information and their association with demographic and socio-economic variables vary according to the competence and health domain addressed. Having a low level of education or a low perceived social status or being male were consistently found to be significantly related to relatively low health
literacy scores, mainly for accessing and understanding health information.

Conclusion Perceived difficulties with health information vary between competences and domains of health. Health literacy competences are associated with indicators of socio-economic position and with the domain in which health information is provided.

Introduction

During the past decades, there has been a growing interest in the concept of health literacy, accompanied by the increased emphasis on the role and responsibility of citizens in health and healthcare.[1-3] The importance of health literacy as a topic of research has been pointed out by a number of studies that suggest health literacy might play a significant role in maintaining or improving health and could be an unexplored predictor of health disparities.[4-6] The aim of the present study is to contribute to the theoretical knowledge being built up about health literacy. An initial insight into the health literacy of the general population will therefore be provided and its association with demographic and socio-economic characteristics will be examined.

An important issue regarding health literacy research is the ongoing debate on the definition and scope of health literacy.[1,7,8] Within this discourse, two main approaches can be distinguished, namely the 'clinical' approach and the 'public health' approach.[7,9] Key elements of definitions from a clinical perspective include elements of behaviour that mainly reflect individual competences needed to function in the role of patient within a healthcare environment.[8,10,11] Studies that define health literacy from a public health point of view extend the concept by addressing the public at large instead of patients and including dimensions beyond the medical context, such as the workplace, political arena or home.[4,12] Most research on health literacy stems from the clinical perspective. Additionally, research that stems from the public health perspective has mainly been carried out outside Europe, although there has been some recently in Switzerland.[4,13-15] Especially in the European situation, little is known about health literacy outside a clinical setting and among the general population.

The present paper is based on data gathered in the Netherlands in the context of the European Health Literacy Survey (HLS-EU). A research consortium with members from Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland and Spain made joint efforts to develop a common tool to measure health literacy in the general population.[16,17] This tool was based on a common definition and conceptual model of health literacy (see additional Figure 1 on page 55). Other measurement tools often measured health literacy as a unidimensional concept by focusing on text comprehension or word recognition.[18-20] The HLS-EU addresses health literacy as a multidimensional concept, embracing competences other than reading skills. More precisely, health literacy is measured as people's perceived ability to access, understand,

appraise, and apply health information. This measure is not limited to a single domain, but involves three domains of health, namely healthcare, disease prevention and health promotion, which have been clarified in more detail elsewhere.[17]

In addition to the development of an instrument (HLS-E-Q), the HLS-EU survey gathered information on socio-economic and demographic characteristics. Previous studies suggest that low health literacy is more prevalent among people with low levels of education and low incomes and those who are older.[5,6,21-24] As far as is known, perceived social status, an increasingly-used measure for socio-economic status, has not been studied in relation to health literacy before, but was included in this study as well.[25] As regards health literacy of men and women, the studies report varying results. Whereas some found no relationship[4,25], others report that one of the sexes is more likely to have low health literacy.[26,27] Better insights into the relationships between demographic and socio-economic characteristics and health literacy will help identify vulnerable groups with limited health literacy who are therefore possibly at risk of being in poor health.[28] Specific questions in our study therefore are 1) to what extent do adults perceive difficulties with the health literacy competences of accessing, understanding, appraising and applying health information in the domains of healthcare, disease prevention and health promotion and 2) to what extent are these competences related to demographic and socio-economic characteristics?

Method

Study design and data collection

A stratified random sampling design was applied to the Dutch population aged 15 years or older, in accordance with the Eurobarometer methodology.[29] The sample was stratified according to province and within provinces according to urban and rural areas, leading to a probability of inclusion that was proportional to population size and density. In the first stage, 699 areas were defined, including a total selection of 24,942 addresses. Households were selected randomly in each of these areas. In each household, one respondent was recruited over the phone or contacted by e-mail, following the closest birthday rule. During July 2011, 221 interviewers administered the questionnaires face-to-face with the pre-recruited respondents in people's homes. The questionnaires were conducted in Dutch. A

total of 2817 people were contacted of whom 1794 were not willing to participate, leading to a sample of 1023 participants (response rate 36%). It was decided to focus the analyses on persons aged 25 years or older, as income, education and social status are more stable after this age, resulting in a final sample of 925 adults.

Assessment of variables

Health literacy

The questionnaire for measuring health literacy in the general population in Europe (the HLS-EU-Q) was developed collectively by the HLS-EU consortium.[16] The questionnaire was based on the definition and conceptual model developed within the HLS-EU consortium, which are presented in the general introduction of the present thesis and described in detail elsewhere.[17] Textbox 2.1 presents four examples of items from the HLS-EU-Q. For the full questionnaire, please contact the fifth author (KS). The HLS-EU-Q was pre-tested for understandability and completeness, using focus groups in Greece, Ireland and the Netherlands (N=6 in each country) and face-to-face interviews in Ireland and the Netherlands (N=50 in each country). Extensive information on the development and pre-testing of the HLS-EU-Q is described elsewhere.[17,30] The final questionnaire, as illustrated in Table 2.1, measured health literacy across three domains of health, namely healthcare, disease prevention and health promotion. Within these domains, the questionnaire focused on (a) accessing, or the ability to seek, find and obtain health information (13 items); (b) understanding, or the ability to comprehend health information (11 items); (c) appraising, or the ability to interpret, filter, judge and evaluate health information (12 items); and (d) applying, or the ability to communicate and use the information to maintain and improve health (11 items). Answer categories on the health literacy questions (all phrased similarly to "On a scale from very easy to very difficult, how easy would you say it is to understand why you need health screenings?") were on a 4-point Likert type scale ranging from 1=very difficult, 2=fairly difficult to 3=fairly easy and 4=very easy. A "don't know" answer option was not provided, but only used when stated spontaneously. This response was coded as a missing value. In order to get an initial insight into perceived difficulties, answers were combined to sum scores per competence and a distinction was made between those who perceive numerous difficulties and those who perceive few difficulties. Those respondents with the lowest scores on all four competences (scores below the first quartile for accessing, understanding,

appraising as well as applying) were categorized as perceiving numerous difficulties; those with the highest scores were considered to perceive few difficulties (scores above the third quartile for accessing, understanding, appraising as well as applying). This was done per domain as well as over all domains.

Box 2.1 Examples of HLS-EU Questionnaire items (competence/health domain)

On a scale from very easy to very difficult, how easy would you say it is for you to…

…find out what to do in case of a medical emergency? (accessing/healthcare)

…understand what your doctor says to you? (understanding/healthcare)

…judge which vaccinations you may need? (appraising/disease prevention)

…make decisions to improve your health? (applying/health promotion)

Table 2.1 Competences and domains included in the HLS-EU Questionnaire

Competences	*Domains*		
	Healthcare	*Disease prevention*	*Health promotion*
Accessing	The ability to seek, find and obtain information on medical or clinical issues.	The ability to seek, find and obtain information on risk factors for health.	The ability to seek, find and obtain information on determinants of health.
Understanding	The ability to comprehend information on medical or clinical issues.	The ability to comprehend information on risk factors and derive meaning.	The ability to comprehend information on determinants of health and derive meaning.
Appraising	The ability to interpret, filter, judge, and evaluate information on medical or clinical issues.	The ability to interpret, filter, judge, and evaluate information on risk factors.	The ability to interpret, filter, judge, and evaluate information on determinants of health.
Applying	The ability to communicate and use information on medical or clinical issues to make informed decision.	The ability to communicate and use information on risk factors to make informed decisions.	The ability to communicate and use information on determinants of health to make informed decisions.

Demographic and socio-economic characteristics

The following demographic and socio-economic characteristics were analysed: sex, age, educational level, net household income per month and social status (see Table 2.2). Age was measured and analysed as a continuous variable. Educational level was measured on a six point scale. For the purpose of the analyses, education was categorized into 1) no education or primary education, 2) lower secondary education, 3) (upper) secondary education or post-secondary non-tertiary education (including vocational education), or 4) tertiary education (bachelor's degree or higher). Net monthly household income was measured on a ten-point scale. In the analyses, income was recoded into quartiles 1) less than 1850 euros, 2) 1850 – 2400 euros, 3) 2400 – 3600 euros, 4) 3600 euros or more. As regards perceived social status: there is evidence that this self-reported variable reflects standard markers of socio-economic status such as education and income, as well as having the advantage of being seen as a more accurate measure of social position.[26] In this study, perceived social status was assessed by the answer to the question: "On the following scale, step 1 corresponds to 'the lowest level in society'; step 10 corresponds to 'the highest level in society'. Could you tell me which step you would say you were on?" This item stemmed from the Eurobarometer.[31] Table 3 presents the scores in the categories low (1-4), medium (5, 6) and high (7-10), continuous scores were included in the analyses.

Statistical analyses

To explore reliability and internal consistency of the questionnaire, factor analyses (principal component analyses with promax rotation: data not shown) were performed and Cronbach's alphas were calculated. The internal consistency of the health literacy items (measuring accessing, understanding, appraising and applying) was satisfactory (Cronbach's α=0.84, 0.83, 0.85 and 0.78 respectively). In accordance with the domains defined beforehand, factor analyses distinguished between the factors 'healthcare', 'disease prevention' and 'health promotion' for the competences 'accessing', 'understanding' and 'applying'. With regard to appraising, the factor analysis identified only two factors, which were labelled 'healthcare and disease prevention' and 'health promotion', combining the items designed to measure health literacy in healthcare and disease prevention. The reliability and internal consistency analyses justified the calculation of sum scores for each combination of competence and domain. Descriptive statistics in terms of sum scores and means per item (sum score/number of items) were performed to answer the first research question.

Multiple linear regression analyses were used to answer the second research question concerning the associations between health literacy and demographic and socio-economic characteristics. For each competence within each domain, a multiple linear regression analysis was performed in SAS 9.2, including the means per item for each health literacy competence, education, income, social status, age, and sex.

Missing values

The dataset contained missing values concerning education (1%, N=9), subjective social status (3%, N=25) and income (16%, N=150), as presented in Table 2.2. Table 2.3 shows the missing values per health literacy domain and competence. The characteristics of the missing values on the health literacy competences are described in additional Table 1 on page 56. The method of multiple imputations by chained equations was used to handle the presence of missing values in the study data, as these were not missing completely at random (see additional Table 1 on page 56 for more details on the missing data).[32] Following this procedure, the original data set was completed 20 times. Each imputed dataset was analysed separately and the outcomes of each analysis were combined according to Rubin's rules to obtain the outcome of the whole analysis, which incorporates the uncertainty due to the missing values.[31] The imputations were done in R 2.14.0, with use of the mice package.[31,32] Recent studies have shown that this technique provides less biased results compared to a complete case analysis and is considered to be the state-of-the-art method for dealing with missing data.[33,34]

Results

The sample distribution in terms of sex, education and income (Table 2.2) was in accordance with the distribution in the Dutch population (not tabulated).[35] Adults aged 65 years or older were overrepresented and adults between 25 and 39 years of age were underrepresented in the studied population.[35]

Table 2.2 Characteristics study participants

Characteristics	*Total (n=925)*		*Men (n=439)*		*Women (n=486)*	
	%	*n*	*%*	*n*	*%*	*n*
Age in categories						
25 – 34	13.1	(121)	14.4	(63)	11.9	(58)
35 – 44	14.5	(134)	13.9	(61)	15.0	(73)
45 – 54	18.7	(173)	16.9	(74)	20.4	(99)
55 – 64	16.0	(148)	15.3	(67)	16.7	(81)
65 – 74	19.4	(179)	21.2	(93)	17.7	(86)
75 – 84	15.1	(140)	15.3	(67)	15.0	(73)
85+	3.2	(30)	3.2	(14)	3.3	(16)
Missing values	0	(0)	0	(0)	0	(0)
Highest completed education level						
No education or primary education	6.9	(64)	5.9	(26)	7.8	(38)
Lower secondary education	26.2	(242)	26.0	(115)	26.1	(127)
(Upper or post-) secondary non-tertiary education	29.1	(269)	29.0	(127)	29.2	(142)
Tertiary education (bachelor's degree or higher)	37.8	(350)	39.0	(171)	36.8	(179)
Missing values	1.0	(9)	0.7	(3)	1.2	(6)
Household net income per month in euros						
<1850	35.3	(326)	29.6	(130)	40.3	(196)
1850 – 2400	16.8	(155)	17.1	(75)	16.5	(80)
2400 – 3600	29.5	(273)	32.1	(141)	27.2	(132)
3600 or >	18.5	(171)	21.2	(93)	16.0	(78)
Missing values	16.2	(150'	16.4	(72)	16.0	(78)
Perceived social status						
Low	3.7	(35)	3.6	(16)	3.8	(19)
Medium	24.2	(224)	22.8	(100)	25.5	(124)
High	72.0	(666)	73.6	(323)	70.6	(343)
Missing values	2.7	(25)	3.4	(15)	2.1	(10)

Concerning the four competences of accessing, understanding, appraising and applying health information, the mean scores per item are all close to 3 (equal to being perceived as easy) where the maximum score is 4 (being perceived as very easy) (see Table 2.3). The mean score per item (over all domains) is lowest for appraising information (3.1) and highest for understanding information (3.4).

The scores presented in Table 3 imply that perceived difficulties vary between the health domains. Accessing health information seems to be perceived as more difficult in the domain of health promotion (mean score per item is 2.6) than in the domain of disease prevention (mean score per item is 3.4).

Table 2.3 Descriptive statistics per health literacy competence and domain (N=925) [a]

Competence Domain	*Items*	*Missings (n)* [b]	*Mean (SD)*	*Mean per item (SD)*	*Mean per item per quartile*		
					25	*50*	*75*
Accessing	11	231	35.2 (5.2)	3.2 (0.5)	2.6	3.2	3.7
Healthcare	3	82	9.7 (1.8)	3.2 (0.6)	2.7	3.3	3.4
Disease prevention	6	122	20.3 (3.1)	3.4 (0.5)	2.8	3.4	4.0
Health promotion	2	118	5.1 (1.7)	2.6 (0.8)	1.7	2.5	3.9
Understanding	11	157	36.8 (4.9)	3.3 (0.5)	2.8	3.4	3.9
Healthcare	4	58	13.5 (2.1)	3.4 (0.5)	2.8	3.4	3.9
Disease prevention	3	29	10.8 (1.5)	3.6 (0.5)	3.0	3.7	4.0
Health promotion	4	108	12.5 (2.6)	3.1 (0.7)	2.4	3.2	3.9
Appraising	12	219	36.7 (5.9)	3.1 (0.5)	2.5	3.1	3.7
Healthcare and prevention	9	201	27.0 (4.8)	3.0 (0.5)	2.4	3.0	3.6
Health promotion	3	47	9.8 (1.9)	3.3 (0.6)	2.7	3.5	4.0
Applying	9	196	28.9 (4.2)	3.2 (0.5)	2.7	3.2	3.8
Healthcare	3	16	10.8 (1.5)	3.6 (0.5)	3.0	3.7	4.0
Disease prevention	2	64	5.7 (1.7)	2.9 (0.8)	1.8	2.8	3.8
Health promotion	4	155	12.4 (2.7)	3.1 (0.7)	2.3	3.1	3.8

[a] Scores ranged from 'very difficult' (lowest score) to 'very easy' (highest score).

[b] Number of missing values per competence and domain before multiple imputation.

Comparing the health domains of healthcare, disease prevention and health promotion, the mean score per item (over all competences) was lowest in the domain of health promotion (3.0) and highest in the domain of healthcare (3.3) (not tabulated). Within the domain of healthcare, 9.6% of Dutch adults (N=89) perceived numerous difficulties, whereas 14.4% (N=134) perceived few difficulties (not tabulated). Furthermore, 4.8% (N=44) perceived numerous difficulties with information on disease prevention and 12.0% (N=111) perceived few difficulties (not tabulated). Finally, 9.2% (N=86) perceived numerous

difficulties with information on health promotion, whereas 8.6% (N=79) perceived few difficulties (not tabulated). Looking at the respondents who perceived numerous difficulties across all three health domains, it appeared that this was the case for 10.4% (N=96) of the respondents (those scoring below the first quartile on accessing, understanding, appraising as well as applying). Subsequently, 11.9% (N=110) of the respondents perceived few difficulties (scores above the third quartile on accessing, understanding, appraising as well as applying) across all domains (not tabulated).

As regards the associations of socio-economic and demographic variables with health literacy, none of the included socio-economic and demographic variables was consistently associated with all health literacy competences and domains addressed. Overall, it was found that people with a lower level of education, or who reported a lower perceived social status or were male perceived more difficulties with health literacy.

Taking into account all demographic and socio-economic variables, the results of the multiple regression analyses indicate a clear association of health literacy with level of education (see Table 2.4). The group with the lowest educational level in particular had significantly lower health literacy scores compared to the group with the highest educational level, indicating that the former group experienced more difficulties. However, this association differed between the competences addressed and was most obvious for the competences of accessing and understanding health information in the domains of healthcare and disease prevention. In the domain of health promotion the association was most obvious for understanding health information. With regard to accessing and understanding, the lowest income group was also found to have lower health literacy scores compared to those with the highest incomes. However, this was only found in the healthcare domain (Table 2.4).

In addition to the socio-economic indicators of education and income, social status was also found to be related to health literacy. The higher the self-reported social status, the higher the health literacy scores, except for accessing information on healthcare and health promotion and applying information on disease prevention. Age was found to be significantly associated with health literacy scores in some domains. Like education, age was mainly significantly related to accessing and understanding health information, but also to some extent to appraising health information in the domain of health promotion. In terms of sex, men perceived more difficulties than women, except for accessing and applying in the domain of health promotion.

*Table 2.4 Associations between socio-economic and demographic characteristics and health literacy competences**

Healthcare	*Accessing*		*Understanding*		*Appraising* [a]		*Applying*	
	B	*95% CI*	*B*	*95% CI*	*B*	*95% CI*	*B*	*95% CI*
Education (reference: tertiary education)								
No education or primary education	**-0.2906**	**(-0.4653 to -0.1160)**	**-0.1949**	**(-0.3497 to -0.0402)**	-0.0562	(-0.2098 to 0.0974)	**-0.1576**	**-0.3021 to -0.0131)**
Lower secondary education	-0.0464	(-0.1558 to 0.0631)	**-0.1838**	**(-0.2772 to -0.0904)**	-0.0074	(-0.1030 to 0.0882)	-0.0678	(-0.1556 to 0.0200)
(Upper or post-) secondary education [b]	0.0557	(-0.0430 to 0.1544)	-0.0587	(-0.1432 to 0.0256)	0.0502	(-0.0368 to 0.1371)	-0.0431	(-0.1229 to 0.0367)
Income (reference group: 3600 or more)								
<1850 euros	**-0.2294**	**(-0.3738 to -0.0849**)	**-0.1283**	**(-0.2444 to -0.0121)**	-0.0418	(-0.1593 to 0.0758)	0.0051	(-0.1082 to 0.1183)
1850 – 2400 euros	-0.0771	(-0.2304 to 0.0762)	0.0065	(-0.1192 to 0.1322)	0.0267	(-0.1000 to 0.1535)	0.0748	(-0.0432 to 0.1927)
400 – 3600 euros	**-0.1426**	**(-0.2610 to -0.0156)**	-0.0510	(-0.1562 to 0.0542)	-0.0554	(-0.1668 to 0.0561)	-0.0122	(-0.1187 to 0.0944)
Social status	**0.0258**	**(0.0067 to 0.0583)**	**0.0371**	**(0.0087 to 0.0654)**	**0.0584**	**(0.0295 to 0.0874)**	**0.0308**	**(0.0036 to 0.0581)**
Age (years)	**-0.0039**	**(-0.0062 to -0.0016)**	-0.0006	(-0.0025 to 0.0014)	0.0010	(-0.0010 to 0.0031)	-0.0002	(-0.0021 to 0.0017)
Male	**0.0810**	**(0.0037 to 0.1582)**	**0.0799**	**(0.0143 to 0.1455)**	**0.1415**	**(0.0734 to 0.2096)**	**0.0673**	**(0.0048 to 0.1298)**

- table 2.4 continues –

- table 2.4 continued -

Disease prevention	*Accessing*		*Understanding*		*Applying*	
	B	*95% CI*	*B*	*95% CI*	*B*	*95% CI*
Education (reference group: tertiary education)						
No education or primary education	**-0.2418**	**(-0.3970 to -0.0866)**	**-0.2069**	**(-0.3489 to -0.0650)**	-0.1217	(-0.3687 to 0.1253)
Lower secondary education	**-0.0989**	**(-0.1897 to -0.0081)**	**-0.1276**	**(-0.2137 to -0.0415)**	-0.1028	(-0.2530 to 0.0473)
(Upper or post-) secondary education [b]	0.0057	(-0.0772 to 0.0887)	-0.0152	(-0.0945 to 0.0640)	-0.0426	(-0.1807 to 0.0955)
Income (reference group: 3600 or more)						
<1850 euros	-0.1025	(-0.2175 to 0.0125)	-0.0516	(-0.1671 to 0.0640)	0.0098	(-0.1840 to 0.2037)
1850 – 2400 euros	0.0506	(-0.0775 to 0.1787)	0.0283	(-0.0927 to 0.1493)	0.0402	(-0.1644 to 0.2447)
2400 – 3600 euros	-0.0236	(-0.1288 to 0.0816)	-0.0138	(-0.1182 to 0.0906)	-0.0137	(-0.1995 to 0.1721)
Social status	**0.0485**	**(0.0208 to 0.0763)**	**0.0313**	**(0.0050 to 0.0577)**	0.0242	(-0.0215 to 0.0699)
Age (years)	**-0.0028**	**(-0.0047 to -0.0008)**	**-0.0020**	**(-0.0039 to -0.0001)**	-0.0011	(-0.0043 to 0.0022)
Male	**0.1498**	**(0.0849 to 0.2148)**	**0.0839**	**(0.0221 to 0.1457)**	**0.1501**	**(0.0427 to 0.2575)**

- table 2.4 continues –

- table 2.4 continued -

Health promotion	*Accessing*		*Understanding*		*Appraising*		*Applying*	
	B	*95% CI*	*B*	*95% CI*	*B*	*95% CI*	*B*	*95% CI*
Education (reference group: tertiary education)								
No education or primary education	-0.0779	(-0.3309 to 0.1751)	**-0.3552**	**(-0.5395 to -0.1709)**	-0.0881	(-0.2678 to 0.0916)	-0.1797	(-0.3774 to 0.0181)
Lower secondary education	-0.0266	(-0.1798 to 0.1266)	**-0.2267**	**(-0.3390 to -0.1143)**	-0.0538	(-0.1642 to 0.0565)	-0.0170	(-0.1350 to 0.1009)
(Upper or post-) secondary education [b]	0.0827	(-0.0578 to 0.2232)	-0.1013	(-0.2057 to 0.0031)	0.0752	(-0.0259 to 0.1762)	-0.0037	(-0.1122 to 0.1049)
Income (reference group: 3600 or more)								
<1850 euros	-0.1036	(-0.2928 to 0.0857)	-0.0296	(-0.1669 to 0.1077)	0.0510	(-0.0919 to 0.1938)	-0.0146	(-0.1656 to 0.1364)
1850 – 2400 euros	0.0513	(-0.1546 to 0.2572)	0.0544	(-0.1003 to 0.2090)	0.1318	(-0.0226 to 0.2862)	0.0683	(-0.0928 to 0.2293)
2400 – 3600 euros	-0.0363	(-0.2068 to 0.1342)	-0.0029	(-0.1331 to 0.1273)	0.0048	(-0.1266 to 0.1362)	-0.0079	(-0.1510 to 0.1351)
Social status	0.0348	(-0.0120 to 0.0815)	**0.0543**	**(0.0200 to 0.0886)**	**0.0686**	**(0.0346 to 0.1027)**	**0.0629**	**(0.0264 to 0.0994)**
Age (years)	**0.0052**	**(0.0018 to 0.0085)**	**-0.0028**	**(-0.0053 to -0.0004)**	**0.0063**	**(0.0039 to 0.0087)**	0.0006	(-0.0020 to 0.0032)
Male	-0.0093	(-0.1183 to 0.0996)	**0.1975**	**(0.1168 to 0.2782)**	**0.1445**	**(0.0651 to 0.2239)**	0.0458	(-0.0398 to 0.1314)

* Analyses are based on mean per item; significant differences are printed in bold ($p<0.05$).[a] Scores for appraising health information in the domain of healthcare and disease prevention were combined based on outcomes of factor analysis. [b] Non-tertiary including vocational education.

Discussion

The aim of this study was to contribute to theoretical knowledge being built up about health literacy and to provide an initial insight into the health literacy of the general population and its associations with demographic and socio-economic characteristics. For that purpose, the Dutch data from the European Health Literacy Survey (HLS-EU) was used.[16,17] The data provided information on health literacy reflected by the competences of accessing, understanding, appraising and applying information in the domains of healthcare, disease prevention and health promotion. The findings of this study suggest that the health literacy scores in a sample of the Dutch general population vary between the four different competences studied. This is consistent with findings from other countries participating in the HLS-EU project.[16] Furthermore, the perceived difficulties with these competences differ according to the health domain which they appeal to. For example, accessing information on healthcare was perceived more difficult than accessing information on disease prevention. It seems that the level of health literacy in the general population is associated with the setting in which the health information is provided.

In terms of health outcomes, low health literacy scores in the three domains and over the four competences might lead to suboptimal health in various ways. For example, those who perceive difficulties with accessing and understanding information about screening might unintentionally be excluded from screening programmes.[36,37] Moreover, those who perceive difficulties understanding their medication leaflets might not be able to use their medication correctly.[38]

As to the extent to which health literacy competences are associated with demographic and socio-economic characteristics, the results indicate that lower health literacy is associated with lower socio-economic position, in accordance with the literature.[4-6,21-23] Educational and income-related differences in health literacy were found in particular in accessing and understanding health information. These can be considered as basic health literacy competences, related to functional health literacy as described by Nutbeam.[7] Differences between educational levels or income groups were found to a lesser extent for appraising and applying health information, which are more complex competences related to the concept of critical health literacy.[7] This indicates that those who are highly educated or have a high income do not have an advantage on the more complex competences of appraising and applying compared to those who are low educated or have a low income, as is the case for the basic competences of accessing and understanding. It is recommended that these

aspects and the aspect of critical health literacy should be addressed in future research.

One striking finding is that perceived social status seems to affect all health literacy competences. This leads to the assumption that this subjective indicator of socio-economic status differs, in relation to health literacy, from the objective indicators of education and income. Given the importance that has been placed on the association between health literacy and socio-economic status, this seems an important topic for future research.[6,7]

This study found mixed results regarding the association between health literacy and age. A negative association was found between age and accessing information on healthcare and disease prevention and understanding information on disease prevention and health promotion, indicating that increasing age is accompanied by lower levels of health literacy on these specific dimensions. This seems in accordance with findings of former studies.[4,6,21,22,24] It has been suggested that the negative association between age and health literacy might be attributable to an age related decline of the ability to perform cognitive tasks that require information processing.[39] Older adults seem to have more difficulty completing tasks that require reasoning or inferences from information presented to them, which has been linked to lower health literacy.[39] However, for accessing and appraising health information on health promotion, the present study suggest a positive association between age and health literacy, which seems contradicting to what was found in other studies. Further research is needed to examine why the direction of the association between age and health literacy differs between health literacy dimensions. The fact that elderly in the Netherlands are relatively high educated could be a possible contributor to the finding of mixed results.

With regard to the association between health literacy and sex, it was found that females perceive fewer difficulties with health information than men, especially in the domains of healthcare and disease prevention. No consistent pattern between sex and health literacy has been reported in the literature.[4,6,26,27]

The results of our study suggest that health information, whether it is about healthcare, disease prevention or health promotion, will most likely not have the same effect across the various socio-economic strata in the Dutch population. This implies that there could be benefits from improving the accessibility and usability of health information. In addition, a more challenging task seems to lie in making information easier to judge and to apply, as this calls upon more complex cognitive capacities.[38] However, to facilitate optimum information transfer, not only the information itself and the sender should be taken into

account, but also the receiver. To this end, attention should be paid to possible ways of increasing the level of health literacy in the population, especially across lower socio-economic strata. For instance, it has been suggested that more attention should be paid to health literacy competences in school curricula.[40]

Strengths and limitations

The health literacy measure that was used in this study differs from other measures, such as the Rapid Estimate of Adults Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA).[18,20] These types of screening instruments largely measure health literacy in terms of reading skills applied in a clinical setting. The ability to read and understand health information is often referred to in the literature as 'functional health literacy'.[2] The HLS-EU-Q goes beyond measuring functional health literacy, as it focuses on multiple steps involved in information processing and decision-making in terms of health. It thereby provides an in-depth insight into health literacy as a multidimensional concept. Furthermore, the HLS-EU-Q aims to encapsulate a broad scope of health by extending across three domains as well as going beyond a merely patient-related context. A valuable addition for further research might be the further exploration of other factors such as motivation to perform the four health literacy competences. This could influence information processing and decision-making and therefore seems relevant for the identification of those at risk of perceived difficulties with health information. [41,42]

An important strength of the methodology used in this study is that questionnaires were administered face-to-face. This facilitated the inclusion of adults with inadequate reading abilities. Adults who were not nationals of a European member state or had insufficient command of Dutch were excluded. Hence, the study does not reflect health literacy of adults with other ethnic backgrounds than European. To provide a rough indication of the proportion of the Dutch population that was not represented: in 2007, 8.3% of the Dutch population were born in a non-EU country.[43] It is likely that adults from ethnic minorities perceive more difficulties with health information, and hence the results might underestimate the health literacy skills of the adult population.

Another limitation is that elderly were overrepresented in the sample, which might have affected variables such as income or perceived social status and could possibly explain the small effect of income found in the current study, as the elderly account for a large proportion of the group of respondents with lower incomes. The educational level of older adults might have counterbalanced the effect of income on health literacy scores. In order to examine whether the

findings of our study also yield for the subgroup of those aged 65 years or older, a subgroup analysis was performed, which indicated similar associations between socio-economic and demographic characteristics and health literacy (not tabulated). Therefore, the overrepresentation of elderly is not expected to have greatly affected the outcomes.

Conclusion

Health literacy can be addressed as a concept that involves multiple dimensions that seem to differ in their perceived difficulty. The current study shows that health literacy varies for the competences of accessing, understanding, appraising and applying information across the domains of healthcare, disease prevention and health promotion. The findings are consistent with other research: those with a low socio-economic position, primarily with a low education level and a low subjective social status, have lower health literacy than those with a high socio-economic position.

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Additional materials

Definition and integrated model of health literacy

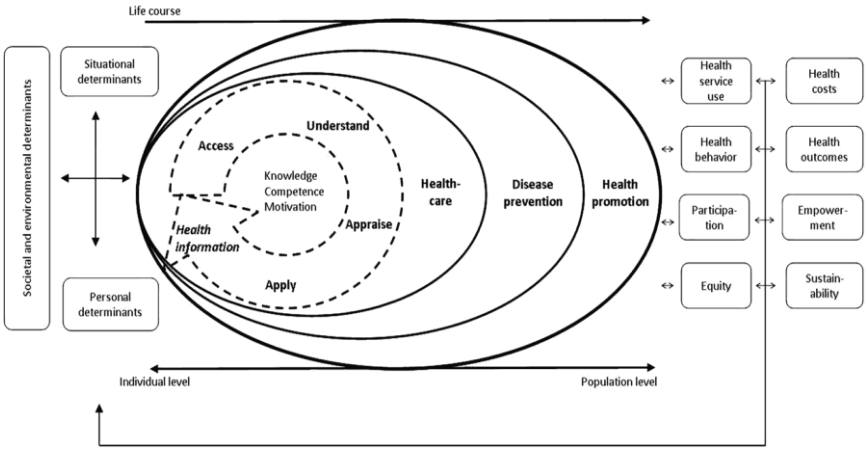
Based on a systematic literature review, a definition for health literacy was developed by the HLS-EU consortium from which a conceptual model was derived.

Definition

Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course (Sørensen et al., 2012).

Integrated model of health literacy

Sørensen, K et al.. 2012: Health literacy and public health: A systematic review and integration of definitions and models, BMC Public Health, 12(80).



Additional Table 1. Characteristics of missing values on health literacy competences (%, N=440)

Characteristics	*Respondents with one or more missing values on the health literacy items*					
	Total (n=440)		*Men (n=221)*		*Women (n=219)*	
	%	*n*	*%*	*n*	*%*	*n*
Age in categories						
25 – 34	9.1	(40)	11.3	(25)	6.8	(15)
35 – 44	8.9	(39)	7.3	(16)	10.5	(23)
45 – 54	14.5	(64)	14.5	(32)	14.6	(32)
55 – 64	12.5	(55)	10.4	(23)	14.6	(32)
65 – 74	21.6	(95)	24.9	(55)	18.3	(40)
75 – 84	19.3	(85)	19.0	(42)	19.6	(43)
85+	5	(22)	4.1	(9)	5.9	(13)
Highest completed education level						
No education or primary education	42.3	(186)	38.0	(84)	46.6	(102)
Lower secondary education	4.5	(20)	3.2	(7)	5.9	(13)
(Upper or post-) secondary non-tertiary education	51.1	(225)	56.1	(124)	46.1	(101)
Tertiary education (bachelor's degree or higher)	0.7	(3)	1.4	(3)	0	(0)
Missing	1.4	(6)	1.4	(3)	1.4	(3)
Household net income per month in Euros						
<1850	33.9	(149)	26.2	(58)	41.6	(91)
1850 – 2400	13.6	(60)	14.5	(32)	12.8	(28)
2400 – 3600	20.7	(91)	23.5	(52)	17.8	(39)
3600 or >	9.5	(42)	11.8	(26)	7.3	(16)
Missing	22.3	(98)	24.0	(53)	20.5	(45)
Perceived social status						
Low	4.8	(21)	6.3	(14)	3.2	(7)
Medium	29.3	(129)	24.4	(54)	34.2	(75)
High	61.8	(272)	64.7	(143)	58.9	(129)
Missing	4.1	(18)	4.5	(10)	3.7	(8)

Chapter 3

The relationship between health, education, and health literacy: results from the Dutch adult literacy and life skills survey

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Journal of Health Communication, 2013;18 Suppl 1:172-84

Abstract

Background Health literacy has been put forward as a potential mechanism explaining the well documented relationship between education and health. However, little empirical research has been undertaken to explore this hypothesis. The present study aims to study whether health literacy could be a pathway by which level of education affects health status.

Method Health literacy was measured by the Health Activities and Literacy Scale, using data from a subsample of 5,136 adults between the ages of 25 and 65 years, gathered within the context of the 2007 Dutch Adult Literacy and Life Skills Survey. Linear regression analyses were used in separate models to estimate the extent to which health literacy mediates educational disparities in self-reported general health, physical health status, and mental health status as measured by the Short Form-12.

Results Health literacy was found to partially mediate the association between low education and low self-reported health status.

Conclusion As such, improving health literacy may be a useful strategy for reducing disparities in health related to education, as health literacy appears to play a role in explaining the underlying mechanism driving the relationship between low level of education and poor health.

Introduction

The scientific literature on health inequalities has repeatedly demonstrated a strong association between lower levels of education and poorer health outcomes.[1-4] However, the mechanisms through which level of education affects health outcomes are not yet well understood.[5,6] Recently, health literacy has been put forward as a potential pathway between level of education and health.[7-11] A definition chosen by the U.S. Institute of Medicine describes health literacy as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (Ratzan & Parker, as cited in Nielsen-Bohlman et al., 2004).[9] In this context, health information can be understood as health-related printed materials, but also as spoken language.[12]

Health literacy skills are conceived as an important asset for maintaining or improving one's health. From this perspective, low health literacy skills may, for example, be a barrier in access to health information and healthcare, medication use, and the prevention of disease.[13] It is, therefore, not surprising that low health literacy has been associated with a range of poor health outcomes.[7,14,15] Not only were people with low health literacy found to be less healthy, but also to be less able to deal with chronic diseases, to have less knowledge about health, and to have difficulties reading and understanding information on medicine packages or hospital forms.[16-19] Low health literacy skills have not only been found to be related to poor health but have also been shown to have a relationship with level of education: People with lower education were found to demonstrate lower health literacy skills in comparison with people with higher education.[7,8,10,13,20] However, most studies to date have been performed among patients with somatic diseases, and less evidence is available for the association between health literacy and mental health.[15]

Although studies have found clear relationships between (a) education and health literacy, (b) education and health, and (c) health literacy and health, this study is among the first to actually examine the possible contribution of health literacy in explaining the relationship between education and health.[7,11,14] The aim of the present study is to examine whether health literacy constitutes a pathway by which education affects health. Attention was also given to possible differences in the role of health literacy between levels of education and between three indicators of health—that is, self-rated general health status, physical health status, and mental health status.

Method

Study design and data collection

The data stemmed from the Adult Literacy and Life Skills Survey (ALL). The ALL is an international cross-sectional survey, which used graded everyday tasks to assess literacy (prose and document), numeracy, and problem-solving skills in nationally representative samples of 16- to 65-year-old individuals. The ALL was conducted in several countries, including The Netherlands.[21] The Dutch Centre for Expertise in Vocational Education and Training (ecbo) translated and adapted test items and a background questionnaire for the Dutch part of the survey. Between July 2007 and January 2008, data were collected from 5,617 non-institutionalized and legal citizens of The Netherlands by interviewing and testing respondents face-to-face in their homes. The response rate was 47%. No information was collected on reasons for nonresponse. Persons born in The Netherlands were overrepresented in this sample (92.1% vs. 88.6% in the Dutch general population in 201).[22] For the purpose of this study, we limited the analyses to respondents 25 years of age or older, because level of education is more stable thereafter. This led to a subsample of 5,136 respondents. Details regarding the test items, study design, and data collection have been reported elsewhere.[21]

Main variables

Level of education

Education was measured by the highest self-reported level of education completed. In all, 25 response options were possible, which were grouped into (a) pre-primary or primary education, (b) lower secondary education, (c) upper secondary education, and (d) tertiary education, in accordance with the International Standard Classification of Education (see Table 3.1). Education was used as a categorical variable in the analyses.

Health literacy

Health literacy was measured by the Health Activities and Literacy Scale (HALS) which was derived from a selection of health-related tasks included in the ALL.[23,24] Respondents were asked, for example, to read a medicine dosage chart and indicate the correct dose for a child of a particular weight and age. By directly testing respondents' performance on a variety of graded tasks, the HALS provides an objective measurement of health literacy. Because not every respondent completed the full set of tasks in the assessment (N=191), imputation

was applied on the basis of an estimation procedure that was used to represent each respondent's proficiency as a probability distribution over all possible scores. This was a standard procedure performed by the Educational Testing Service. The Educational Testing Service scaled and transformed the HALS scores to a 0 to 500 metric. Individual sum scores on this scale reflect the progression of health literacy skills from very poor skills (level 1) to very strong skills (level 4; see additional Table 1 on page 77). The Organisation for Economic Co-operation and Development considers level 3 as the minimum level needed to function adequately in a knowledge society.[25] Health literacy was used as a continuous variable in the analyses.

Health status

Health status was measured by three indicators—self-reported general health, self-reported physical health score and self-reported mental health score, using the Medical Outcomes Study Short Form 12.[26] Self-reported general health was assessed by a single item,: "In general, how is your health?" Answer options were provided on a 5-point Likert scale ranging from 1 (poor) to 5 (excellent). The physical health scores and mental health score scores were each derived from six items and standardized to population norms (based on a U.S. norm sample). The Short Form 12 has been found to be valid for the Dutch situation.[27] Self-reported general health status, physical health scores, and mental health scores were used as continuous variables in the analyses, after a prior check for linearity.

Statistical analyses

To test the hypothesis that health literacy is a pathway by which education affects health, we examined the mediation effect of health literacy on the relationship between education and health status (i.e., self-reported general health, self-reported physical health, and self-reported mental health). Separate mediation models were applied for all three indicators of health status on the basis of linear regression analyses (see Figure 3.1). All linear regression analyses were controlled for age and sex as covariates, because both were expected to be associated with health, education, and health literacy.[8-10,28,29] The product-of-coefficients test by MacKinnon was used to estimate the mediating effect on the basis of four steps, as illustrated in Figure 3.1: (a) regress the mediator health literacy on the independent variable education (a-coefficient); (b) regress the dependent variable health on the mediator health literacy while controlling for the independent variable education as a potential confounder (b-coefficient); (c) calculate the total effect by regressing the dependent variable health on the

independent variable education (c-coefficient); (d) calculate the direct effect by regressing the dependent variable health on the independent variable education while controlling for the mediator health literacy (c'-coefficient).[30]

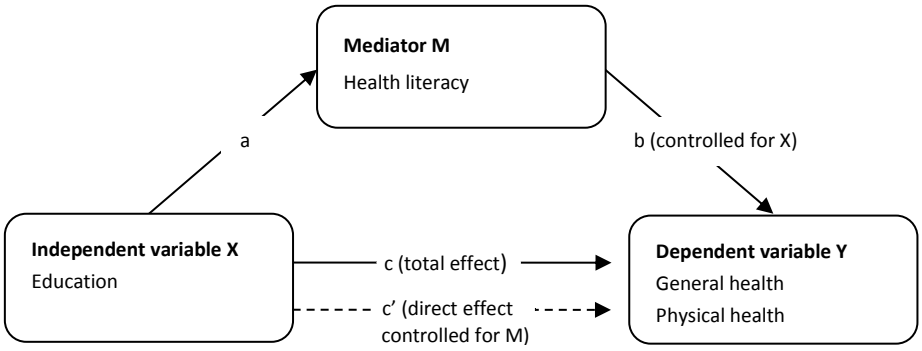

Figure 3.1 *Conceptual model of health literacy as a mediator between education and self-reported general health, self-reported physical health and self-reported mental health, adjusting for age and sex in all steps of the model*

The ab-coefficient (a*b) represents the mediation effect.[31,32] Complete mediation is indicated when the ab-coefficient is significant, as estimated by the Sobel test, and the c'-coefficient is equal to 0. Partial mediation is indicated when the ab-coefficient is significant and c' is reduced. The analyses were performed using SAS (version 9.3). The mediation effect size (ab/(ab+c') × 100%) was used to indicate the extent of the mediating role of health literacy in the relationship between education and health status. The effect size percentages can be interpreted as the proportion of the association between a specific level of education and health that is explained by health literacy. The calculated proportions provide insight into the relative importance of the mediating role of health literacy. Because the data contained few missing values, complete case analysis was applied.

Results

Sample characteristics and health literacy

Table 3.1 shows the sample characteristics. The mean age is 46.7 years (*SD*=11.2), and most of the respondents completed upper secondary education (30.3%) or tertiary education (39.5%). As for health status, scores ranged from 12.0 to 65.4 for physical health (*M*=49.9, *SD*=8.8) and from 11.3 to 70.5 for mental health (*M*=52.9, *SD*=8.5), whereby the mean scores were above the cut-off for good health (not tabulated). As for health literacy, a substantial proportion of the respondents demonstrated poor (43.4%) or very poor health literacy (10.6%). Table 3.2 shows that the higher the level of education, the greater the proportion of respondents who scored in the levels of adequate and strong health literacy. Half the respondents (51.1%) who had completed preprimary/primary education scored in level 1, compared with only 2.1% of those who had completed tertiary education.

Table 3.1 Sample characteristics and health literacy (N=5136)

Characteristics [a]	*Percentage (n)*	
Female	55.7	(2863)
Age		
25 – 35	20.8	(1070)
36 – 45	28.7	(1473)
46 – 55	23.9	(1230)
56 – 65	26.5	(1363)
Level of education		
(Pre-)primary education	5.5	(284)
Lower secondary education	24.5	(1256)
Upper secondary	30.2	(1553)
Tertiary education	39.5	(2027)
Missing	0.3	(16)
Self-reported general health		
Excellent	15.5	(797)
Very good	23.3	(1198)
Good	45.8	(2354)
Fair	13.1	(675)
Poor	2.0	(103)
Missing	0.2	(9)

- table 3.1 continues -

- table 3.1 continued -

Characteristics [a]	*Percentage (n)*	
Mental health [b]		
Good mental health	88.3	(4537)
Physical health [c]		
Good physical health	68.9	(3505)
Health literacy level		
Level 1 (very poor)	10.6	(542)
Level 2 (poor)	43.4	(2227)
Level 3 (adequate)	41.6	(2138)
Level 4 (strong)	4.5	(229)

[a] Missing values are reported when applicable.

[b] Norm score for good mental health>41 (Ware et al., 1995).

[c] Norm score for good physical health>49 (Ware et al., 1995).

Table 3.2 Health literacy by level of education

Level of education	*Health literacy levels in % (n) within level of education (N=5120)*							
	Level 1 (very poor)		*Level 2 (poor)*		*Level 3 (adequate)*		*Level 4 (strong)*	
Tertiary	2.1	(42)	30.1	(610)	59.1	(1198)	8.7	(177)
Upper secondary	7.7	(120)	48.6	(755)	40.9	(635)	2.8	(43)
Lower secondary	18.0	(226)	58.6	(736)	22.9	(287)	0.6	(7)
(pre-)Primary	51.1	(145)	42.6	(121)	5.6	(16)	0.7	(2)

Association between education and health literacy (a-path)

To assess whether health literacy is a mediator in the relationship between education and health, the association between health literacy and education was tested first, controlling for age and gender (a-path). Linear regression analysis indicated that compared with those who had completed tertiary education, respondents who had completed upper secondary education demonstrated lower health literacy proficiency (B=–17.6, SE=1.20, p<.001), followed by respondents who had completed lower secondary education (B=–31.7, SE=1.09, p<.001) and preprimary/primary education (B=–60.5, SE=2.15, p<.001; not tabulated).

Association between health literacy and health (b-path)

Second, the associations between health literacy and each of the health outcomes (i.e., self-reported general health, physical health, and mental health) were estimated by linear regression analyses, controlling for age, gender, and education (b-path). Those with higher health literacy skills had better self-reported general health (B=0.002, SE=0.0006, p<.001), physical health (B=0.017, SE=0.006, p=.005) as well as mental health (B=0.012, SE=0.004, p=.007) than those with lower health literacy skills (not tabulated).

Association between education and health (c-path)

Table 3.3 shows the results for the total effect of education on health (c-coefficient) and the direct effect of education on health, adjusted for health literacy as covariate (c'-coefficient). Lower education was associated with poorer self-reported general health, physical health, and mental health (c-coefficients). As for mental health, only those who had completed preprimary/primary education reported worse mental health. For all three health outcomes, the c'-coefficients are smaller than the c-coefficients, indicating that the effect of education on health is partly mediated by health literacy.

Table 3.3 Results regression analyses for the total effect (c) and direct effect (c') of education on health

	Education [a] (reference: tertiary education)	*Total effect (c) [b] (without health literacy)*		*Direct effect (c') [c] (including health literacy)*	
		B	*SE*	*B*	*SE*
Self-reported general health	Upper secondary education	-0.18**	0.032	-0.14**	0.033
	Lower secondary education	-0.20**	0.034	-0.12*	0.039
	(pre-)Primary education	-0.53**	0.060	-0.37**	0.071
Self-reported physical health	Upper secondary education	-1.79**	0.287	-1.47**	0.304
	Lower secondary education	-1.86**	0.311	-1.30*	0.356
	(pre-)Primary education	-4.49**	0.551	-3.43**	0.646

- table 3.3 continues –

- table 3.3 continued -

	Education [a] *(reference: tertiary education)*	*Total effect (c)* [b] *(without health literacy)*		*Direct effect (c')* [c] *(including health literacy)*	
		B	*SE*	*B*	*SE*
Self-reported mental health	Upper secondary education	-0.54	0.284	-0.32	0.294
	Lower secondary education	-0.40	0.308	-0.01	0.338
	(pre-)Primary education	-2.42**	0.545	-1.68*	0.607

* Significant regression coefficient at p<0.05.

** Significant regression coefficient at p<0.0001.

[a] Including covariates age and sex in the linear regression model.

[b] c-path: association between education and health.

[c] c'-path: association between education and health via health literacy.

Mediation effect of health literacy (ab-path)

Table 3.4 presents the mediation effects of health literacy (ab-coefficient). The results indicate that health literacy mediates the associations between education and self-reported general health, self-reported physical health, and self-reported mental health. For both self-reported physical health as well as self-reported general health, health literacy mediates a larger proportion (effect size) of the association between lower secondary education and health compared to preprimary/primary education or upper secondary education. For mental health, no total (c) or direct (c') effects were found for upper and lower secondary education; therefore, the mediation effect was calculated only for preprimary/primary education. Comparing the effect sizes for preprimary/primary education and self-reported general health, self-reported mental health, and self-reported physical health, the mediating role of health literacy seemed smallest between preprimary/primary education and physical health (23.1%), followed by self-reported general health (24.5%) and mental health (30.3%; see Table 3.4).

Table 3.4 Mediation effect of health literacy in the association between education and health (ab)

	Education (reference: tertiary education)	*Mediated effect (ab)*		*Effect size %*
		B	*SE*	
Self-reported general health	Upper secondary education	-0.04*	0.011	22.2
	Lower secondary education	-0.06**	0.019	33.3
	(pre-)Primary education	-0.12**	0.037	24.5
Self-reported physical health	Upper secondary education	-0.30*	0.108	16.9
	Lower secondary education	-0.54*	0.191	29.3
	(pre-)Primary education	-1.03*	0.365	23.1
Self-reported mental health [a]	(pre-)Primary education	-0.73*	0.243	30.3

* Significant regression coefficient at p<0.01.

** Significant regression coefficient at p<0.0005.

[a] No total (c) or direct (c') effects were found for upper and lower secondary education, therefore the mediation effect was only calculated for (pre-)primary education.

Discussion

This study examined whether health literacy is a pathway by which level of education affects health. Consistent with the literature on the association between education and health, our results confirm that low education is a predictor of having low self-reported health.[2-4] Also in accordance with literature, the present study confirms that low education is associated with low health literacy. [20] Furthermore, low health literacy is associated with low self-reported general health, low self-reported physical health and low self-reported mental health, a finding that again is in line with current research.[7,8,10,15] Thus, our findings confirm the existence of interrelationships among education, health literacy, and health status. We subsequently studied the nature of this mutual relationship in greater detail by examining whether health literacy serves as a mediator in the relationship between education and health, as has been found in a few other studies.[7,14] The mediation analysis indicated that this is indeed the case.

As to the relative importance of health literacy as a pathway between education and health status, the results of the mediation analysis indicate that

health literacy plays a larger role among those with lower education than among those with higher education, but health literacy seems to be a more important pathway for lower secondary educated than for preprimary/primary educated. This indicates that the mediating role of health literacy exhibits no linear gradient as education increases. To determine to what extent improving health literacy could contribute to reducing education-related disparities in health, further research is needed on the relative importance of the mediating role of health literacy among different levels of education.

The mediating role of health literacy appeared to vary for each of the three measures of health status included in this study—that is, self-reported general health, self-reported physical health, and self-reported mental health. Health literacy seemed to be a larger mediator between level of education and mental health than the other two indicators of health status.

Regarding the implications for further research, the finding that a substantial proportion of highly educated respondents demonstrated poor health literacy needs further attention. Only a small percentage of respondents scored at the level of strong health literacy, which seems remarkable given the fact that this Dutch sample included many highly educated adults and few adults with low education. However, the distribution of low and high health literacy scores is in accordance with findings from the ALL in Australia and the United States with only 6% of those national samples demonstrating strong health literacy.[23,33] This indicates that just like literacy and education, health literacy is not equivalent to level of education despite strong correlations. Reading daily for work or leisure seems to have a positive effect on health literacy, suggesting that literacy-related habits in daily life could contribute to health literacy and compensate for low levels of education.[24] Alternatively, infrequent reading might contribute to lower health literacy.

Another implication for further research is to apply the analyses of the present study on data that include objective health measures. Most studies on the association between health literacy and health have used subjective measures for health. To obtain a better understanding of the association between health literacy and health outcomes, objective measures of the latter may provide important evidence.

In the present study, we focused on education-related disparities in health, which is a frequently used indicator of socio-economic status. In future research, the mediating role of other indictors of socio-economic status, such as income and occupation, can also be examined in order to explore the associations between socio-economic status, health literacy and health in greater depth.

The present study is subject to some limitations. First, the number of respondents who completed upper secondary or tertiary education was higher than in the general population aged 25 to 65.[34] However, this is not expected to affect our conclusions about the mediating effect of health literacy because the numbers of respondents in all educational levels were sufficient to perform the analyses.

A second limitation is that the linear parameterization of self-reported general health may have led to an underestimation of the effect of education on this particular health measure. The differences in mean scores seemed larger between those with preprimary/primary and higher education than between those with lower secondary, upper secondary and tertiary education.

A third limitation is that the health literacy tasks may not reflect the full range of some respondents' skills or resources in a more natural setting. The test called on respondents to perform activities completely alone, while situations in real life often enable persons to sort through materials with the help of others. Furthermore, in real life people may use health information in stressful situations or may lack the time and/or motivation to read information thoroughly. Stress or lack of concentration and motivation may affect people's ability to understand and use health information.

A final limitation of the present study, as in most other studies addressing the concept of health literacy, is that it does not measure health literacy to its fullest extent. Health literacy also encompasses oral literacy, which seems to be an underexplored domain so far [9,12] or, even more broadly, it can be considered "a package of competences for health".[35] That said, the HALS is one of the broadest assessments of health literacy, going far beyond functional health-related reading skills in clinical settings, and methodologically among the strongest assessments, as the exercises were developed, graded, and scored by educational testing professionals.

In summary, this study provides strong evidence that health literacy serves as a pathway by which education affects health and it quantified this association. Although the relationship between low education and poor health can be explained in part by health literacy, poor health literacy is also relatively common among those with a high level of education. The findings of this study suggest that strategies for reducing disparities in health related to education may benefit from attention to health literacy. For example, adapting health information in a way that can be more readily accessed, understood, and used by those with difficulties in reading and calculating, may improve their opportunities to maintain or improve their health.

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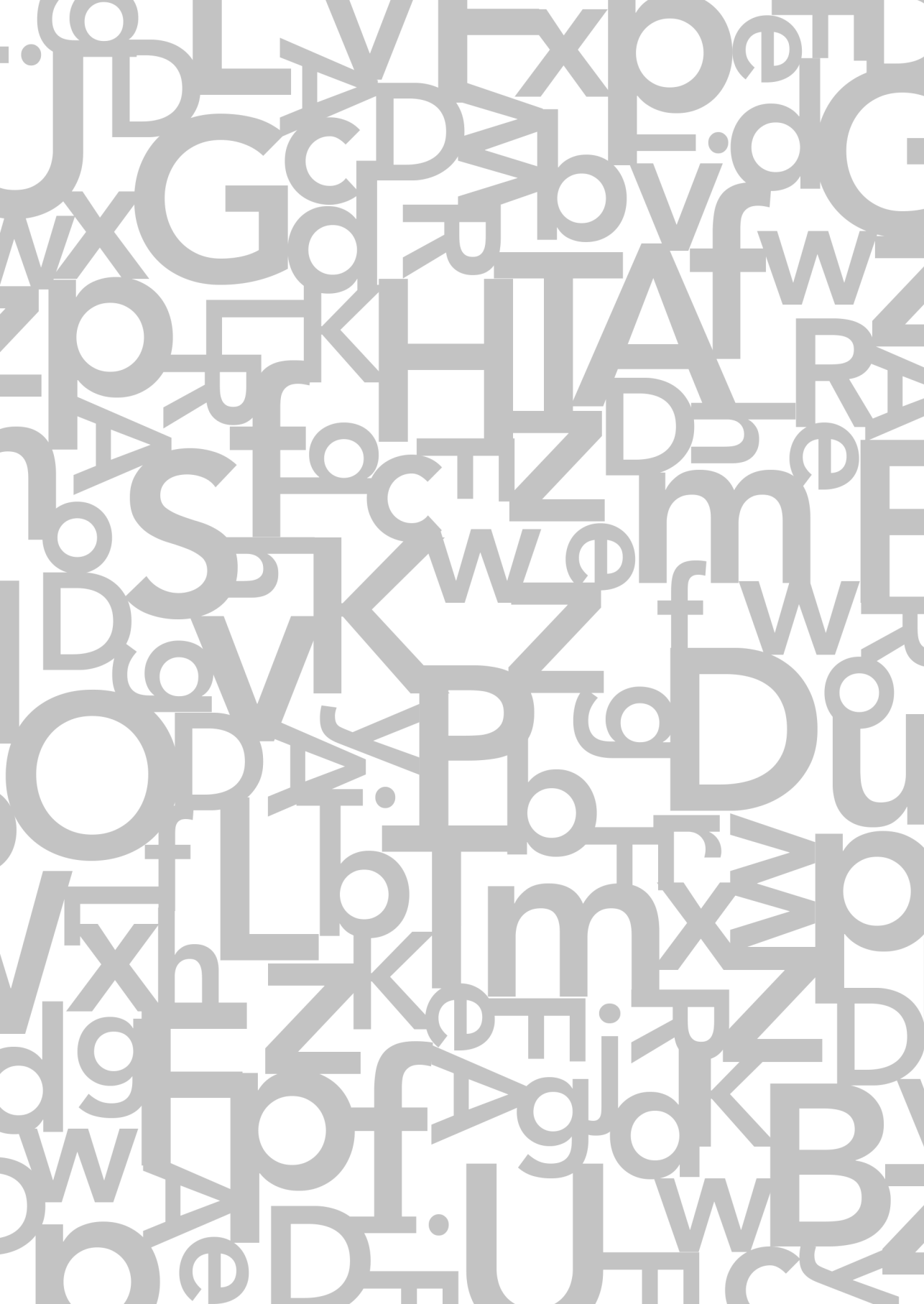
Additional materials

Additional Table 1. Interpretation of health literacy levels

Level	*Score*	*Interpretation*
1	0-225	Very poor health literacy skills. An individual at this level may, for example, be unable to determine from a package label the correct amount of medicine to give a child. Tasks at this level require the ability to read relatively short text, locate or enter a piece of information and complete simple, one- step tasks such as counting, sorting dates or performing simple arithmetic.
2	226-275	Poor health literacy skills. The capacity to deal only with simple, clear material involving uncomplicated tasks. People at this level may develop everyday coping skills, but their poor literacy makes it hard to conquer challenges such as learning new job skills. Tasks at this level require, for example, the ability to sort through distractors (plausible but incorrect pieces of information), integrate two or more pieces of information, compare and contrast information, and interpret simple graphs.
3	276-325	Adequate health literacy skills. An individual at this level has the ability to cope with the demands of everyday life and work in an advanced society. It roughly denotes the skill level required for successful high-school completion and college entry. These tasks require the ability to integrate information from dense or lengthy text, integrate multiple pieces of information and demonstrate understanding of mathematical information represented in a range of different forms. Tasks typically involve a number of steps or processes in order to solve problems.
4	326-375	Strong health literacy skills. An individual at these levels can process information of a complex and demanding nature. Tasks at this level involve multiple steps to find solutions to abstract problems. Tasks require the ability to integrate and synthesize multiple pieces of information from lengthy or complex passages and make inferences from the information.
5	376-500	Very strong health literacy skills. Tasks at this level require the ability to search for information in dense text which has a number of distractors, make high-level inferences or use specialised background knowledge and to understand complex representations of abstract formal and informal mathematical ideas.

Additional Table 2. Health literacy by level of education weighted for the Dutch population

Level of education	*Weighted mean health literacy score (SE)*	*Equal to health literacy level*
Total	267.60 (0.805)	Poor health literacy skills (2)
Tertiary	287.68 (1.189)	Adequate health literacy skills (3)
Upper secondary	268.71 (1.116)	Poor health literacy skills (2)
Lower secondary	252.98 (1.249)	Poor health literacy skills (2)
(pre-)Primary	220.57 (2.912)	Very poor health literacy skills (1)



Part II

Health Literacy in the context of chronic care

Chapter 4

Associations between health literacy, diabetes knowledge and self-management behaviour among adults with diabetes: results of a Dutch cross-sectional study

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Journal of Health Communication, 2014; 19 Suppl 2:115-31

Abstract

Background Various studies examined the association between health literacy and self-management behaviour but few explored ways through which this occurs. The present study examines to what extent health literacy is associated with diabetes self-management behaviour and to what extent diabetes knowledge is a mechanism in this association.

Method The study was based on cross-sectional data retrieved from patient registrations and questionnaires completed in 2010. The sample included 1714 predominantly type 2 diabetes patients, with a mean age of 67. Diabetes self-management was indicated by HbA1c level, glucose self-control and self-reported monitoring of glucose levels, physical activity and smoking. Multilevel analyses were applied based on multiple imputed data.

Results Lower health literacy was significantly associated with less diabetes knowledge, higher HbA1c level, less self-control of glucose level and less physical activity. Participants with more diabetes knowledge were less likely to smoke and more likely to control glucose levels. Diabetes knowledge was a mediator in the association between health literacy and glucose self-control and between health literacy and smoking.

Conclusion This study indicates that higher health literacy may contribute to participation in certain self-management activities, in some cases via diabetes knowledge. Diabetes knowledge and health literacy skills may be important targets for interventions promoting diabetes self-management.

Introduction

Self-management is a core element of diabetes care, in the course of which patients fulfil a significant role in the care for their disease. Adequate self-management can positively affect health-outcomes among diabetes patients and involves managing the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with diabetes.[1-4] Diabetes self-management can be indicated by various tasks, including glucose monitoring, physical activity, nutritional management and medication utilization.[5]

The performance of self-management tasks requires certain skills, such as the ability to understand information on how lifestyle behaviours affect the course of diabetes.[6] Being able to understand health-related information is considered one element of the concept of health literacy, which can be defined as the competences that are needed to access, understand, appraise and apply health related information.[7] Research indicates that lower health literacy is common among those who suffer from a chronic condition, including diabetes.[8] Yet individuals with a chronic illness need to apply health literacy skills on a regular basis, for instance when interpreting blood glucose levels.

Health literacy is not merely considered important for understanding information, but also for generating knowledge regarding health issues.[9] When information is not understood, for instance, it seems unlikely that this information is stored in one's memory to be remembered and used at a later time.[9] The relationship between health literacy and knowledge is also present in the context of diabetes care; lower health literacy is found to be associated with less diabetes knowledge.[5,10] Furthermore, studies found that patients with less diabetes knowledge are less likely to perform self-management tasks.[5]

With respect to the interrelationship between health literacy, diabetes knowledge and self-management, little research has been undertaken. Recently, Osborn and colleagues found no evidence for a direct effect of health literacy on diabetes self-care, based on a sample of 130 type 2 diabetes patients, nor an indirect effect via diabetes knowledge.[11] However, based on the theoretical framework as presented by von Wagner and colleagues, one would expect health literacy to be related to self-management, partly via diabetes knowledge.[6] This framework, developed to guide research on health literacy and health actions, hypotheses that health literacy influences socio-cognitive and psychological factors, like knowledge, which in turn determine health actions, including disease management.[6] Von Wagner and colleagues argue that it is important for

their framework to be tested and possibly revised so that interventions that mitigate the influence of lower health literacy on health related behaviour, such as diabetes self-management, are informed.[6]

In this context, the aim of the present study is to investigate whether diabetes knowledge can account for part of the relationship between health literacy and diabetes self-management behaviour. We thereby contribute to the knowledge base regarding determinants of diabetes self-management. The focus on diabetes knowledge as a mechanism linking health literacy to diabetes self-management is considered a first step in studying pathways between health literacy and self-management behaviour. Our specific research questions are: 1) To what extent is health literacy associated with diabetes knowledge? 2) To what extent is health literacy associated with indicators of self-management behaviour? and 3) To what extent does diabetes knowledge mediate the association between health literacy and indicators of self-management behaviour?

Research design and methods

Study design

This study was part of a larger observational study performed between January 2008 and June 2010 that focused on disease management programs and related bundled payments.[12] Details about the design of this study are reported elsewhere.[12,13] For the present study, we used data from June 2009 to June 2010.

Data collection

Data were retrieved from GP registrations, which were on an individual basis linked to survey data that was collected by a questionnaire.[13] This questionnaire was administered in a random sample of 4265 diabetes patients clustered within a random sample of 78 GP practices. The response rate to the patient questionnaire was 46% (n=1941). No information was available on reasons for nonresponse. For 1714 respondents, questionnaires could be linked to patient medical records; the other 227 were no longer under treatment. All respondents gave informed consent for linking the survey data to their medical records for the purpose of the study.

Main variables

Health literacy

Health literacy was assessed by Chew's Set of Brief Screening Questions (SBSQ),

which is a validated subjective measure of health literacy.[14,15] The SBSQ consists of three items: 'How confident are you filling out forms by yourself?' (Confident with Forms), 'How often do you have someone (like a family member, friend, hospital/clinic worker or caregiver) help you read hospital materials?' (Help Read), and 'How often do you have problems learning about your medical condition because of difficulty understanding written information?' (Problems Reading). Responses were scored on a 5-point Likert scale ranging from 0 (always/not at all confident) to 4 (never/extremely confident). Lower scores reflect lower health literacy skills.[14,15] The mean score on the three items was used in analyses as a continuous variable.

Diabetes knowledge

Diabetes knowledge was assessed by the 14 item Diabetes Knowledge Test (DKT), which has shown to be a reliable and valid instrument based on data from the United States.[16] A forward-backward translation procedure was applied and done by JNS and a specialist in the field of English literature. The minor discrepancies that occurred with the original DKT were discussed and solved during a consensus meeting. The items and answer options are presented in additional Table 1 on page 104. Sum scores were included in the analyses as a continuous variable ranging from 0 (lowest score) indicating little diabetes knowledge to 14 (highest score) indicating much diabetes knowledge. The Dutch version of the DKT is available on request.

Self-management behaviour

Self-management behaviour was indicated by five variables, which were selected based on previous research and on the GPs guideline for diabetes care as formulated by The Dutch College of General Practitioners.[17] These indicators include glucose self-control, self-reported monitoring of glucose levels, physical activity, smoking and HbA1c level. Glycemic control (HbA1c level), is the standard marker of diabetes control, and can be considered an indicator of self-management behaviour since poor glycemic control is associated with a sedentary lifestyle and a poor diet.[18] HbA1c level was obtained from GP registrations (in mmol/mol), and analysed as a continuous variable. Self-reported smoking behaviour (Are you a smoker? yes or no) was analysed as a dichotomous variable. Self-reported glucose self-control (Do you control your blood sugar, for example by the use of an insulin self-injection? yes or no) and self-reported monitoring of glucose levels (Do you use the glucose diary to register your glucose level? yes or no) were analysed as dichotomous variables. Finally,

physical activity was assessed by self-reported physical activity other than sports (How often are you involved in active physical activity (other than sports)? not at all; 1 to 2 hours a week; 2 to 4 hours a week; 4 to 6 hours a week; more than 6 hours a week) and self-reported involvement in sports (How often are you involved in sportive physical activity? not at all; up to 2 hours a week; 2 to 4 hours a week; more than 4 hours a week). To obtain a broader indicator of physical activity, the items measuring physical activity other than sports and involvement in sports were combined, leading to a variable ranging from 0 (no physical activity on a weekly basis) to 7 (more than 6 hours physical active and more than 4 hours sport on a weekly basis), which was analysed as a continuous variable and referred to as 'physical activity'.

Other variables

Diabetes duration, insulin use, perceived health status, presence of comorbidities, age, education and sex were included as control variables. Age and diabetes duration were measured in years and analysed as continuous variables. Education was measured by self-reported highest completed level of education, categorised into low (primary school, lower occupational education or less), medium (secondary level education) and high (university, higher occupational education or corresponding education). Insulin use was self-reported and analysed as a dichotomous variable. The presence of comorbidities was determined through a list of 15 diseases that was derived from the Permanent Survey Living Conditions.[19] Using this list, patients indicated whether they suffered from one or more of 15 diseases in the 12 months prior to the study (including depression). The presence of comorbidity was then analysed as a dichotomous variable (no comorbidities versus one or more comorbidities). Perceived health status was measured with a single item (first item of the Short Form 12). Answer options were given on a 5-point Likert scale and analysed as a continuous variable.[20]

Missing values

Missing values on health literacy, diabetes knowledge and self-management questions varied from 1% (for glucose self-control) to 12% (for one DKT item). Missing values were computed, for both patient registration data (i.e. HbA1c) and survey data (i.e. health literacy) using Multivariate Imputation by Chained Equations (MICE) procedure in R.[21] Twenty imputation datasets were created. Analyses were performed with the multiple imputed datasets.[22] The necessary number of iterations for each missing value was 40 based on the Gibbs sampler.[21]

Results of the analyses on the twenty imputed datasets were pooled by the MIANALYZE procedure in SAS.

Statistical analysis

The internal consistency of the DKT was low (α=0.512). Since excluding items did not improve the internal consistency, the scores on the fourteen items were combined into sum scores. To answer the research questions, multilevel analyses were performed taking GP practice level into account in order to control for clustering on GP practice level. To answer the first research question, we estimated the associated between health literacy and diabetes knowledge (a-path Figure 4.1). To answer the second research question, we estimated the association between health literacy and indicators of self-management behaviour in five separate analyses, including respectively HbA1c level, physical activity, smoking, glucose self-control, and self-reported monitoring of glucose levels. The analyses were first performed without diabetes knowledge (c-path Figure 4.1), and secondly including diabetes knowledge (c'-path Figure 4.1). To answer the third research question, we applied mediation analysis as proposed by MacKinnon.[24] Therefore, we examined whether adding diabetes knowledge to the models changed the associations between health literacy and self-management. Secondly, we estimated the association between diabetes knowledge and each indicator of self-management (b-path Figure 4.1). Thirdly, the Sobel test was used to estimate the possible mediating role of diabetes knowledge in the association between health literacy and self-management (the significance of a*b).[24] The mediation framework as proposed by MacKinnon and colleagues suggests that potential mediation effects should be analysed if there is a significant association between the independent variable and the mediator (a-path) and between the mediator and the dependent variable (b-path).[24] All analyses were adjusted for diabetes duration, insulin use, perceived health, presence of one or more co-morbidities, age, education and sex. Analyses were performed by using the GLIMMIX procedure in SAS (version 9.3). Associations were considered significant at $p \leq 0.05$.

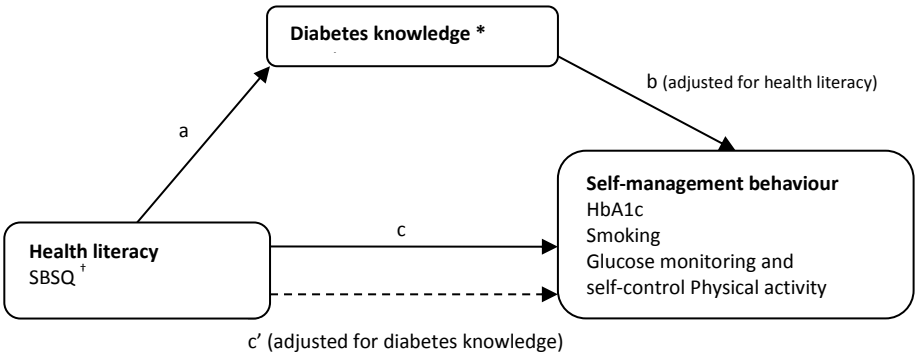

Figure 4.1 *Conceptual model of the studied associations between health literacy, diabetes knowledge and self-management. * Diabetes Knowledge Test † Set of Brief Screening Questions*

Results

Sample Characteristics

As to health literacy, 90% of the respondents had a mean health literacy score higher than 2, implying that most respondents felt confident with filling out forms and perceived little difficulty with understanding and reading information (see Table 4.1). The mean score on the DKT was 9.2 (SD:2.2). As to self-management indicators, 66.7% had an HbA1c value below 53 mmol/mol. Furthermore, a minority of the respondents smoked (14.0%) and a substantial part of the sample controlled (41.8%) and registered (48.9%) blood sugar levels by themselves. The mean score on the physical activity scale was 3.0 (SD: 1.8), which indicated several possibilities, including: patients were involved in sports for more than 4 hours a week; patients were physically active in ways other than sports for 4 to 6 hours a week; or patients combined sports up to 4 hours a week with 1 to 4 hours of other types of physical activity.

Table 4.1 Sample characteristics

Characteristics	*Total (N=1714)*		*Health literacy mean score (range 0 to 4)*			
			≤ 2 (Lower health literacy) (N=167)		*> 2 (Higher health literacy) (N=1547)*	
Female % (n)	49.6	(850)	64.2	(107)	48.0	(743)
Age % (n)						
≤ 24	0.3	(5)	0.6	(1)	0.3	(4)
25 – 54	14.5	(249)	18.9	(16)	15.0	(233)
55 – 64	27.6	(473)	13.6	(23)	29.1	(451)
65 – 74	31.7	(542)	29.2	(49)	31.9	(494)
≥ 75	25.9	(444)	47.1	(79)	23.6	(365)
Level of education % (n)						
Low	44.9	(770)	79.3	(132)	41.2	(638)
Middle	39.7	(680)	19.4	(32)	41.9	(648)
High	15.4	(264)	1.3	(2)	16.9	(262)
Diabetes type % (n)						
Type 1	2.2	(38)	1.7	(3)	2.3	(35)
Type 2	97.8	(1676)	98.3	(164)	97.7	(1512)
Diabetes duration % (n) *						
≤ 3 years	26.5	(454)	27.4	(46)	26.4	(408)
4 to 10 years	45.2	(775)	39.4	(66)	45.8	(709)
≥ 10 years	28.3	(485)	33.2	(55)	27.8	(430)
Medication use % (n)						
Oral diabetic medication (pills)	72.0	(1228)	69.2	(115)	71.9	(1113)
Insulin	25.5	(438)	37.7	(63)	24.2	(375)
Self-reported general health status % (n)						
Good/very good/excellent	94.4	(1617)	85.2	(142)	95.3	(1475)
Poor/moderate	5.6	(97)	14.8	(25)	4.7	(73)
Comorbidity % (n)						
Discordant comorbidity	44.2	(757)	41.7	(69)	44.4	(688)
Concordant comorbidity	5.4	(93)	4.2	(7)	5.6	(86)
Discordant and concordant comorbidity	19.7	(337)	30.8	(51)	18.5	(286)
Diabetes knowledge test						
Mean (SD) †	9.2	(2.2)	8.3	(2.2)	9.3	(2.2)

- table 4.1 continues -

- table 4.1 continued -

Characteristics	*Total (N=1714)*		*Health literacy mean score (range 0 to 4)*			
			≤ 2 (Lower health literacy) (N=167)		*> 2 (Higher health literacy) (N=1547)*	
HbA1c level<53 mmol/mol						
% (n) ‡	66.7	(1137)	57.9	(96)	67.6	(1041)
Excluded because of extreme values		(9)		(2)		(7)
Smoking % (n)	14.0	(238)	13.8	(23)	13.9	(215)
Glucose monitoring % (n)						
Glucose self-control	41.8	(717)	40.8	(68)	41.9	(649)
Self-reported monitoring of glucose levels	48.9	(839)	53.4	(89)	48.4	(750)
Physical activity Mean (SD) §	3.0	(1.8)	2.5	(1.8)	3.1	(1.8)

* As diagnosed by the physician or not. †Range: 0 (lowest score) to 14 (highest score). ‡ 53 mmol/mol=7.0% § Range: 0 (no physical activity on a weekly basis) to 7 (more than 4 hours sport and more than 6 hours non-sportive physical activity on a weekly basis).

Health literacy and patient characteristics

Table 4.1 indicates some noticeable differences in characteristics between patients with lower health literacy and higher health literacy. Compared to those with higher health literacy, those with lower health literacy showed a relative large proportion of respondents aged 75 year or older (47.1% versus 23.6%) and who obtained a low level of education (79.3% versus 41.2%). The mean score on the diabetes knowledge test was lower among those with lower health literacy (Mean: 8.3) than among those with higher health literacy (Mean: 9.3). As to glycemic control, 57.9% of patients with lower health literacy showed an HbA1c level lower than 53 mmol/mol compared to 67.6% of those with higher health literacy.

Association between health literacy and diabetes knowledge

The mean DKT scores for those with higher and lower health literacy (see Table 4.1) suggested an association between health literacy and diabetes knowledge (a-path Figure 4.1). Multilevel analysis, adjusted for diabetes duration, insulin use, perceived health status, presence of comorbidities, age, education and sex,

confirmed that lower health literacy was significantly associated with less diabetes knowledge (B: 0.27, SE: 0.07) (not tabulated).

Associations between health literacy and self-management behaviour

As to the direct association between health literacy and indicators of diabetes self-management behaviour (c-path Figure 1), no significant associations were found between health literacy and self-reported monitoring of glucose levels and smoking (not tabulated). Lower health literacy was significantly associated with higher HbA1c level (B: -0.71, SE: 0.33) and less physical activity (B: 0.14, SE: 0.06). Those with lower health literacy also had higher odds for no self-control of glucose level than those with lower health literacy (OR: 0.7, 95%CI: 0.58-0.87) (not tabulated). These findings were adjusted for diabetes duration, insulin use, perceived health status, presence of comorbidities, age, education and sex. In analyses including diabetes knowledge (c'-path Figure 4.1), lower health literacy was again not associated with smoking and self-reported monitoring of glucose levels, but was significantly associated with higher HbA1c level (B: -0.76, SE: 0.32), less physical activity (B: 0.13, SE: 0.06) and no self-control of glucose level (OR: 0.74, 95%CI: 0.60-0.91) (see Table 4.2).

Associations between diabetes knowledge and self-management behaviour

Analyses of the association between diabetes knowledge and self-management (b-path Figure 4.1) revealed that more diabetes knowledge was associated with lower odds for no self-control of glucose level (OR: 0.87, 95%CI: 0.81-0.93) and lower odds for smoking (OR: 0.90, 95%CI: 0.84-0.97) (see Table 4.2). Diabetes knowledge was not associated with HbA1c level, physical activity or self-reported monitoring of glucose levels (see Table 4.2). These analyses were adjusted for diabetes duration, insulin use, perceived health status, presence of comorbidities, age, education, sex and health literacy. Figure 4.2 summarizes the associations found between health literacy, diabetes knowledge and each of the self-management indicators.

Mediating role of diabetes knowledge

The Sobel test indicated that diabetes knowledge was a mediator between health literacy and glucose self-control ($p<0.01$) and between health literacy and smoking ($p<0.05$).

Table 4.2 *Associations between health literacy and self-management indicators (c' path figure 4.1) and between diabetes knowledge and self-management indicators (b path figure 4.1)*

*Variables**	*HbA1c*[†]	*Physical activity*	*No glucose self-control (vs. glucose self-control)*	*No monitoring of glucose levels (vs. monitoring glucose levels)*	*Smoking (vs. not smoking)*
	B (SE)	*B (SE)*	*OR (95% CI)*	*OR (95% CI)*	*OR (95% CI)*
Diabetes duration	**0.14 (0.05)**	-0.0002 (0.008)	**0.94 (0.91-0.97)**	0.99 (0.97-1.02)	0.97 (0.94-1.01)
Insulin use	**7.72 (0.64)**	-0.13 (0.11)	**0.02 (0.01-0.03)**	**0.08 (0.06-0.12)**	1.15 (0.78-1.69)
Perceived health	0.33 (0.38)	**-0.67 (0.07)**	**0.78 (0.63-0.97)**	0.95 (0.79-1.14)	1.06 (0.85-1.33)
Presence of comorbidity	-0.12 (0.56)	-0.17 (0.10)	1.01 (0.74-1.36)	0.99 (0.75-1.29)	1.11 (0.79-1.55)
Age	**-0.0**6 **(0.02)**	**-0.02 (0.004)**	**1.03 (1.01-1.04)**	**0.99 (0.98-1.00)**	**0.96 (0.95-0.97)**
Level of education					
Medium	0.15 (0.56)	0.12 (0.10)	1.14 (0.82-1.58)	1.14 (0.86-1.51)	0.79 (0.56-1.11)
High	-1.10 (0.80)	-0.15 (0.14)	1.04 (0.66-1.63)	**1.89 (1.24-2.88)**	**0.58 (0.35-0.97)**
Male	**-1.55 (0.49)**	**-0.20 (0.09)**	1.17 (0.89-1.55)	1.25 (0.98-1.59)	**0.74 (0.55-1.00)**
Health literacy (c'-coefficient)	**-0.76 (0.33)**	**0.13 (0.06)**	**0.74 (0.60-0.91)**	1.00 (0.84-1.19)	0.99 (0.81-1.22)
Diabetes knowledge (b-coefficient)	0.13 (0.11)	0.04 (0.02)	**0.87 (0.81- 0.93)**	0.94 (0.89-1.00)	**0.90 (0.84-0.97)**

* Presented estimates are adjusted for all included covariates. Significant associations (at $p<0.05$) are printed in bold.

[†] Extreme values (n=9) were excluded from this analysis.

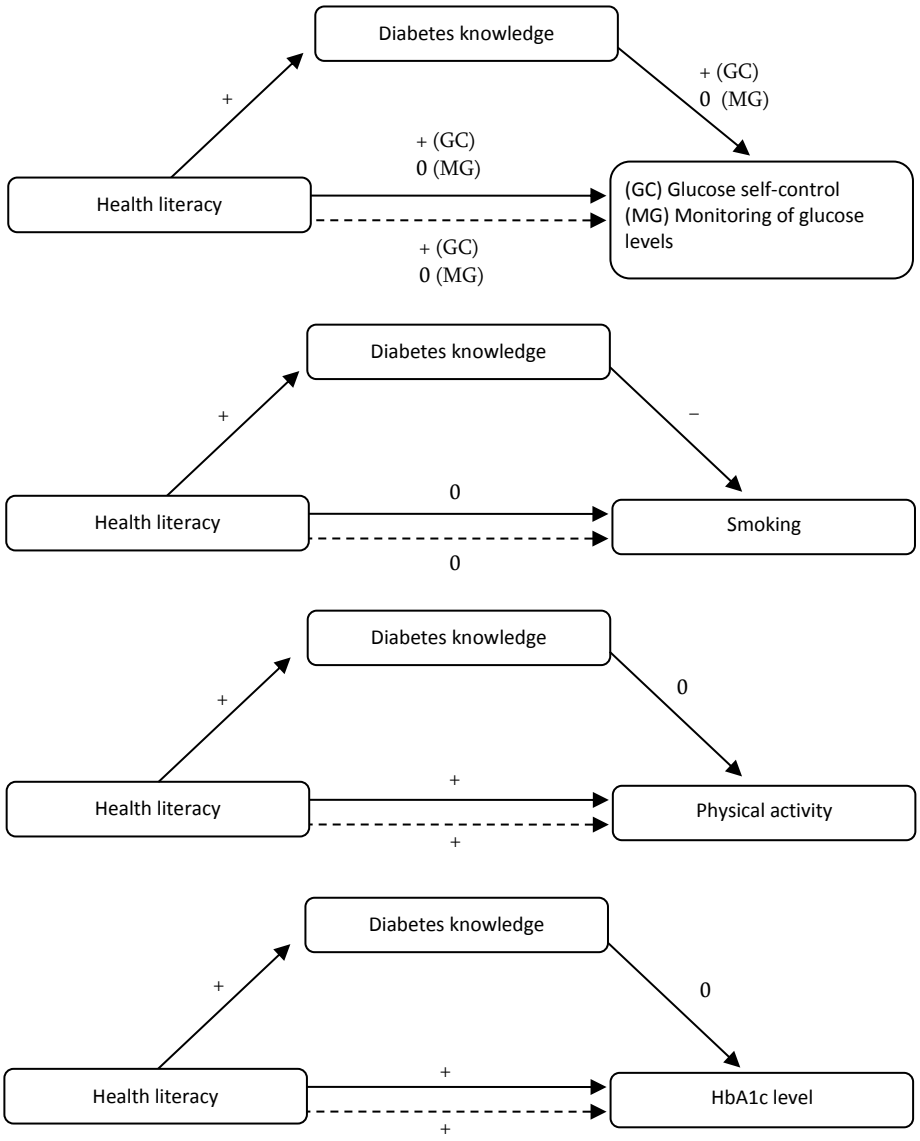

Figure 4.2 *Associations between health literacy, diabetes knowledge and self-management activities adjusted for diabetes diagnose duration, insulin use, perceived health, the presence of co-morbidities, age, level of education and sex in all steps, indicating: a significant positive association (+), a significant negative association (-) or no significant association (0)*

Discussion

This study investigated the interrelationship between health literacy, diabetes knowledge and self-management behaviour. The results show that those with lower health literacy have lower scores on the DKT, are less physically active, less likely to perform glucose self-control, and have higher HbA1c levels than those with higher health literacy. The results also show that there are no differences between those with lower and higher health literacy when it comes to smoking and self-reported monitoring of glucose levels. This means that the association between health literacy and self-management is not straightforward and depends on the type of self-management behaviour, which nuances the theoretical model as proposed by von Wagner and colleagues.[6] The relationship between health literacy and knowledge, as conceptualized by this model, is reflected by our findings, although the direction of this relationship could not be determined due to our cross-sectional study design.

Furthermore, the results indicate that patients with less diabetes knowledge are more likely to smoke and less likely to control their glucose levels themselves, but that there is no difference between less or more knowledgeable patients when it comes to self-reported monitoring of glucose levels, physical activity and HbA1c level. This implies that diabetes knowledge may be more important for certain tasks than for others, or that patients are less aware of the importance of physical activity compared to the importance of glucose level control or smoking behaviour regardless of their diabetes knowledge.

Since there are theoretical grounds to expect that having less diabetes knowledge can partly account for the relationship between lower health literacy and less self-management behaviour[6], we examined to what extent diabetes knowledge clarifies the association between health literacy and self-management behaviour. Less diabetes knowledge partly accounts for the association between having lower health literacy and being less likely to control glucose levels. This suggests that increasing diabetes knowledge among those with lower health literacy may lead to increases in self-control of glucose levels, although we cannot infer causation from our study design. This also yields for smoking; diabetes knowledge seems to be a binding factor between health literacy and smoking behaviour. Diabetes knowledge can on the other hand not explain the association between health literacy and physical activity, or the association between health literacy and HbA1c. This implies that increasing diabetes knowledge among patients with lower health literacy will probably not lead to

increased physical activity, or improved HbA1c levels among this group.

In light of previous studies, the associations we found between health literacy and certain self-management indicators (self-control of glucose level, physical activity and HbA1c) are not supported by a number of other studies.[11,25-27] As to HbA1c, this may be due to differences in operationalization: studies that adopted a dichotomous operationalization of HbA1c found no association between health literacy and HbA1c level.[8,25,28] Therefore, we repeated our analyses including HbA1c as dichotomous variable (HbA1c<53 versus HbA1c ≥ 53). This did not lead to significant associations, implying that differences between our study and other studies could partly be attributed to the way HbA1c is operationalized.

Differences between our findings and findings of others could also be due to sample size, as most studies reporting on the association between health literacy and diabetes self-management behaviour were based on relatively small samples (n=92 to n=398).[5] Furthermore, the instruments we used to measure health literacy and self-management behaviour differ from the instruments used by others.[5] The Rapid Estimate of Adult Literacy in Medicine (REALM)[29] and the Test of Functional Health Literacy in Adults (TOFHLA)[30], instruments mostly used in previous studies, reflect pronunciation and reading comprehension, which may lead to different estimations of health literacy compared to our estimation. As to self-management behaviour, the Summary of Diabetes Self-Care Activities Measure (SDSCA) was often adopted in previous studies.[5] The SDSCA assesses self-care behaviour in the past 7 days, where in our study, the self-management measures are not time bound, except for physical activity. Therefore, the number of patients that performs self-management may be relatively high in our study compared to studies that used the SDSCA.

To summarize, health literacy and diabetes knowledge can be relevant determinants of self-management behaviour depending on the type of self-management task. However, health literacy and diabetes knowledge are not the only factors that determine how a person interprets self-management tasks. There are theoretical and empirical grounds to expect that factors such as self-efficacy, attitudes, motivation, perceived susceptibility and severity and social influences are determinants as well.[5,6] Furthermore, self-management behaviour may vary by patients' healthcare providers, as some healthcare providers may promote self-management behaviour to a greater extent than others. Although our data showed that the proportion of people performing self-management tasks varies to some extent according to GP practice, we have too little information on the support that was given by the various GPs for a proper insight into this

variation and to make any inferences regarding the influence of GP support in self-management behaviour.

Strengths and Limitations

Main strengths of the present study include its quantification of the presumed relationship between health literacy and diabetes self-management via diabetes knowledge. The results of this study thereby contribute to the foundation of theories concerning determinants of self-management behaviour. Other strengths of this study include the relatively large sample size and the use of state-of-the-art statistical techniques for data analysis.

This study is, however, also subject to some limitations. Firstly, a written questionnaire may have limitations when studying health literacy, as non-participation is likely among patients who have difficulty reading and writing. Our results may therefore reflect an overestimation of diabetes patients' health literacy skills and an underestimation of its association with self-management behaviour.

As to the health literacy instrument, the SBSQ, it is short, easy-to-complete and validated among those with a chronic illness.[14,15] The drawback of the SBSQ is that it provides a limited measure of health literacy, since it was developed as a screening instrument for clinical practise. Compared to more objective measures of health literacy, such as the Newest Vital Sign (NVS) or the Rapid Estimate of Adult Literacy in Medicine (REALM), the SBSQ can lead to an overestimation of adequate health literacy.[15] We therefore may have underestimated the number of patients with lower health literacy as would have been indicated by objective health literacy measures. The use of an objective health literacy measure may show stronger associations with diabetes self-management than a subjective health literacy measure, which implies that our findings may be toning down associations that are present in real life.

Another limitation is that to our knowledge the DKT has not yet been validated for use in the Netherlands. Furthermore, the internal consistency of the DKT as indicated in the present study was relatively low (α=0.512) compared to an American validation study (α=0.7).[16] Nevertheless, the fact that the DKT outcomes are in line with our expectations is reassuring; higher diabetes knowledge is associated with higher level of education, longer diabetes duration and higher health literacy. A more important limitation opposed to the low internal consistency of the DKT, is the lack of test-retest information on this version of the DKT, which would provide a proper indication of reliability.

Furthermore, the DKT does not measure specific knowledge regarding smoking and self-reported monitoring of glucose levels, although we related diabetes knowledge to both behaviours. We presupposed that knowledge regarding various topics of diabetes self-management would provide an indication of the general knowledge base of diabetes patients. The association we found between more diabetes knowledge and being less likely to smoke provides some support for this assumption.

Fifthly, the present study covered two domains of diabetes self-management (blood glucose monitoring and physical activity).[5] However, health literacy could affect the other two domains as well, namely nutritional management and medication utilization. Given the differences in results regarding the two domains that were studied, research on the other two domains is needed in order to obtain a complete picture of the relationship between health literacy and diabetes self-management.

Conclusions

The present study indicates that higher health literacy may contribute to involvement in certain self-management activities, in some cases via diabetes knowledge. Diabetes knowledge and health literacy skills may be important targets for interventions promoting diabetes self-management. Increasing health literacy skills among diabetes patients as well as adapting interventions to be suitable for patients of all literacy skills may help support patients in the management of their diabetes.

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Additional materials

Additional Table 1. Diabetes knowledge test

Questions
1. The diabetes diet is: a. the way most American people eat b. a healthy diet for most people* c. too high in carbohydrate for most people d. too high in protein for most people
2. Which of the following is highest in carbohydrate? a. Baked chicken b. Swiss cheese c. Baked potato* d. Peanut butter
3. Which of the following is highest in fat? a. Low fat milk* b. Orange juice c. Corn d. Honey
4. Which of the following is a "free food"? a. Any unsweetened food b. Any dietetic food c. Any food that says "sugar free" on the label d. Any food that has less than 20 calories per serving*
5. Glycosylated hemoglobin (hemoglobin Al) is a test that is a measure of your average blood glucose level for the past: a. day b. week c. 6-10 weeks* d. 6 months
6. Which is the best method for testing blood glucose? a. Urine testing b. Blood testing* c. Both are equally good
7. What effect does unsweetened fruit juice have on blood glucose? a. Lowers it b. Raises it* c. Has no effect
8. Which should not be used to treat low blood glucose?

Questions

a. 3 hard candies
b. 1/2 cup orange juice
c. 1 cup diet soft drink*
d. 1 cup skim milk

9. For a person in good control, what effect does exercise have on blood glucose?
a. Lowers it*
b. Raises it
c. Has no effect

10. Infection is likely to cause:
a. an increase in blood glucose*
b. a decrease in blood glucose
c. no change in blood glucose

11. The best way to take care of your feet is to:
a. look at and wash them each day*
b. massage them with alcohol each day
c. soak them for one hour each day
d. buy shoes a size larger than usual

12. Eating foods lower in fat decreases your risk for:
a. nerve disease
b. kidney disease
c. heart disease*
d. eye disease

13. Numbness and tingling may be symptoms of:
a. kidney disease
b. nerve disease*
c. eye disease
d. liver disease

14. Which of the following is usually not associated with diabetes:
a. vision problems
b. kidney problems
c. nerve problems
d. lung problems*

* Correct answer

(Based on Fitzgerald JT, Funnell MM, Hess GE, Barr PA, Anderson RM, Hiss RG, Davis WK. The reliability and validity of a brief diabetes knowledge test. Diabetes Care. 1998;21(5):706-10.)

Chapter 5

Functional, interactive and critical health literacy: varying relations with control over care and number of GP visits

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Accepted for publication in Patient Education and Counseling

Abstract

Objective The aim of this study is to examine to what extent functional, interactive and critical health literacy are associated with patients' perceived control over care and frequency of GP visits.

Methods Data from the Dutch 'National Panel of people with Chronic illness or Disability' were used (N=2508). Health literacy was assessed by the Functional, Communicative and Critical Health Literacy measure. Perceived control over care was indicated by perceived ability to: (a) organize care, (b) interact with providers and (c) perform self-care. By multivariate linear and logistic regression analyses, associations between health literacy and perceived control over care and subsequently frequency of GP visits were studied.

Results Mainly interactive health literacy skills were associated with patients' perceived ability to organize care, interact with healthcare providers and perform self-care, whereas only functional health literacy was associated with number of GP visits.

Conclusion The results imply that some patients' may be less able to exert control over their care because of lower health literacy. Functional, interactive and critical health literacy vary in their relevance for patients' ability to exert control.

Practice Implications Initiatives to strengthen patients' role in healthcare may be improved by attention for patients' health literacy, specifically functional and interactive health literacy.

Introduction

In chronic care, patients are expected to fulfil an active role in the care for their condition, for instance by fulfilling care tasks in their home environment. This active patient role is considered important for obtaining or maintaining the best possible state of health[1,2] and to reduce the burden on healthcare.[3,4] However, previous studies imply that not all adults with a chronic condition are able to fulfil this role[5], either because they are not interested and/or because they lack the knowledge or the skills.[6] Health literacy skills, referring to the ability to access, understand, appraise and apply health-related information, is considered relevant in this regard.[7-9] Patients with higher health literacy skills are found to fulfil a more active role with respect to their care[10-13] and to make less use of healthcare services than those with lower health literacy skills.[14]

To date most studies on health literacy have focused on functional health literacy, which reflects basic skills in reading and writing.[15] However, attention for interactive/communicative and critical health literacy skills is growing.[15,16] The terms interactive and communicative health literacy have both been used in literature to refer to the skills that can be used to actively participate in everyday situations, extract health information and derive meaning from different forms of health communication, and apply this to changing circumstances.[15] This includes for example searching for online health information and interacting with healthcare providers. In the present chapter we will use the term interactive health literacy to refer to these skills. Critical health literacy refers to cognitive and social skills to critically appraise health information on its applicability to personal situations or on its reliability, such as information on the performance of healthcare providers.[15] Some consider critical health literacy to be especially relevant for individuals' ability to exert control over life events and situations.[15,16] Few studies have actually addressed the relative importance of functional, interactive and critical health literacy skills for patients' ability to fulfil an active role in their care.[17]

In order to develop theory driven interventions to stimulate active patient participation, it is important to obtain insight into the extent to which different types of health literacy are related to patients' abilities to fulfil an active role in the care for their condition. In that context, the present study will focus on health literacy in relation to patients' perceived control over the care for their illness and the frequency of their visits to the general practitioner (GP). Being able to exert a certain degree of control is considered a precondition for active

patient participation and is often discussed in relation to health literacy.[15,16,18] Patients' perceived control over their care is in the current study indicated by their perceived ability to perform self-care activities in the home environment, to effectively interact with healthcare providers and to organize care at the right moment.[2]

In the Netherlands, GPs function as gatekeepers in the sense that a referral from the GP is required for most specialists and for hospital treatment. GPs are generally the first contact in healthcare when people face problems with their health. Frequency of GP visits therefore provides a good indication of the support needs of adults with a chronic condition. The association between patients' health literacy skills and the frequency of their GP visits will indicate whether patients with lower health literacy skills may need more support from their GP than patients with higher health literacy skills.

Literature suggests that older patients, patients who are lower educated and/or are less knowledgeable regarding their condition, are more likely to have lower health literacy skills, more frequently visit their healthcare provider and perceive more difficulties with exerting control over their care than younger, higher educated and more knowledgeable patients.[19-24] The association between age and health literacy may in part be explained by age-related cognitive decline.[25] Furthermore, lower health literacy is associated with poorer health status and those who are in poorer health are more likely to visit their GP and to be less able to exert control over care than those who are in better health.[14,26] These factors will therefore be taken into account in the present study.

The objective of the current study is to obtain insight into the extent to which functional, interactive and critical health literacy are related to patients' perceived control over their care and to the frequency of their GP visits. Thereby, we are specifically interested whether the three types of health literacy show varying associations with perceived control over care and frequency of GP visits. Accordingly, the following research questions are stated:

1 *To what extent are functional, interactive and critical health literacy associated with patients' perceived ability to perform self-care activities, interact with healthcare providers and organize care?*
2 *To what extent are functional, interactive and critical health literacy associated with patients' frequency of GP visits?*

Method

Study design and sample selection

For the purpose of this study, data form the 'National Panel of people with Chronic illness or Disability' (NPCD) were used. This is a Dutch nationwide prospective panel-study on the consequences of chronic illness or a long term disability.[27] Panel members with a chronic illness were recruited from the patient files of general practices (national random samples of general practices, drawn from the Netherlands registration of General Practice). For these panel member, general practitioners provided medical data at inclusion. Panel member with a disability were recruited from national surveys. Selection criteria for chronic patients were: diagnosis of a somatic chronic disease by a certified medical practitioner, aged ≥ 15 years, being non institutionalized, being aware of the diagnosis, not being terminally ill (life expectancy>6 months according to the GP), being mentally able to participate, and having sufficient mastery of the Dutch language. Disabled individuals were included when being moderate to severe disabled based on self-reports. Individuals who agreed to participate filled in self-report questionnaires twice a year (for a maximum of four years). The NPCD is registered with the Dutch Data Protection Authority; all data were collected and handled in accordance with the privacy protection guidelines of the Authority. More detailed information on the sample selection is reported elsewhere.[28] Data for the present study were derived from panel members who filled in a questionnaire that was sent to them in April 2013 as well as a questionnaire that was sent to them in October 2013. In total 2532 respondents returned both questionnaires. For the purpose of the present study a selection was made of adults aged 25 years or older (since highest attained level of education is more stable after this age), which led to a final sample of 2508 adults that filled in both questionnaires.

Assessment of variables

Assessment of health literacy

Health literacy was assessed by the Functional Communicative Critical Health Literacy (FCCHL) scale[29], which is validated for the Netherlands.[30,31] The FCCHL is based on items that assess frequency of perceived difficulty with functional health literacy (5 items), interactive/communicative health literacy (5 items) and critical health literacy (4 items) (see additional Table 1 on page 128). Answers were given on 4-point Likert scales ranging from never perceiving difficulties (1) to often perceiving difficulties (4). Mean scores per health literacy scale were

calculated by summing (reversed) item scores divided by the total number of items, resulting in a score ranging from 1 (lower health literacy) to 4 (higher health literacy). The mean scores were included in the analyses as continuous variables. A previous study based on the same data as used in the present study, indicates that the three subscales measuring functional, interactive/ communicative and critical health literacy can be distinguished and show good internal consistency.[32]

Assessment of perceived control over care

Patients' perceived control over their care was assessed by a measure of self-reported ability to exert control over healthcare, assessed by a questionnaire that was developed and validated in the context of the Longitudinal Aging Study Amsterdam (LASA) study.[33] This questionnaire will in the current study be referred to as the Perceived Control over Care (PCC) scale. Three subscales were differentiated to reflect perceived ability to exert control with respect to: the organization of care (8 items); interaction with healthcare providers (4 items); and self-care (4 items) (see additional Table 1 on page 128). Answers on all items could be given on 5-point Likert scales ranging from 1 (not able to or with great effort) to 5 (with great ease). Mean scores were calculated per scale, resulting in a score ranging from 1 (less able to exert control) to 5 (more able to exert control). The mean scores were analysed as continuous variables.

Assessment of GP visits

Frequency of GP visits was assessed by self-reported frequency GP visits during the last year. Because the distribution of GP visits was skewed to the right and leptokurtic, frequency of GP visits was analyzed as a dichotomous variable, using the median/modus (both equal to 4 visit) as a cut-off point.

Assessment of other variables

The following variables were included in the analyses as covariates: gender, age, level of education, perceived knowledge, cognitive functioning and health status. Self-reported age was assessed and analysed as continuous variable. Highest completed level of education was assessed on a 7-point scale and analysed as categorical variable including the categories low (primary school or preparatory vocational training), intermediate (intermediate or advanced general education or intermediate vocational training), and high (high vocational education or university). Patients' perceived knowledge of their condition was assessed by a

subscale of the Dutch Partners in Health Scale (PIH-Dutch)[32] which is based on two items assessing perceived general knowledge of the condition and perceived general knowledge of medication and care of the condition (range 0=very little to 8=very much). The mean score on these two items was analysed as continuous variable. Perceived cognitive functioning (one item of the EQ-6D measuring no problems with cognitive functioning; some problems with cognitive functioning; or many problems with cognitive functioning) was analysed as dichotomous variable including the categories 'no problems with cognitive functioning' and 'some or many problems with cognitive functioning'.[34] Functional health status (10 items) and perceived general health status (5 items) were assessed by the general health scale derived from the RAND-36. Functional and perceived general health status were analysed as continuous variables on a 100-point metric (sum scores – minimum scale score/score range * 100) with higher scores indicating a better state of health.[35] Type of condition (8 categories) as derived from GP records and type of disability (4 categories), were reported as sample characteristic.

Missing values

The method of multiple imputations by chained equations was used to handle the presence of missing values in the study data. Following this procedure, the original data set was imputed 20 times. The outcomes of each analysis were combined to obtain the outcome of the whole analysis, incorporating the uncertainty due to the missing values.[36] The imputations were done in R 2.14.0.[36, 37] Recent studies have shown that this technique provides less biased results compared to a complete case analysis and is considered to be the state-of-the-art method for dealing with missing data.[38,39]

Statistical analysis

Since patients' ability to exert control in healthcare and health literacy seem closely related constructs, first the discriminant validity of the FCCHL and the PCC was determined by the use of exploratory factor analyses. The factor analysis was conducted based on all items of the FCCHL and PCC (n=29). If the presumed subscales (n=6) were reflected in the factor structure and the internal consistency of the subscales proved to be sufficient ($\alpha \geq .7$) mean scores per subscale were calculated. Pearson's correlation coefficients were calculated between the mean scores on the subscales in order to obtain insight into crude associations.

To answer the research questions, associations between functional, interactive and critical health literacy (independent variables) and perceived ability to organize care, perceived ability to interact with healthcare providers, perceived ability to perform self-care activities and number of GP visits on a yearly basis (dependent variables) were estimated. Five multiple linear regression analyses were conducted per dependent variable, including in the first model gender, age, level of education, knowledge, cognitive functioning, self-reported general health status and self-reported functional health status. In the second model functional health literacy was added, in the third model interactive health literacy, in the fourth model critical health literacy and in the fifth model all three types of health literacy. Linear regression modelling was used for the PCC variables and logistic regression modelling for frequency of GP visits. The factor analyses and the regression analyses were conducted in SAS 9.3 using subsequently the MI procedure and the MIANALYZE procedure.

Results

Sample characteristics

Table 5.1 presents the sample characteristics. Most of the respondents were female (58.4%), aged 45 to 64 (38.4%), attained a low (34.5%) or intermediate level of education (43.0%) and reported no problems with cognitive functioning (70.6%). The mean score on the perceived knowledge scale was 6.7 ± 1.1. Indicating that in general patient feel that they had a lot of knowledge about their care and medications. Most respondents of whom the presence of a chronic condition was registered (n=1817) suffered from lung disease (29.3%). The mean scores on the perceived general health status and functional health status scales were respectively 47.3 ± 20.8 and 55.2 ± 30.2 (national scores are respectively 70.7 ± 20.7 and 83.0 ± 22.8).[40] With respect to the health literacy subscales, mean scores were slightly lower according to the type of health literacy, with 3.1 (± 0.7) for functional health literacy, 3.0 (± 0.7) for interactive health literacy and 2.6 (± 0.8) for critical health literacy. With respect to perceived control over care, mean scores were quite alike as well, with 3.8 (± 0.7) for the organization of care, 3.7 (± 0.8) for interaction with healthcare providers and 3.9 (± 0.7) for self-care. The mean frequency of contact with the GP on a yearly basis was 5 times (± 5.3).

Table 5.1 Sample characteristics (n=2508)

Characteristics	*%*	*Mean (SD)*	*Observed range*
Female	58.4		
Age (in years)		63.8 (13.2)	25 – 93
<45	9.4		
45 to 64	38.4		
65 to 74	30.9		
≥75	21.3		
Dutch	91.1		
Attained level of education			
Low	34.5		
Intermediate	43.0		
High	22.5		
Knowledge		6.7 (1.1)	0 – 8
Cognitive functioning			
No problems	70.6		
Some problems	27.8		
Serious problems	1.6		
Perceived general health status		47.3 (20.8)	0 – 100
Functional health status		55.2 (30.2)	0 – 100
Health literacy			
Functional health literacy		3.1 (0.7)	1 – 4
Interactive health literacy		3.0 (0.7)	1 – 4
Critical health literacy		2.6 (0.8)	1 – 4
Perceived control over care			
Perceived ability to organize care		3.8 (0.7)	1 – 5
Perceived ability to interact with care provider		3.7 (0.8)	1 – 5
Perceived ability to perform self-care [a]		3.9 (0.7)	1 – 5
Frequency contact with GP during the last year		5.0 (5.3)	0 – 80
Four visits or less	60.1		
Five visits or more	39.9		

- table 5.1 continues -

- table 5.1 continued -

Characteristics	*%*	*Mean (SD)*	*Observed range*
Type of chronic disease [b]			
Diabetes mellitus	10.6		
Cardiovascular disease	16.8		
Lung disease	29.3		
Musculoskeletal disease	14.9		
Cancer	4.9		
Neurological disease	6.6		
Digestive disease	3.5		
Other	13.5		
Type of physical disability [c]			
No or minor disabilities	45.2		
Motor disability	38.3		
Only visual and/or auditory	2.0		
Motor and/or visual and/or auditory	14.5		

[a] For two items of the self-care subscale 'not applicable' was an answer option. For respondents who filled in 'not applicable' (6% and 11%) mean scores were calculated based on the remaining three or two items.

[b] Percentages based on respondents for which information on a chronic disease was provided based on GP records (n=1817).

[c] Percentages based on respondents for which information on a physical disability was reported (n=2415).

Discriminant validity of health literacy and control over care

The factor analysis distracted six factors (eigenvalues above 1), reflecting the theoretically presumed subscales for health literacy and control over healthcare (see additional Table 1 on page 128 for factor loadings). The Cronbach's alpha's justified the calculation of sum scores for each of the six subscales of the FCCHL and the PCC (α between 0.8 and 0.9). All subscales were significantly correlated (see Table 5.2).

Table 5.2 Correlations between health literacy and control over healthcare

		Pearson's r					
		1	*2*	*3*	*4*	*5*	*6*
1	Functional health literacy	1					
2	Interactive health literacy	0.54	1				
3	Critical health literacy	0.47	0.66	1			
4	Organizing care	0.33	0.45	0.34	1		
5	Interaction with providers	0.26	0.40	0.29	0.69	1	
6	Self-care	0.27	0.35	0.27	0.53	0.49	1

All correlations are significant at p<.0001

Health literacy and control over care

In separate regression models, higher functional, interactive and critical health literacy were associated with a higher perceived ability to organize care (see Table 5.3), interact with healthcare providers (see Table 5.4) and perform self-care (see Table 5.5). The models including merely interactive health literacy accounted for more variance than the models including merely functional or critical health literacy skills. When including the three types of health literacy simultaneously in the regression models (the complete models), associations were no longer significant for functional health literacy with respect to perceived ability to interact with healthcare providers (see Table 5.4). With respect to perceived ability to organize care and perceived ability to perform self-care, critical health literacy was no longer significant when including all three types of health literacy simultaneously in the model (see Table 5.3 and Table 5.5). The complete models accounted for 29% of the variance in perceived ability to organize care, 22% of the variance in perceived ability to interact with healthcare providers and 27% of the variance in perceived ability to perform self-care.

Table 5.3 Outcomes multiple linear regression analyses including health literacy and perceived ability to organize care (n=2508)

Independent variables	*Dependent variable Perceived ability to organize care*				
	Model 1 B	*Model 2* B	*Model 3* B	*Model 4* B	*Model 5* B
Step 1					
Low educated	**-0.20**	**-0.15**	**-0.12**	**-0.19**	**-0.12**
Intermediate educated (ref. high educated)	-0.05	-0.02	-0.02	-0.04	-0.01
Problems with cognitive functioning (ref. no problems)	**-0.30**	**-0.27**	**-0.24**	**-0.28**	-0.23
Knowledge	**0.19**	**0.17**	**0.14**	**0.16**	**0.13**
Functional health status	**0.002**	**0.002**	**0.002**	**0.002**	**0.001**
Perceived general health status	**0.003**	**0.003**	**0.002**	**0.003**	**0.002**
Male	0.01	0.02	-0.01	-0.004	-0.002
Age	-0.002	-0.0003	0.00002	-0.0005	0.0007
Step 2					
Functional health literacy	**-**	**0.17**	-	-	**0.06**
Interactive health literacy	**-**	**-**	**0.29**	-	**0.23**
Critical health literacy	**-**	**-**	-	**0.17**	0.04
$\mathbf{R^2}$	0.23	0.25	0.28	0.26	0.29

* Significant associations at p<.05 are printed in bold

Table 5.4 Outcomes multiple linear regression analyses including health literacy and perceived ability to interact with healthcare providers (n=2508)

Independent variables	*Dependent variable Perceived ability to interact with providers*				
	Model 1 B	*Model 2* B	*Model 3* B	*Model 4* B	*Model 5* B
Step 1					
Low educated	**-0.24**	**-0.19**	**-0.15**	**-0.23**	**-0.15**
Intermediate educated (ref. high educated)	-0.08	-0.05	-0.04	-0.06	-0.04
Problems with cognitive functioning (ref. no problems)	**-0.29**	**-0.26**	**-0.22**	**-0.27**	**-0.21**
Knowledge	**0.18**	**0.17**	**0.12**	**0.15**	**0.12**
Functional health status	0.00001	-0.0005	-0.0006	-0.0003	-0.0007

- table 5.4 continues -

- table 5.4 continued -

Independent variables	*Dependent variable Perceived ability to interact with providers*				
	Model 1 B	*Model 2 B*	*Model 3 B*	*Model 4 B*	*Model 5 B*
Perceived general health status	**0.004**	**0.003**	**0.002**	**0.003**	**0.002**
Male	0.17	**0.18**	**0.15**	**0.16**	**0.16**
Age	**-0.004**	-0.002	-0.001	-0.002	-0.001
Step 2					
Functional health literacy	-	**0.16**	**-**	-	0.03
Interactive health literacy	-	-	**0.32**	-	**0.29**
Critical health literacy	-	-	**-**	**0.17**	0.02
R^2	0.16	0.17	0.22	0.18	0.22

* Significant associations at p<.05 are printed in bold

Table 5.5 Outcomes multiple linear regression analyses including health literacy and perceived ability to perform self-care (n=2508)

Independent variables	*Dependent variables Perceived ability to perform self-care*				
	Model 1 B	*Model 2 B*	*Model 3 B*	*Model 4 B*	*Model 5 B*
Step 1					
Low educated	-0.02	0.01	0.03	-0.02	0.03
Intermediate educated (ref. high educated)	0.01	0.02	0.02	0.01	0.03
Problems with cognitive functioning (ref. no problems)	**-0.28**	**-0.25**	**-0.24**	**-0.26**	**-0.23**
Knowledge	**0.14**	**0.13**	**0.11**	**0.12**	**0.11**
Functional health status	**0.003**	**0.003**	**0.003**	**0.003**	**0.003**
Perceived general health status	**0.008**	**0.007**	**0.007**	**0.007**	**0.007**
Male	-0.02	-0.02	-0.03	-0.03	-0.03
Age	**0.003**	**0.004**	**0.004**	**0.004**	**0.005**
Step 2					
Functional health literacy	-	**0.12**	**-**	**-**	**0.05**
Interactive health literacy	-	-	**0.17**	**-**	**0.13**
Critical health literacy	-	-	**-**	**0.11**	0.03
R^2	0.24	0.25	0.27	0.26	0.27

* Significant associations at p<.05 are printed in bold

Health literacy and GP visits

Functional and interactive health literacy were significantly associated with frequency of GP visits in separate regression analyses (see Table 5.6). When including all three types of health literacy simultaneously in a regression model, only functional health literacy remained significantly associated with frequency of GP visits: patients with lower functional health literacy more frequently visited their GP on a yearly basis than patients with higher functional health literacy. This last model explained 10% in the variance of GP visits.

Table 5.6 Outcomes multiple logistic regression analyses including health literacy and frequency of GP visits (n=2508)

Independent variables	*Dependent variables* *Estimated odds for more than 4 GP visits on a yearly basis*				
	Model 1	*Model 2*	*Model 3*	*Model 4*	*Model 5*
	OR	*OR*	*OR*	*OR*	*OR*
Step 1					
Low educated	1.20	1.11	1.15	1.19	1.10
Intermediate educated (ref. high educated)	1.10	1.06	1.08	1.09	1.05
Problems with cognitive functioning (ref. no problems)	1.00	0.95	0.96	0.98	0.94
Knowledge	1.04	1.07	**1.07**	1.06	**1.08**
Functional health status	**0.99**	**0.99**	**0.99**	**0.99**	**0.99**
Perceived general health status	**0.98**	**0.98**	**0.98**	**0.98**	**0.98**
Male	0.84	**0.82**	**0.84**	**0.84**	**0.82**
Age	1.00	1.00	1.00	1.00	1.00
Step 2					
Functional health literacy	-	**0.77**	**-**	**-**	**0.79**
Interactive health literacy	-	-	**0.85**	**-**	0.96
Critical health literacy	-	-	**-**	**0.89**	0.98
R^2	0.10	0.10	0.10	0.10	0.10

* Significant associations at p<.05 are printed in bold

Discussion and Conclusion

Discussion

This study adds new insights to the research field of health literacy by showing that interactive health literacy is a more important contributor in explaining variance in chronic patients' perceived control over their care than functional or critical health literacy. On the other hand, functional health literacy is the only type of health literacy that is associated with the frequency of GP visits on a yearly basis: chronic patients with lower health literacy visit their GP more often than patients with higher health literacy. This study showed how health literacy might affect certain aspects of chronic care, which is relevant for Western countries that face the challenges of the increase in people suffering from chronic diseases.[41]

When it comes to patients' control over care, the present study focused on actions that refer to self-care and interaction with the healthcare system. This could in part explain the finding that critical health literacy seems less relevant for explaining differences in patients' control over their care than functional and interactive health literacy. Critical skills could become more relevant with respect to health actions that require the appraisal of information or the weighing of pros and cons, for instance when deciding whether or not to participate in screening or deciding on care options. Future research is needed to explore whether the impact of different types of health literacy indeed varies between specific domains and health behaviours.

The findings of this study imply that patients' functional health literacy may influence their use of primary care. To our knowledge, no study has related health literacy to frequency of GP visits in the Netherlands. Studies do show that patients with a lower socio-economic position and a lower level of activation, which are both associated with health literacy, visit their GP more often than those who have a higher socio-economic position and level of activation.[42] Furthermore, a review of international studies shows that lower health literacy is associated with more hospitalizations and use of emergency care.[14]

A plausible explanation for the association between lower functional health literacy and more GP visits would be that being unable to fully understand (written) information may lead to insecurity/lower self-efficacy, driving people to visit their GP more often. However, a recent study among Japanese diabetes patients indicates that not functional health literacy, but interactive and critical health literacy were associated with self-efficacy.[17] It could also be that because

individuals with lower health literacy are more likely to have a poorer health status than those with higher health literacy, they have a higher rate of GP visits.[11] Our data indicated that patients with lower health literacy skills have poorer perceived health than patients with higher health literacy skills. However, in our analyses we controlled for perceived functional and general health status, which implies that being in poorer health may not fully account for the association between functional health literacy and frequency of GP visits. The explanation that patients with lower functional health literacy need more support from their GP in the care for their condition than patients with higher functional health literacy is therefore more plausible. Since we cannot confirm this explanation based on our data, we suggest more research in order to obtain a better understanding of the association between lower functional health literacy and more GP visits.

Additionally, future research may reveal whether GP contact is effective for patients with lower health literacy or whether other types of support could be more helpful for this group. Furthermore, future research may examine whether the associations we found with respect to GP visits, also yield for other types of care, such as care from specialists or emergency care. This seems especially valuable for countries that have healthcare systems that differ from the Dutch system, providing directly accessible specialist care.

Given the lack of clarity surrounding the interrelation between functional, interactive and critical health literacy[15,16,18,29], the three types of health literacy were treated as distinct constructs in our analyses. Some scholars consider health literacy to be a hierarchical construct, in which functional skills form the base for interactive/communicative skills and subsequently critical skills, providing a growing ability to exert control over situations.[16,18] Others see health literacy rather as a complementary set of skills.[15,16,29] Our study indicates that there might not be a hierarchy in the three types of health literacy in the sense that it increasingly enables people to exert control over situations. The outcomes of the regression models show that models including interactive health literacy explain more variance than models that include critical health literacy. Furthermore, functional health literacy remains significantly associated with the organization of care and self-care after adjusting for interactive and critical health literacy. This implies that functional health literacy provides a unique contribution to these aspects of patients' control, which is not covered by the other types of health literacy. Our findings imply that the three types of health literacy are important for different dimensions of exerting control over care. In that respect

functional, interactive and critical health literacy skills can be considered complementary.

Another complex relation is the relation between health literacy and knowledge. Some consider knowledge to be a part of health literacy. In the present study, perceived knowledge and health literacy were found to be moderately associated. Additionally, the two concepts show some overlap in the variance they can explain in perceived control over care and frequency of GP visits. However, both concepts also provide a unique contribution in explaining variation. It is therefore recommended to consider knowledge as covariate in future research on health literacy and health-related behaviour or health outcomes, instead of considering it to be part of health literacy. Yet this approach may be dependent on the way health literacy and knowledge are operationalized.

This study is subject to a number of limitations. In the first place, the questionnaires were administered in print. We have no information on non-response, but it is possible that those who poses great difficulty with reading did not participate in the present study. This means that, especially with respect to the association between functional health literacy and GP visits, associations may be underestimated and stronger in real life. A second limitation of this study is that due to the cross-sectional design no inferences could be made with respect to the direction of the associations that were found. Thirdly, the study was based on self-reports of both health literacy as well as perceived ability to interact with healthcare providers, self-care and the organization of care. Self-report may lead to observations that differ from actual behaviour, because respondents might give social desirable answers or have little self-awareness. In a real life situation people may have more difficulties with both health literacy as well as exerting control over healthcare than they reported, for instance because of emotions such as stress or fear. On the other hand, people could receive help from family or friends, which may lower any adverse influences of lower health literacy on their control over care. Future research could examine to what extent this type of contextual and emotional influences affect the use and the consequences of health literacy skills.

Conclusion

In conclusion, health literacy seems related to patients' control over their care. Especially interactive health literacy seems relevant as possible determinant of the extent to which patients' are able to exert control over their care. The results

imply that some patients may be willing but unable to actively engage in the care for their condition, because of lower health literacy skills. Furthermore, patients with lower functional health literacy visit their GP more often, implying they may need more support from their GP in the care for their condition than patient with higher functional health literacy. In order to strengthen the role of patients in the care for their disease and reduce the burden on healthcare, attention for health literacy is required in research and practice.

Practice Implications

In order to increase patients' engagement in their healthcare, focusing only on functional health literacy will not be sufficient. It may be effective to focus especially on patients' interactive health literacy skills, for instance by increasing patients' as well as healthcare providers' interaction skills. To our knowledge there is currently no recognized way to test the interactive health literacy of patients during consultations. Tools that have been developed for practice generally address functional health literacy. Since interactive health literacy is gaining attention in research, the development of tools that address this type of health literacy that can be used in practice, might follow in the near future. Efforts to make health-related information more accessible and understandable, for instance information on medication use, may help people to take care for their condition themselves with less support from their GP.

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Additional materials

Additional Table 1. Factor structure of health literacy and control over healthcare items based on promax rotation

Items	*Factor structure (correlations)*					
	Factor 1	*Factor 2*	*Factor 3*	*Factor 4*	*Factor 5*	*Factor 6*
Functional health literacy [a]						
When you receive a leaflet/brochure from your general practitioner/the hospital/the pharmacist, how often does it happen that:						
The letters are too small to read even when you are wearing glasses?	-0.161	**0.695**	0.258	0.243	-0.093	-0.216
There are words or signs that you do not understand?	-0.248	**0.854**	0.378	0.419	-0.209	-0.188
The content is too difficult to understand?	-0.290	**0.898**	0.388	0.470	-0.265	-0.224
It takes a long time to understand the content?	-0.326	**0.898**	0.375	0.542	-0.298	-0.253
You need help from others to understand the content?	-0.348	**0.818**	0.341	0.517	-0.277	-0.246
Interactive health literacy[a]						
When you are searching for health information, how difficult is it for you to:						
Collect information about your illness via various ways (for example internet, encyclopaedias, friends or family?	-0.411	0.432	0.452	**0.855**	-0.286	-0.235
To find exact the information you are looking for?	-0.400	0.399	0.536	**0.868**	-0.293	-0.225
To share your thoughts about your illness with others? (for example family, friends or healthcare providers?	-0.355	0.359	0.450	**0.709**	-0.479	-0.313

- additional table 1 continues -

- additional table 1continued -

Items	*Factor structure (correlations)*					
	Factor 1	*Factor 2*	*Factor 3*	*Factor 4*	*Factor 5*	*Factor 6*
To understand the information you obtained?	-0.397	0.536	0.513	**0.862**	-0.403	-0.310
To use the information in daily life?	-0.360	0.411	0.532	**0.789**	-0.448	-0.395
Critical health literacy[a]						
When you are searching for health information, how difficult is it for you to:						
Judge whether the information applies to you?	-0.366	0.416	**0.856**	0.609	-0.349	-0.275
Check whether the information is correct and reliable?	-0.319	0.393	**0.933**	0.527	-0.292	-0.233
Judge whether the information is correct and reliable?	-0.330	0.401	**0.937**	0.527	-0.285	-0.240
Use the information to make decisions about your health? (like medication or daily activities?)	-0.305	0.390	**0.868**	0.550	-0.314	-0.255
Organization of care[b]						
I know the right moment to call in care	**0.679**	-0.204	-0.249	-0.301	0.575	0.495
When I need information on health or care, I can find it	**0.784**	-0.320	-0.377	-0.449	0.597	0.474
When there are tools or services that I can use I can find out	**0.843**	-0.228	-0.286	-0.364	0.489	0.379
I know where to request care, tools or services	**0.827**	-0.184	-0.306	-0.330	0.449	0.317
I can arrange care, tools or services	**0.854**	-0.275	-0.251	-0.406	0.549	0.402
I understand the rules of healthcare institutions that are important to me	**0.798**	-0.296	-0.348	-0.398	0.501	0.368

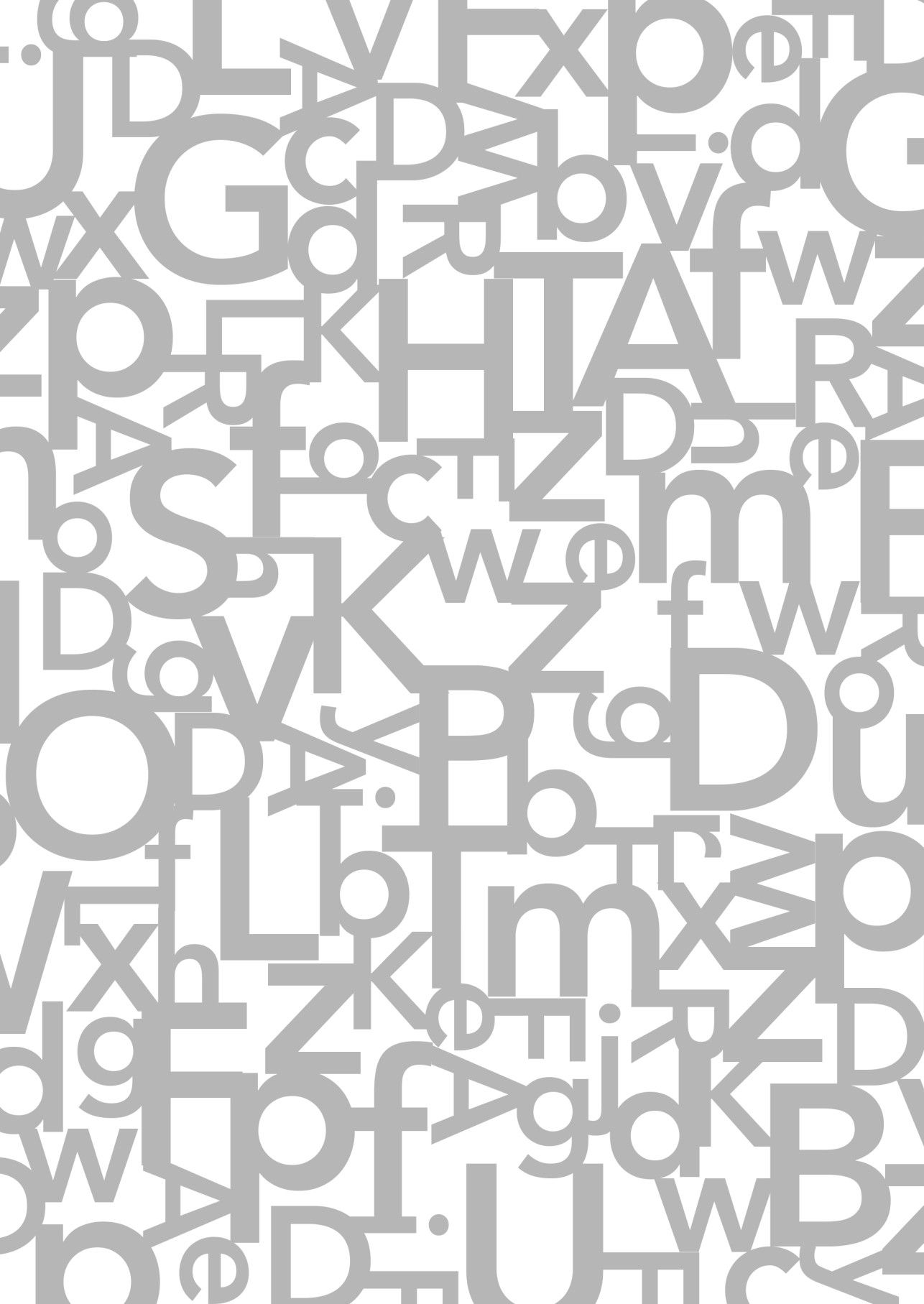
- additional table 1 continues –

- additional table 1 continued -

Items	*Factor structure (correlations)*					
	Factor 1	*Factor 2*	*Factor 3*	*Factor 4*	*Factor 5*	*Factor 6*
When I need to travel to my healthcare provider(s) I can manage	**0.696**	-0.336	-0.221	-0.371	0.433	0.461
I have an overview of the meeting with my healthcare provider(s)	**0.743**	-0.316	-0.191	-0.335	0.518	0.438
Interaction with healthcare providers						
I make clear to my healthcare provider(s) what is going on	0.617	-0.308	-0.276	-0.414	**0.884**	0.465
When I have questions regarding my health or care, I will ask them	0.633	-0.269	-0.257	-0.398	**0.889**	0.465
When I have requests, I will state them	0.619	-0.239	-0.293	-0.387	**0.911**	0.452
When I feel that the care situation is not satisfactory, I stand up for myself	0.514	-0.185	-0.323	-0.353	**0.829**	0.429
Self-care[b]						
I can deal with the medication that my healthcare providers subscribe	0.474	-0.284	-0.176	-0.327	0.399	**0.715**
I can execute the advices given by my healthcare providers	0.409	-0.254	-0.198	-0.311	0.364	**0.843**
I can do what is needed to keep my health as good as possible	0.391	-0.188	-0.218	-0.240	0.433	**0.843**
I can adapt to setbacks in my health- or care situation	0.404	-0.193	-0.296	-0.255	0.479	**0.750**

[a] Answers ranged from (1) not or with great effort to (5) with great ease.

[b] Answers ranged from (1) not or with great efforts to (5) easy.



Part III

Health Literacy in the context of prevention

Chapter 6

Health literacy and informed decision-making regarding colorectal cancer screening: a systematic review

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European Journal of Public Health, 2015; Epub ahead of print

Abstract

Background Making an informed decision about participation in colorectal cancer (CRC) screening may be challenging for invitees with lower health literacy skills. The aim of this systematic review is to explore to what extent the level of a person's health literacy is related to their informed decision making concerning CRC screening.

Methods We searched for peer-reviewed studies published between 1950 and May 2013 in MEDLINE, EMBASE, SciSearch and PsycINFO. Studies were included when health literacy was studied in relation to concepts underpinning informed decision making (awareness, risk perception, perceived barriers and benefits, knowledge, attitude, deliberation). The quality of the studies was determined and related to the study results.

Results The search returned 2254 papers. Eight studies in total were included, amongst which seven focused on knowledge, four focused on attitudes or beliefs concerning CRC screening, and one focused on risk perception. The studies found either no association or a positive association between health literacy and concepts underpinning informed decision making. Some studies showed that higher health literacy was associated with more CRC screening knowledge and a more positive attitude towards CRC screening. The results of studies that obtained a lower quality score were no different than studies that obtained a higher quality score.

Conclusion In order to obtain more insight into the association between health literacy and informed decision making in CRC cancer screening, future research should study the multiple aspects of informed decision making in conjunction instead of single aspects.

Introduction

Colorectal cancer (CRC) is one of the most common causes of cancer-related deaths worldwide.[1] As screening for CRC can identify precancerous polyps or cancers in their early stages, and thereby improve the survival rates of colorectal cancer, several countries have implemented national CRC screening programs.[2-4] Building on the idea of individual autonomy when making decisions about screening, it is increasingly being recognized that screening programs should not aim to pursue screening invitees to participate. Instead screening programs should adopt an informed decision making approach.[5-8] In accordance, invitees should receive information on CRC screening and the pros and cons of the screening program in such a way that enables them to make a well-informed decision whether or not to participate.

Informed decision making can be seen as a process that includes various stages (awareness, perception, evaluation and decision making) during which the gathering of information is an important element (see additional Figure 1 on page 158).[9] During the first stage, the decision maker becomes aware of the issue about which a decision needs to be made. In the current context, this is CRC screening. During the second stage, the perceptions of CRC screening, for instance its pros and cons and the decision options (e.g. participate, not participate, participate in the future), are determined. The third stage refers to the evaluation of these decision options, including determining the utility of the decision options. In the last stage the decision is made based on the preceding stages.[9] An informed decision reflects the outcome of this process.[10] According to various definitions, a decision is considered to be informed when it is based on sufficient knowledge of the relevant aspects of the available alternatives and is consistent with the decision maker's values or attitude towards the issue at hand.[10-12] Van den Berg and colleagues additionally included the evaluation of alternatives and the weighing up of their pros and cons (deliberation) as an indicator of an informed decision.[10] This implies that in the context of CRC screening, an informed decision has been made when an invitee has sufficient knowledge concerning the consequences of CRC and the pros and cons of CRC screening, has deliberated about these pros and cons and has made a decision that is consistent with his or her attitude regarding CRC screening. So far, few studies have measured all of these aspects, but rather focus on one of these elements instead.[13]

A distinction can thus be drawn between the process of informed decision making and informed decisions as an outcome of this process. Informed decision

making, as well as indicators of informed decisions (knowledge, attitudes and deliberation about pros and cons), seem highly dependent on an individual's ability to understand and use information. Understanding and using information about CRC screening is challenging, especially for those who have difficulty comprehending health related information.[14] Health literacy reflects the ability to access, understand, appraise and apply health related information.[15] Since informed decision making is founded on the use of information, those with lower health literacy skills may be subordinated to those with higher health literacy skills when it comes to the opportunity to make an informed decision concerning participation in CRC screening. Studies indicate that individuals with lower health literacy skills are less familiar with cancer screening and have greater difficulties in making informed decisions about participation in cancer screening.[16-20] It is important that all invitees for CRC screening, including those with lower health literacy skills, make an informed and well-considered decision whether or not to participate. This is important since individuals that make informed and well-considered decisions have less decisional regret than those individuals whose decisions are not informed and well-considered.[9]

The aim of the present systematic review is to determine whether, and in what respect, health literacy is associated with informed decision making concerning CRC screening. More specifically, our objectives are to examine in which aspects of the informed decision making process individuals with lower health literacy differ from those with higher health literacy. In addition our aim is to examine whether health literacy is associated with the extent to which informed decisions are made. CRC screening uptake (isolated from informed decision making) will not be part of this review. A recent review already reflects on the association between health literacy and CRC screening uptake.[21] The result of this review can provide a knowledge base for the development of interventions in order to provide tailored support for individuals with lower health literacy in their CRC screening decision making process. Furthermore, the results can indicate knowledge gaps in this area and provide direction for future research.

Methods

Search strategy and study selection

We searched for original peer-reviewed studies on health literacy and informed decision making in CRC screening, published in English and Dutch between January 1950 and May 2013 in the following computerized bibliographic databases: MEDLINE, EMBASE, SciSearch and PsycINFO. The search strategy is included in Table 6.1.

Table 6.1 Search strategy

Search strategy in MEDLINE (this search was adapted to be used in EMBASE, SciSearch and PsycINFO)
1 (colorectal cancer or colon* cancer or colorectal neoplasms or crc or colon* neoplasms or bowel cancer or bowel neoplasms).ti.
2 exp colorectal neoplasms/or exp colonic neoplasms/or rectal neoplasms/
3 1 or 2
4 screening.ti. or mass screening/or early detection of cancer/or early diagnosis/or population surveillance/
5 (fecal occult blood test* or faecal occult blood test* or stool guaiac test* or fobt or gfobt or ifobt or fecal immunochemical test* or faecal immunochemical test* or fecal dna test* or faecal dna test* or double contrast barium or dcbe or barium x-ray or colonoscop* or sigmoidoscop* or colonograph* or digital rectal).ti.
6 fit.ti. and immunochemical.ab.
7 colonoscopy/or sigmoidoscopy/or digital rectal examination/or colonography, computed tomographic/
8 4 or 5 or 6 or 7
9 (literacy or literate or numeracy or education or evidence based risk information or evidence based information or informed choice* or informed decision* or shared decision making or shared-decision making or knowledge or cognitive ability or (retention adj5 information) or (recall adj5 information) or information processing or "ability to seek" or information seeking or self-efficacy or perceive confidence or comprehension or understanding or "locus of control" or adequate information or inadequate information).ti.
10 *health education/or *educational status/or *"health knowledge, attitudes, practice"/or *health literacy/or *self-efficacy/or *informed consent/or *educational measurement/
11 *mental processes/or *cognition/or *comprehension/
12 (attitude* or acceptance or acceptability or willingness or unwilling* or hesitant or hesitate or motivation or intention* or belief* or opinion* or views or standpoint or preference* or prefers or refusal or adherence or delay or perceived benefits or barrier* or anxiety or fear or concern* or perception* or decision* or decided or deliberation* or considerations or decision making or attitude-uptake concistency).ti.
13 (debate or discussion* or awareness or eligibility or intention*or initiation or preference* or compliance or behavio*or choice or choose or reason* or consent).ti.
14 *attitude/or *attitude to health/or *"patient acceptance of health care"/or *retention/or *choice behaviour/or *decision making/
15 (risk information or communication or communicating or risk presentation or leaflet* or pamphlet* or notification or pre-notification or promot* or intervention* or readability or effective health promotion or (source*

adj4 information) or decision aid or decision support or influencing factors).ti.
16 *communication/or *health communication/or *communication barriers/or *information systems/or *decision making/or *decision support techniques/or *pamphlets/or *"patient education as topic"/or *information services/
17 (media or internet or website* or "social networking" or social networks or message* or media campaign or informatics).ti.
18 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
19 3 and 8 and 18
20 19 and (english or dutch).lg.
23 remove duplicates from 19

Health literacy

Health literacy is often defined as an individual's ability to access, understand, appraise and apply health-related information.[15] Studies that related one or more of these four elements to informed decision making or informed decisions were considered for inclusion. Studies were also considered for inclusion when health literacy was not explicitly defined as such (Sharma et al. for example investigated whether trainees in internal medicine had adequate understanding of colorectal cancer screening[22]). Additionally, studies that reported on health numeracy in relation to informed decision making in CRC screening were also considered for inclusion. Health numeracy is considered by some researchers to be an element of health literacy and reflects the ability of the person to understand and use numerical health-related information, which is often part of risk communication.

Informed decision making

It was decided to adopt a broad approach to informed decision making by selecting studies that focused on (indicators of) the process of informed decision making or on (indicators of) informed decisions as the outcome of this process. The process of informed decision making included four stages: awareness of CRC screening; perception about CRC screening; evaluation of the decision options; and decision making.[9] Informed decisions are generally characterized by knowledge, attitude-uptake consistency and deliberation.[10,11,16] Henceforth, the term "informed decision making" will be used to refer to the process of informed decision making, as well as to informed decisions as an outcome. Studies that did not explicitly indicate the study of informed decision making, but included, for example, knowledge as a single concept were still considered relevant for inclusion in the present review.

Pairs of researchers (IvdH and EU or MF) selected papers firstly based on the title, secondly based on the abstract and finally based on the contents of full paper. Studies were excluded when:

- The role of health literacy or an element of health literacy (i.e., numeracy, accessing, understanding, appraising, applying)[15] was not studied in relation to informed decision making (indicated by awareness, risk perception, perceived barriers and benefits, knowledge, attitude, deliberation or synonyms for these terms)[9-11] relating to CRC screening.
- It was not an original peer-reviewed study.
- The study was not performed in a Western country (as defined by Statistics Netherlands).
- The study had no quantitative design.

Figure 6.1 presents a flow diagram of the review process. The initial search yielded 2254 papers. After two reviewers screened the titles, this number was reduced to 542 papers. Most of the titles, abstracts and full papers were excluded because health literacy was not related to informed decision making in CRC screening (1712 papers were excluded based on title; 480 based on abstract; 84 based on the full paper). This resulted in a final total number of 8 papers that could be included in the review.

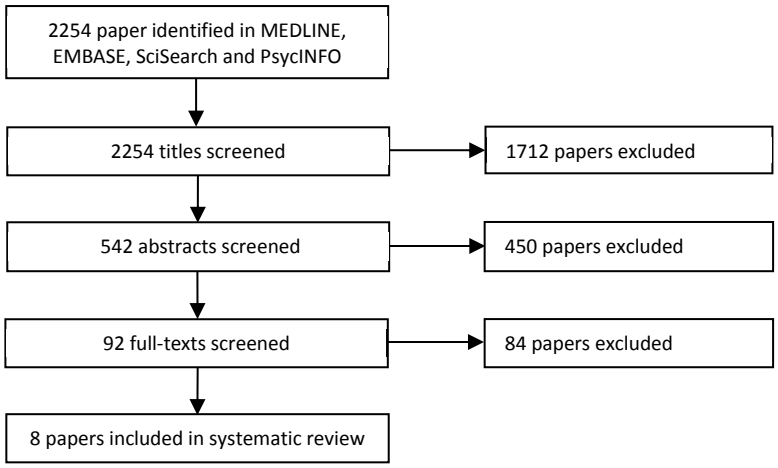

Figure 6.1 Flow diagram of review process

Data extraction and quality assessment

After determining article inclusion, one reviewer (IvdH) extracted relevant data from all the included publications and a second reviewer checked the information for accuracy and completeness (EU or MF). Extracted data included the aim of the study, sample characteristics, measure of health literacy, measure of informed decision making (aspect), context of CRC screening, statistical analyses and study results (see additional Table 1 on page 159). Pairs of authors (IvdH and EU or MF) independently scored the quality of each study according to a selection of eight predefined criteria, as developed by the Dutch Cochrane Centre.[23] Studies were scored based on the description of the sample characteristics and the data collection, the definition and operationalization of health literacy and informed decision making, and control for confounders (see Table 6.2). In cases where reviewers disagreed about quality scores, consensus was achieved during a consensus meeting. The quality of the studies was used to interpret the study findings in light of their quality. The quality of each individual study was expressed by the number of criteria met. The score 'partly' was given when a criterion was partly met and counted as 0.5 when calculating the number of criteria met.

Results

Included papers and characteristics

Eight studies were included, of which the characteristics are described in additional Table 1 on page 159. Five studies were carried out in the USA[24-28], one in Japan[29], one in Switzerland[30] and one in the UK[18]. The selection included one quasi-experimental design[30] and seven cross-sectional studies[18, 24-29]. The aims of the studies are described in additional Table 1 as well as the type of CRC screening tests that were included in the studies (i.e., fecal occult blood test, flexible sigmoidoscopy and colonoscopy). All studies concentrated on single concepts related to informed decision making, including knowledge, attitude or beliefs, and the perception of risk information concerning CRC screening, instead of studying multiple concepts in coherence. No studies investigated health literacy in relation to attitude-uptake consistency or deliberation.

Findings on health literacy and concepts of informed decision making

CRC (screening) knowledge

Seven studies reported on the association between health literacy and CRC (screening) knowledge (see additional Table 1).[18,24-29] Three studies assessed knowledge as indicated by the participants awareness of the possibility of CRC screening by ask respondents to name screening tests[24,25,28]; four studies applied more extended knowledge measures based on true or false statements.[18,26,27,29] Three studies found no association between health literacy and CRC (screening) knowledge.[18,26,27] Four studies implied that those with lower health literacy tend to have less knowledge regarding CRC screening, with the aside that different aspects of knowledge were measured (see additional Table 1).[24,25,28,29]

Studies did not differ remarkably from one another when it came to the age and gender of the participants. The way in which health literacy was assessed may have partly contributed to the differences in the findings. Three of the four studies that found an association between health literacy and CRC knowledge applied the Rapid Estimate of Adult Literacy in Medicine (REALM) as a health literacy measure. Studies that did not find an association applied the Test of Functional Health Literacy in Adults (TOFHLA) or the REALM. The way knowledge was measured appears to have provided a more plausible explanation for the differences in study findings. Namely, studies that found an association applied more limited measures of knowledge that mainly assessed whether people had heard of CRC screening, knew screening was an option, or were able to name a screening test. These measures were mostly based on two to four items (leaving the study of Mitsutake aside).[24,25,28] The studies that did not find an association applied more extended measures of knowledge in the form of true-false questions based on fifteen to twenty items.[18,27] This distinction between findings based on limited and more extended measures of knowledge, could imply that individuals with higher health literacy score just as bad on more complex knowledge as those with lower health literacy. The findings of two studies indeed indicate that CRC screening knowledge, assessed with a more extended measure of knowledge, is generally poor among those with higher and lower health literacy.[18,26] One other study indicates that CRC screening knowledge, assessed by a relative extended measure, is not that poor among those with higher and lower health literacy.[27]

Attitudes and beliefs

Four studies reported on the association between health literacy and attitude and/or beliefs towards CRC screening (see additional Table 1).[24-27] Two studies reported on attitudes and beliefs concerning CRC screening, without drawing a distinction between the two concepts, based on questions concerning perceived benefits, perceived barriers and perceived susceptibility towards CRC screening.[25,26] One study assessed beliefs and perceived barriers towards CRC (screening).[24] Another study measured CRC screening beliefs by assessing perceived benefits, barriers and perceived risk.[27]

These concepts were measured by various questionnaires (see additional Table 1). Since all of them reflected either beliefs, which can be seen as underpinning for attitudes[31], or attitudes themselves, the findings were gathered under the current header of "attitudes and beliefs".

The findings of the studies appear to be mixed. With respect to perceived barriers, two studies found no association with health literacy[24,26], whereas two other studies found an association between health literacy and (part of) the included indicators of perceived barriers.[25,27] For instance, one study found that respondents with limited health literacy were more likely to believe that the faecal occult blood test FOBT was messy and inconvenient than those with adequate health literacy skills.[25] As to perceived benefits, two studies found no association with health literacy[25,27] as opposed to one other study.[24] The latter study found that individuals with low health literacy were less likely to believe that CRC screening would help to find colon and rectal problems early and thereby decrease the chances of dying from CRC as compared to those with adequate health literacy. With respect to perceived susceptibility to CRC, no association with health literacy was indicated by two studies.[26,27] whereas one other study did find an association.[25] More detailed information on the findings of the studies is reported in additional Table 1.

Differences in findings were unlikely to be due to sample characteristics such as age and gender, which were quite similar between studies. Applied health literacy measures also seem unlikely explanations for the differences between study findings, as three studies applied the REALM[24,25,27] and one the TOFHLA.[26] What does differ between studies is the measure of attitudes and beliefs, and although the questionnaires show similarities, differences are also present. For instance, as opposed to other studies, Peterson and colleagues included questions about costs as possible barrier.[27] And when it comes to perceived susceptibility, Dolan and colleagues assessed whether respondents perceived their chances of

CRC to be very high, whereas Guerra and colleagues and Peterson and colleagues, assessed perceived susceptibility to CRC in comparison to age peers.[25-27] Furthermore, a methodological difference between the studies is that Peterson and colleagues calculated a mean score based on questions concerning barriers and benefits, whereas others studied each item separately.

Perception of risk information

One study focused on risk perception by studying whether different presentations of risks concerning CRC were perceived differently by individuals with differing numeracy skills.[30] They concluded that different communication formats could lead to differences in risk perception, but that this was dependent on a person's numeracy skills.[30] Respondents with low numeracy skills perceived no difference in risk when high or low risks were presented, regardless of the format in which the risks were presented. Highly-numerate respondents, on the other hand, reacted differently to higher risks and lower risks when they were presented in a Paling Perspective Scale, but not when they were presented as a ratio or a pictogram.

Methodological quality of the papers

Table 6.2 summarizes the methodological quality of the included studies, which indicates that all studies clearly defined health literacy, as well as the informed decision making concept(s) included in the particular study. Health literacy was considered to be clearly defined when the researchers provided either a definition of health literacy or described what was considered to be higher or lower health literacy in light of the applied instrument. All of the included studies applied a validated measure of health literacy. Most studies applied the REALM to assess health literacy.[24,25,27,28] Other instruments included the TOFHLA[18,26], the J-eHEALS (for e-health literacy)[29], and the Lipkus scale (for health numeracy)[30]. Five studies described that health literacy was administered verbally[24-27,30], which is relevant since those with lower health literacy may perceive answering written questions to be more difficult. As to the informed decision making aspects, Table 6.2 shows that two studies described that a validated instrument was applied to assess knowledge, attitude and beliefs.[24,27] Two other studies provided a description of how an instrument to assess knowledge, attitudes and beliefs concerning CRC screening was carefully designed, including testing the understandability of the instrument and pilot testing the instrument.[25,26] Seven studies controlled for relevant confounders in

the design or in the analyses (including at least an indication of SES, ethnicity and age).[18,24-29] Concerning the sample selection and description, five studies obtained the score "partly" because either the method of recruitment[18], the ethnic background of the sample[29], the geographic location[28] or the period[26, 30] was unclear. All studies provided insufficient information concerning the original population. The quality per study ranged from 3[30] to 7[27] out of 8 points possible (see Table 6.2). Differences in study findings are unlikely to be due to the quality of the studies, as quality scores were relatively high overall and no remarkable differences in study findings were detected when comparing studies of lower quality with studies of higher quality (see additional Table 1).

Table 6.2 Studies (n=8) meeting the quality criteria[23]

Criteria	*Studies meeting the criteria*								
	Arnold 2012	*Mitsutake 2012*	*Von Wagner 2009*	*Keller 2009*	*Miller 2007*	*Peterson 2007*	*Guerra 2005*	*Dolan 2004*	*Total number of studies meeting the criteria (partly)*
1. The study population and the recruitment method were clearly described [a]	1	0.5	0.5	0.5	0.5	1	0.5	1	3 (5)
2. The original population was clearly described.	0	1	0	1	1	1	1	1	6
3. The study population was an adequate reflection of the original population.	0	0	0	0	0	0	0	0	0 [b]
4. Health literacy was clearly defined.	1	1	0	1	1	1	1	1	7
5. Health literacy was assessed by a validated instrument.	1	1	1	1	1	1	1	1	8

- table 6.2 continues -

- table 6.2 continued -

Criteria	*Studies meeting the criteria*								
	Arnold 2012	*Mitsutake 2012*	*Von Wagner 2009*	*Keller 2009*	*Miller 2007*	*Peterson 2007*	*Guerra 2005*	*Dolan 2004*	*Total number of studies meeting the criteria (partly)*
6. The outcome measure was clearly defined.	1	1	1	1	1	1	1	1	8
7. The outcome measure was assessed by a validated instrument.	1	0	0	0	0	1	0.5	0.5	2 (2) [c]
8. Important confounders taken into account in the analyses or in the research design. (SES, age, ethnicity and sex.)	1	0.5	1	0	1	1	1	1	6 (1)
Total number of criteria met per study	6	5	3.5	4.5	5.5	7	6	6.5	-

[a] Information was given on sample size, age, gender, SES, ethnicity, study setting, geographic location, timeframe and method of recruitment.

[b] None of the included studies provided sufficient information regarding this criterion; [c] Studies that partly met this criterion did not apply a validated instrument but the instrument was carefully designed and described.

Discussion

Discussion of main findings

The results of the present review indicate that the body of literature on the association between health literacy and informed decision making concerning CRC screening is limited. Studies included in this review focused on individual concepts underpinning informed decision making, including knowledge, attitudes or beliefs, and risk information perception rather than focusing on multiple indicators of informed decisions or on multiple stages of the process of informed decision making. Most of the included studies presented either no association between health literacy and these concepts or an association in the expected direction, namely lower health literacy was associated with less knowledge or a less positive attitude towards CRC screening. No consistent pattern was found with respect to study findings and study quality; both studies of higher and lower quality showed no association or an association as expected. The most frequently studied concept of informed decision making was CRC screening knowledge, which was the subject of seven studies. Four of these studies indicated that those with lower health literacy have less CRC screening knowledge. Furthermore, four studies reported on the association between health literacy and attitudes and beliefs and showed varying results. A single study reported on the perception of risk information according to health literacy. The focus on knowledge is a deficiency of the current theory base, since knowledge is not the only determinant in the decision as to whether or not to participate in CRC screening.

The studies included in this review stemmed from various countries in which CRC screening is organized differently. The US and Switzerland both offer organized as well as opportunistic CRC screening, depending on the region, whereas Japan and the UK have organized national screening programs.[4] The way CRC screening is organized may influence the extent to which people are aware and knowledgeable about CRC screening. However, we were unable to link CRC screening organization to the study findings, as most of the studies stemmed from the US with single studies coming from the UK, Switzerland and Japan.

Studies applied various measures of functional health literacy. Furthermore, the studies included in the present review measured various aspects of knowledge and attitudes. When it comes to knowledge, some operationalizations reflected familiarity with or awareness of CRC screening[25], whereas other operationalizations were more in-depth and included rather complex (true/false)

knowledge questions like, "About one in 20 people in the UK develop bowel cancer during their lifetime."[18] Differences in CRC screening knowledge between those with lower and higher health literacy skills seemed present less often when studies applied more extended measures of CRC screening knowledge.[17,32,33] The heterogeneity in the operationalizations of both health literacy and concepts underpinning informed decision made it more difficult to obtain a clear insight into the relation between health literacy and informed decision making. Furthermore, the methodological distinction between concepts was sometimes unclear; the questions studied applied to assess attitudes or beliefs were in some cases difficult to disentangle from knowledge questions. Nevertheless, this review provides indications that informed decision making may be more complicated for those with lower health literacy skills than for those with higher health literacy skills.

Reflection on knowledge and decision making

Informed decision making is based on the assumption that during the decision making process information regarding the issue at hand is gathered and used (see additional Figure 1 on page 158). A possible explanation for the finding indicating that those with lower health literacy are less knowledgeable concerning CRC screening as compared to those with higher health literacy is that those with lower health literacy may have had less exposure to information on CRC screening. Individuals with lower health literacy have, for instance, been found to be less likely to seek out information, less likely to utilize health information resources and have reported a lower frequency in reading and computer use than those with higher health literacy.[17,18,34] Subsequently, individuals with lower health literacy seem more likely to avoid information about diseases they do not have and to seek information about cancer prevention or screening from a healthcare professional instead of turning to the Internet.[17] This implies that before receiving an invitation, those with higher health literacy are more likely to have thought about screening and have perhaps already formed an opinion concerning screening than those with lower health literacy. It is also possible that individuals with higher health literacy are more likely to have discussed the pros and cons of screening with relatives, friends or colleagues than those with lower health literacy, which leads to a more reasonable and informed initial opinion regarding CRC screening upfront.[35,36] This assumption is supported by the conceptualization of health literacy by Nutbeam, in which the ability to interact with others on health-related issues (interactive health

literacy) is considered a key aspect of health literacy.[37] Among the studies that were included in this review, no study investigated the association between interactive health literacy and informed decision making. Differences in exposure to CRC (screening) information as well as in interaction on CRC (screening) with others could influence the way information concerning CRC screening is perceived and evaluated. This reflects the second and third stage of the process of informed decision making and may thereby affect the fourth stage of the process, namely the decision that is made.

Reflection on measuring health literacy

All of the studies included in the present review operationalized health literacy as functional health literacy. Being functionally health literate means being able to read and understand basic health related information, including an invitation for screening. However, health literacy entails the ability to judge, discuss and apply information to ones situation as well. These types of skills are also referred to as interactive and critical health literacy[37], which are relevant when it comes to decision making concerning CRC screening.[38] It is therefore important that future research addressing health literacy in relationship to informed decision making applies a health literacy measure that includes interactive and critical skills as well. As Smith and colleagues demonstrate, functional, interactive and critical health literacy have different roles in the process of decision making for CRC screening.[38] Research that reflects on multiple aspects in relation to CRC screening decision making, can better inform the type of initiatives that could support informed decision making, than research that reflects merely on functional health literacy.

Implications

We formulated implications with respect to the conceptualization of informed decisions, the measurement of CRC (screening) knowledge and the inclusion of deliberation in future research. The idea behind informed decisions is that a person's autonomy is respected and that invitees do not feel coerced into or deterred from participating in CRC screening. It seems however important to consider whether the conceptualization of informed decisions in the literature to date is feasible or suitable for CRC screening in general and for screening invitees with low health literacy in particular. Namely, informed decisions conceptualized as a combination of sufficient knowledge, deliberation of pros and cons, and a decision that is consistent with personal values assumes that

invitees are rational decision makers that apply analytical decision making strategies. Analytical decision making is most likely to occur in a situation that is characterized by clear pros and cons, when deciding on a healthcare insurance for example. However, when it comes to CRC screening, pros and cons are difficult to weigh and decisions are very likely to be influenced by emotions or social influences.[9] The operationalization of informed decisions in screening research often does no justice to the way in which people make decisions in their daily lives and may therefore need to be reconsidered. For instance, studies could assess (qualitatively) whether invitees have the feeling that the decisions they make are sufficiently informed.

Furthermore, we found that knowledge is relatively often studied in relation to health literacy and CRC screening, but that studies apply various measures of knowledge. We suggest that since knowledge is considered a prerequisite for informed decision making, it is essential to gain a better understanding of what knowledge is crucial in making informed decisions, and whether the amount or type of knowledge needed to make informed decisions differs according to one's health literacy skills. Based on previous studies, which indicate that individuals with lower health literacy are less likely to seek information concerning CRC screening when compared to those with higher health literacy, it seems likely that those with higher health literacy may prefer more information, whereas those with lower health literacy may prefer less or different information. It is possible that a distinction could be made between basic knowledge, such as knowing what CRC screening is and how screening can help prevent CRC[28] and advanced knowledge, such as knowing the pros and cons of participation in CRC screening. Further deliberation is needed to determine what basic knowledge and more advanced knowledge should entail and what people should really know as a minimum in order to make informed decisions. For instance, since people often have difficulties understanding the idea of informed decision making explaining the concept of informed decisions could be considered essential information that everyone should receive, as opposed to encouraging screening participation.[20]

Further research should also be undertaken to determine differences in information needs between those with lower and higher health literacy concerning CRC screening, whether various standards should be used in order to determine when a decision can be considered informed for different people, and who should determine these standards. When we have identified the knowledge that is essential and how we should assess this, then the development of effective

interventions to facilitate informed decision making for people with varying levels of health literacy will be possible.

Thirdly, no study was found that focused on the process of deliberation in relation to health literacy and CRC screening. Future research may want to focus more on this aspect of informed decision making, as this may be difficult for both those with higher and lower health literacy. In this context it is relevant to explore whether people with higher health literacy are more likely to discuss the option of CRC screening with friends and family as compared to people with lower health literacy and whether talking about CRC screening in the lay network influences the decision making process. This would provide us with insights into whether stimulating talking about CRC screening would facilitate informed decisions. More (qualitative) research should be carried out to evaluate in which ways people would like to be supported in their decision making concerning CRC screening participation.

Conclusion

It can be concluded that there is either no association or a positive association between health literacy and concepts underpinning informed decision making, including knowledge and attitudes. The present review indicates that studies to date mainly focus on single aspects of informed decision making, instead of a combination of aspects. Although this provides valuable insights, a more comprehensive examination of informed decision making in which aspects are studied in conjunction may provide additional insights into how health literacy relates to informed decision making. A future direction for research would be to obtain a better understanding of what informed decision making should encompass in the context of CRC screening and to what extent this may differ according to an invitee's health literacy skills.

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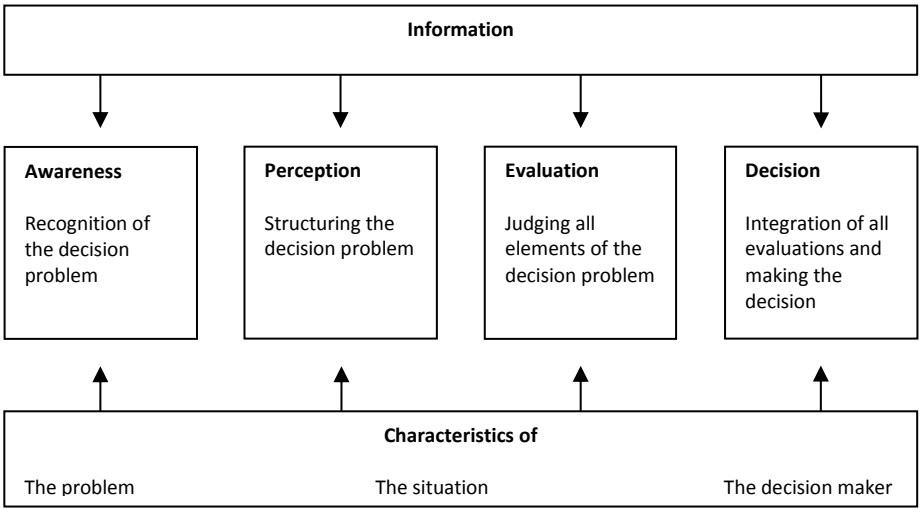
Additional materials

Additional Figure 1. Elements of decision-making



Free translation of: Timmermans, D. (2013). What motivates the decision maker? The meaning of well-considered and informed decision for health and prevention [Wat beweegt de kiezer? Over de betekenis van weloverwogen en geïnformeerde keuzes voor gezondheid en preventie]. Retrieved from: http://www.zonmw.nl

Additional Table 1. Studies reporting on health literacy and decision making regarding participation in CRC screening (n=8)

	Arnold et al., 2012 USA
Design	CSS
Aim	Examine the relationship between literacy and CRC screening knowledge, beliefs and experiences.
Study population (sample size, sex, age, ethnicity and/or first language, cancer history, setting)	N=975 (77% female); aged 50 years or older; 67% African American; no previous history of cancer other than melanoma or other skin cancer; clinic based sample.
Relevant measures (validated or pilot teste, method of assessment)	Health literacy: REALM (validated). CRC knowledge, awareness, beliefs, barriers: 46 items (validated). In-person interviews.
Screening context (type of screening, location, costs)	FOBT
Analyses	Chi-square test, Logistic regression.
Relevant findings (unadjusted and adjusted)	Unadjusted analyses: participants with low health literacy were significant less likely to: Know someone who had CRC Ever heard of a test for CRC Ever seen/heard advertisement encouraging CRC test Find it helpful to find CRC early Want to know about having CRC Disagree with getting CRC during life Think that FOBT helps finding colon problems early Think that FOBT decreases chances of dying from CRC No significant differences for: Ever heard of CRC Ever seen one of presented FOBTs Worried about CRC Fear for finding out something wrong when doing FOBT Adjusted analyses (for age, gender, race, location): participants with low health literacy were significant less likely to: Know someone who had CRC Ever heard of a test for CRC Ever seen/heard advertisement encouraging CRC test Find it helpful to find CRC early Think FOBT helps finding colon/rectal problems early Think FOBT decreases chances of dying from CRC No significant differences for: Perceived barriers
	Mitsutake et al., 2012, Japan
Design	CSS
Aim	Examination of associations between eHealth literacy, knowledge of CRC and CRC screening practices.
Study population (sample size, sex, age, ethnicity and/or first language,	N=2970 (50% female); aged 20 to 59; ethnicity NS;

cancer history, setting)	registrants of a Japanese Internet research service company.
Relevant measures (validated or pilot teste, method of assessment)	Health literacy: J-eHEALS (validated) CRC knowledge: 20 true/false items regarding the definition, risk factors and screening of CRC. Internet-based questionnaires.
Screening context (type of screening, location, costs)	NS
Analyses	T-test, chi-square, One-way ANOVA, Multiple logistic regression models.
Relevant findings (unadjusted and adjusted)	In models adjusted for sex, age, marital status, and household income, eHealth literacy was found to be positively associated with CRC knowledge (β= .116, structure coefficient=.602).
	Von Wagner et al., 2009, UK
Design	CSS
Aim	To document the association between health literacy and willingness and ability to seek information about the new CRC screening program. Secondly, to assess self-efficacy for screening to determine the impact of health literacy on perceived confidence to participate in screening.
Study population (sample size, sex, age, ethnicity and/or first language, cancer history, setting)	N=96 (66.7% female); aged 50 – 69; 19.8% non-white; clinic based sample.
Relevant measures (validated or pilot teste, method of assessment)	Health literacy: UK-TOFHLA (validated). Knowledge: 12 true or false statements to assess knowledge of the CRC screening program. Questionnaires administered in a private setting.
Screening context (type of screening, location, costs)	FOBT
Analyses	Bivariate analyses and multivariate linear regression models.
Relevant findings (unadjusted and adjusted)	Unadjusted analysis demonstrated no association between health literacy and CRC screening knowledge.
	Keller et al., 2009, Switzerland
Design	QES
Aim	To examine the influence of numeracy on interpreting various risk communication formats.
Study population (sample size, sex, age, ethnicity and/or first language, cancer history, setting)	N=266 (100% female); aged 18 to 75; ethnicity NS; history of cancer NS, community based sample.
Relevant measures (validated or pilot teste, method of assessment)	Health numeracy: Lipkus scale (validated). Perceived risk: 6-point Likert-scale. In-person interviews.

Screening context (type of screening, location, costs)	NS
Analyses	Analysis of variance and t-test.
Relevant findings (unadjusted and adjusted)	Low-numerate individuals did not differentiate between high- and low-risk levels of colon cancer when presented with the ratio, the pictogram, and the Paling Perspective Scale. High-numerate individuals did not differentiate between high- and low-risk levels when presented with either the ratio format or the pictogram. Presented with the Paling Perspective Scale, they significantly differentiated between high and low-risk levels (t44=6.49; P<0.001), perceiving the high-risk level as higher risk and the low-risk level as lower risk.
	Miller et al., 2007, USA
Design	Pilot
Aim	To determine whether low literacy affects patients' knowledge or receipt of CRC screening.
Study population (sample size, sex, age, ethnicity and/or first language, cancer history, setting)	N=50 (72% female); age ≥ 50; 58% African-American, 42% white; clinical based sample.
Relevant measures (validated or pilot teste, method of assessment)	Health literacy: REALM (validated). Knowledge: two items. Questionnaires administered in a private setting.
Screening context (type of screening, location, costs)	FOBT, FS, COL
Analyses	Chi-square, Fisher's Exact tests and logistic regression analysis.
Relevant findings (unadjusted and adjusted)	Unadjusted analyses: Limited literacy patients were less likely than adequate literacy patients to be able to name (13% v 69%) or describe any CRC Screening test (50% v 96%) at p<.01. Adjusted analysis (for race): Limited literacy patients were less likely to name (RR 0.21 (95% CI: 0.07- 0.64) or describe any CRC screening test (RR 0.56 (95%CI: 0.38 – 0.83) at p<.01.
	Peterson et al., 2007, USA
Design	CSS
Aim	To determine if health literacy is associated with knowledge of CRC and CRC screening tests, perceived benefits and perceived barriers to CRC screening, perceived risks of CRC, self-efficacy of completing CRC screening and receipt of CRC tests.

Study population (sample size, sex, age, ethnicity and/or first language, cancer history, setting)	N=99 (56% female); aged ≥ 50; 66% white, 32% black or African American, 1% American Indian/Alaskan native, 1% Asian, 1% Hispanic; clinic based sample.
Relevant measures (validated or pilot teste, method of assessment)	Health literacy: REALM (validated). CRC knowledge (15 items), perceived benefits (8 items) and barriers (18 items) to screening with FOBT and colonoscopy: 5-point Likert scale (validated). Perceived risk: 4 items to rate the chances of getting CRC in the next 10 years and compared to peers. In-person or telephone interviews.
Screening context (type of screening location, costs)	FOBT, COL
Analyses	Chi-square, Student t-test, Multivariate linear regression analysis, Logistic regression analysis.
Relevant findings (unadjusted and adjusted)	Unadjusted analyses: Limited health literacy is significantly associated with: Less knowledge (64% correct v 75% correct); More perceived barriers (Mean 2.67 (SD:0.68) v 2.12 (SD:0.46) for FOBT and 2.58 (0.68) v 2.24 (0.41) for COL, but not with perceived benefits of CRC screening and being screened for CRC. Adjusted analyses (for age, sex, race, insurance status): Limited health literacy is significantly associated with: Reporting more barriers to completing FOBT and COL, not with CRC knowledge when including health literacy as a dichotomous variable, but significant when including health literacy as continuous variable. No associations between health literacy and risk perception.

	Guerra et al., 2005, USA
Design	CSS
Aim	To explore the association between functional health literacy and knowledge, beliefs and attitudes about CRC, and reported usage of CRC screening tests.
Study population (sample size, sex, age, ethnicity and/or first language, cancer history, setting)	N=136 (39% female); aged ≥ 50; 47% Latino, 33% white, 20% African American; no prior history of colorectal cancer; clinic based sample.

Relevant measures (validated or pilot teste, method of assessment)	Health literacy: S-TOFHLA (validated). Knowledge, beliefs, attitudes, behaviour and influences regarding CRC: 46-item correct/incorrect or true/false items (pilot tested). In-person interviews in English or Spanish.	
Screening context (type of screening, location, costs)	FOBT, FS, COL	
Analyses	Chi-square or fisher exact tests; Logistic regression analysis	
Relevant findings (unadjusted and adjusted)	Unadjusted analyses: Lower health literacy was significant associated with: Less knowledge assessed by 7 knowledge items; Less likely to have had a FOBT (OR:2.75; 95%CI 1.28–5.97) and a sigmoidoscopy or COL (OR:6.15; 95%CI 2.69–14.24). No significant associations for 2 knowledge items.	Adjusted analyses (for ethnicity, Medicaid, insurance status, education, and income): Those with limited health literacy less often wanted to know if they had cancer compared to adequate health literacy (84% v 95%) No significant associations for the knowledge items and the remaining 8 belief and attitude items.
	Dolan et al., 2004, USA	
Design	CSS	
Aim	To evaluate whether lower literacy is associated with poorer knowledge and more negative attitudes and beliefs towards CRC screening.	
Study population (sample size, sex, age, ethnicity and/or first language, cancer history, setting)	N=377 men; aged ≥ 50; 51% white and 41% black; no recent colorectal cancer screening; no personal history of colorectal cancer or polyps or of inflammatory bowel disease; no family history of colorectal cancer or polyps; clinic based sample.	
Relevant measures (validated or pilot teste, method of assessment)	Health literacy: REALM (validated). CRC screening knowledge, attitudes and beliefs: CCKAB (items reviewed by experts for relevance and medical accuracy; pilot tested for understandability and length). Administered verbally.	
Screening context (type of screening, location, costs)	FOBT, FS	
Analyses	Chi-square, student t-test, and logistic regression analysis.	

Relevant findings (unadjusted and adjusted)	Unadjusted analyses: men with limited health literacy were significantly less likely to: Be familiar with colorectal cancer (8.8% v 2.5%); Be familiar with screening tests for colorectal cancer (58.4% v 40.9%); Be able to describe what was involved in performing a FOBT test (94.9% v 65.8%) or a flexible sigmoidoscopy procedure (84.7% v 63.3%). And significantly more likely to: Be concerned that a FOBT was messy (27.7% v 13.3%) and inconvenient (28.7% v 18.0%); Indicate that they would not use a FOBT kit even if recommended by their physician (17.9% v 4.0%); State that procrastination was a primary reason for not getting a flexible sigmoidoscopy (7.4% v 1.2%); Believe they were at average-to-high risk to develop colorectal cancer (69.6% v 55.2%; p=.01). No significant differences for: knowing at what age most physicians would recommend screening for colorectal cancer.	After adjusting for race and employment status literacy-related differences in measures of knowledge and attitudes were apparent (data not shown).

CSS: Cross Sectional Survey; QES: Quasi-Experimental; SAHLSA: Short Assessment of Health Literacy for Spanish Adults (Scale 0–50); TOFHLA: Test of Functional Health Literacy in Adults; S-TOFHLA: Short Test of Functional Health Literacy in Adults (Scale: 0–36); REALM: Rapid Estimate of Adult Literacy in Medicine (Scale: 0–66); NP: not provided; FOBT: faecal occult blood test; FS: flexible sigmoidoscopy; COL: colonoscopy; CRC: colorectal cancer; SR: self-report; NS: not specified.

Chapter 7

Preferences for vaccination: does health literacy make a difference?

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Submitted

Abstract

Background Sufficient vaccination coverage is needed to ensure the preventive effect on a population level. Since people differ in their decision about vaccination, it is important to understand reasons for vaccination and differences between subgroups. The aim of this study is to examine to what extent health literacy is associated with parental preferences concerning childhood vaccination.

Methods A cross-sectional study was conducted among 1250 Dutch parents of newborns aged 6 weeks (response rate of 37%). A self-reported questionnaire was used to measure health literacy by means of Chew's Set of Brief Screening Questions, as well as parental preferences for rotavirus vaccination by means of a Discrete Choice Experiment. Five rotavirus related characteristics were included (i.e., vaccine effectiveness, frequency of severe side effects, location of vaccination, protection duration and out-of-pocket costs). Panel latent class models were conducted, health literacy and educational level were added to the class probability model to determine the association between health literacy and study outcomes.

Results Results show that lower educated and lower health literate respondents considered protection duration to be more important and vaccine effectiveness and frequency of severe side-effects to be less important compared to higher educated and health literate respondents. While all respondents were willing to vaccinate against rotavirus when the vaccine was offered as part of the National Immunization Program (NIP), only lower educated and lower health literate parents were willing to vaccinate when the vaccine was offered on the free market.

Conclusions In conclusion, health literacy is associated with parents' preferences for rotavirus vaccination. Whether differences in vaccination decisions are actually due to varying preferences or might be better explained by varying levels of understanding should be further investigated. To contribute to more accurate interpretation of study results, it seems advisable that researchers measure and report health literacy when studying vaccination decision behaviour.

Introduction

Two developments in the public domain appear to affect acceptance of vaccines in the Netherlands. First, there is a tendency to stimulate citizens to exert autonomy and to make well-considered decisions with respect to their health[1], such as vaccination decisions. At the same time, the necessity of vaccination has become a more prominent part of the public discourse in the Netherlands and other Western countries.[2-6] With respect to for instance HPV vaccination, both girls and their parents reported a distrust in the communication of governmental institutes about the vaccine[6-9], which in this case led to hesitation among the target population[1,7,8,10] and subsequent lower vaccination coverage. However, for the prevention of most infectious diseases, vaccination of the majority of the population is essential to reach herd immunity. The Netherlands so far has had a highly efficient National Immunization Program (NIP), with vaccination coverage rates of around 96% among young children aged 0 to 9 years.[11] To keep Dutch childhood vaccination rates high, insight into factors that determine parents' decisions about childhood vaccination is crucial in order to develop or revise vaccination education strategies.

Several studies already investigated the influence of psychosocial determinants (e.g., attitude towards vaccination and perceived severity of the disease at hand) on vaccination decisions.[7,12-15] There is also a growing body of literature describing the effect of specific vaccine aspects such as vaccine safety and efficacy on parental preferences for vaccination and ultimately also their willingness to vaccinate.[8,13,16-22] Parental preferences are increasingly being elicited in order to guide policy measures such as the introduction of new vaccines, and may serve as a starting point for communication strategies when the vaccine is introduced.[23]

Parental characteristics such as educational attainment is associated with the valuation of vaccine characteristics.[15-19] A concept that is related to educational attainment and has received increasingly attention in the field of prevention, is health literacy. Health literacy, the ability to access, understand, appraise and apply health related information, is likely to influence parental preferences for vaccination as well, although studies concerning this topic are currently lacking.[24-27] At the same time health literacy is considered an important set of cognitive, psychological and social skills in contemporary society[28], given the tendency that citizens are stimulated to exert autonomy and to make well-considered decisions with respect to their health.[1] Health literacy is highly relevant in the light of measuring vaccination preferences, since measuring

preferences usually requires respondents to interpret and value risk information (e.g., risk of side effects). Previous research shows that specifically individuals with a lower educational level and a lower health literacy have difficulties processing such information.[29-31] Misinterpreting information or being unable to understand information could influence parental preferences for vaccination and thereby their willingness to vaccinate their newborn.[32] Therefore, the current study aims to determine to what extent health literacy is associated with parental preferences for vaccination. Rotavirus vaccination served as a case for this study since this vaccine is currently considered for inclusion in the Dutch NIP. Rotavirus is the most common cause of severe acute gastroenteritis in infants and young children worldwide and can be prevented by vaccination of 6 to 10 weeks old infants, as is recommended by WHO.[33,34]

Methods

Sample selection

This study is part of a larger study investigating parental preferences for rotavirus vaccination.[13] The target population was identified via Praeventis, which is a national register that registers the vaccination status of all Dutch newborns. A random sample of parents of 1250 newborn babies aged six weeks received a questionnaire. Due to confidentiality agreements with Praeventis, no reminder letters could be sent. For this reason no non-response information was available. The Institutional Review Board of the University Medical Centre Utrecht advised that formal testing by a medical ethical committee was not necessary, as parents were only required to complete an anonymous questionnaire once, which is in accordance with the guidelines laid down in the Declaration of Helsinki.

Assessment of rotavirus vaccination preferences

A Discrete Choice Experiment (DCE) was used to measure parents preferences for rotavirus vaccination. DCEs are increasingly being used to determine the relative importance of different intervention characteristics.[23,35,36] The Random Utility Theory is the basis of this method, which assumes that any intervention can be described by its characteristics or 'attributes' (such as vaccine effectiveness). The individual's preference for an intervention is determined based on the levels (e.g., effectiveness of 50% versus 80% versus 95%) of those attributes.[23,35,36] Scenarios are constructed by varying the levels of the attributes.

Respondents are provided with a series of 'choice tasks' that consist of at least two scenarios. They have to choose the scenario they prefer most within every choice task.

Attributes, levels and experimental design

Possible attributes and levels were identified from previously published literature[8,9,16,18,19,21,22,37], expert interviews (n=2), and group interviews with 25 parents of newborns. Finally, five attributes were selected for this DCE (Table 7.1). Using NGene 1.0 (ChoiceMetrics, 2011) software, a D-efficient design with 18 unique choice tasks was constructed.[38,39] These were divided into two sets of nine choice tasks, and each set of nine choice tasks was randomly distributed among half of the study population. Before participants were asked to complete these choice tasks, they received detailed information on the meaning of all attributes and levels as well as an explanation on how to complete a choice task, including an example. The draft questionnaire was pilot tested among a convenience subgroup (n=48) of our study population. The attribute estimates that were retrieved from this pilot study served as priors for the design of the final DCE questionnaire. For further details on this procedure see Veldwijk et al..[13]

Table 7.1 Attributes and levels that were included in the DCE

Attributes	*Level 1*	*Level 2*	*Level 3*
Vaccine effectiveness			
The percentage of children that will be protected against a rotavirus infection when vaccinated.			
	55%	75%	95%
Frequency of severe side effects			
The number of vaccinated children that will suffer from intussusception due to vaccination. Intussusception is an acute condition in which part of the bowel telescopes into another adjacent part of the bowel, resulting in obstruction.			
	1 in 10,000	1 in 100,000	1 in 1,000,000
Protection duration			
The number of years that the vaccine protects against a rotavirus infection.			
	1 year	3 years	6 years

- table 7.1 continues -

- table 7.1 contined -

Attributes	*Level 1*	*Level 2*	*Level 3*
Healthcare facility of vaccine administration			
Within the Netherlands all vaccines in the NIP are administrated at a child welfare center, The GP office was included because the rotavirus vaccine may not become part of the NIP; in that case it is likely that this vaccine is administrated at the GP.			
	Child welfare center	General practitioner	
Out-of-pocket costs			
Parents may have to pay (part) of the vaccine costs out-of-pocket.			
	€0	€30	€140

Assessment of health literacy

Health literacy was assessed by Chew's Set of Brief Screening Questions (SBSQ), which is a validated subjective measure of health literacy.[40-42] The SBSQ provides a feasible and reliable indication of those who are likely to have lower health literacy skills.[42] Respondents were asked how often someone helps them to read letters from their GP/specialist, how sure they are that they complete medical forms correctly and how often they find it hard to learn more about their health because written information is not well understood. Responses were scored on a 5-point Likert scale ranging from zero to four. Respondents' sum scores and mean scores over the three included items were calculated.

Assessment of demographic factors, attitude and vaccination intention

Different demographic factors were additionally included in the questionnaire among which, parents' age in years, gender, ethnicity (Dutch versus non Dutch) and highest attained level of education. Self-reported highest attained level of education was categorized into four categories: no or primary education, lower secondary education, upper secondary or vocational education, or tertiary education (bachelor's degree or higher). By means of theorems that could be answered on a five-point Likert scale ranging from totally agree to totally disagree, parents' attitude towards vaccination and their intention to vaccinate were measured. Attitude was measured by two items: 'I think vaccination is a good way to protect my child against rotavirus' and 'I think it is self-evident to vaccinate my child against rotavirus'. Intention to vaccinate was measured by

one item 'I would vaccinate my child against the rotavirus when a vaccine would become available'.

Statistical analyses

Data were analysed using panel latent class models. Such models take into account the multilevel structure of our data (i.e., every respondent answered nine choice sets). By means of this latent class model it can be determined whether different preferences exist across unobserved subgroups of the population. Class membership is not assigned by researchers, but is latent, so each respondent has a certain probability to belong to a class. However, demographic measures can be incorporated into the modelling procedure, which provides some insights about which respondents belong to what class.

Respondents with >10% missing answers on their choice tasks were excluded from the analysis (n=12). All attributes were tested for linearity. For that purpose a spline was added to the regression model described below. This spline enables to test whether the slope of the regression line between level one and two of an attribute significantly differs from the slope of the regression line between level two and three.[43] The spline consisted of a main effect of the attribute, a dummy variable (coded zero for the first and second attribute level and coded one for the third attribute level) and an interaction variable (main effect*dummy variable). A statistically significant interaction term indicates a non-linear attribute. All non-linear attributes were recoded using effect codes.[44] This coding procedure codes the reference category as -1 and the sum of the effect coded attribute levels is always 0.[44, 45] Based on model fit tests (AIC, Log likelihood) it was tested what model fitted best to our data, which resulted in the following utility equation being tested:

$$V_{rta|c} = \beta 0_{|c} + \beta 1_{|c}\ \text{vaccine effectiveness}_{rta|c} + \beta 2_{|c}\ \text{severe side effects}_{1\text{ in }100{,}000\ rta|c} + \beta 3_{|c}\ \text{severe side effects}_{1\text{ in }10{,}000\ rta|c} + \beta 4_{|c}\ \text{protection}_{3\text{ years }rta|c} + \beta 5|c\ \text{protection}_{6\text{ years }rta|c} + \beta 6_{|c}\ \text{location}_{\text{Child Welfare Center }rta|c} + \beta 7_{|c}\ \text{out-of-pocket costs}_{€30\ rta|c} + \beta 8_{|c}\ \text{out-of-pocket costs}_{€140\ rta|c}$$

The systematic utility component (V) describes the measurable utility that respondent 'r' belonging to class 'c' reported for alternative 'a' in choice task 't'. The β0 represents the alternative specific constant and β1 – β8 are the attribute level estimates that indicate the relative importance of each attribute level. A significant attribute estimate within a certain class indicates that this attribute contributes to the decision making procedure of respondents that belong to that

class. The utility for the opt-out option was modelled as zero. In addition to the above-specified utility function, a class assignment model was fitted. All demographic measures were tested for a significant contribution to the class assignment mode, and the final class assignment utility function was:

$V_{nc} = \beta 0_{|c} + \beta 1_{|c}$ health literacy mean score$_r$ + $\beta 2_{|c}$ high educational level$_r$

A significant demographic variable indicates that this variable contributes to the class assignment (e.g., if the beta of the health literacy mean score variable is positive and significant for class 1, respondents with a higher health literacy mean score are more likely to belong to class 1).

Importance weights were calculated based on the results of the panel latent class models, separately for both classes. Per attribute, the difference between the highest and lowest attribute level estimate was calculated. The largest difference value received an importance score of one, representing the attribute that was deemed most important by respondents, the other difference values were divided by the largest difference value, resulting in a relative distance between all attributes to the most important attribute.

Scenario specific utility scores were calculated for both classes separately. A realistic vaccine scenario was used were the vaccine was expected to have a 95% effectiveness, a 1 in 100,000 frequency of severe side effects, and a protection duration of 3 years. Scores were calculated separately for a scenario in which the vaccine would be implemented within a NIP (i.e., free of charge and administered at a child welfare center) or on the free market (i.e., €140 out-of-pocket costs and administered at the general practitioner). A positive utility score that is larger than 0 implies that respondents prefer vaccination over no vaccination, while a utility below zero implies that respondents prefer not to vaccinate their newborn.

Results

Sample characteristics

In total 467 out of 1,250 questionnaires were returned and included in the analyses (response rate of 37.4%). The mean age of the respondents was 31 years and most respondents were female (82%) (Table 7.2). The majority of the responders had a Dutch origin (92%), and attained a tertiary educational level (58%). On average respondents reported a positive attitude towards rotavirus

vaccination, since 77% reported that they thought vaccination is a good way to protect their child against rotavirus and 91% thought that vaccination against rotavirus was self-evident (Table 7.2). In addition, about 79% of the parents intended to vaccinate their child against rotavirus if this vaccine would become available (Table 7.2).

Table 7.2 Sample characteristics (N= 466)

Demographics		*Mean (SD)*	*Percentage*
Age (in years)		31.2 (5.1)	
Gender	Female		81.5
Ethnicity	Dutch		91.8
Educational level	No or primary		0.4
	Lower secondary		7.8
	Upper secondary or vocational education		33.7
	High tertiary		58.0
Theorems*			
Attitude	I think vaccination is a good way to protect my child against rotavirus.		76.6
	I think it is self-evident to vaccinate my child against rotavirus.		89.5
Intention	I would vaccinate my child against the rotavirus when a vaccine would become available.		79.4

* Proportion of respondents who (totally) agreed with these theorems

Health literacy

The majority of the respondents indicated that they never need any help reading letters and leaflets from their GP or the hospital (84%), they are very/fairly certain that they fill in medical forms correctly (93%) and that they never find it difficult to learn more about their health because they do not understand written information (64%) (Table 7.3). The mean sum score of the respondent over these three items was 10.7, resulting in a mean score of 3.6. Among lower educated respondents the mean health literacy score was 3.4, while a mean health literacy score of 3.7 was found among high-educated respondents (i.e., tertiary education).

*Table 7.3 Health literacy scores, both combined and separate per item of the SBSQ**

Health literacy scores		
	Mean (SD)	*Range*
Sum score over 3 items	10.7 (1.5)	3-12
Mean score of 3 items	3.6 (0.5)	1-4

Distributions of respondents answers to the three items separately			
	*How often does someone help you to read letters and leaflets from your GP** or the hospital?*	*How certain are you that you fill in medical forms correctly?*	*How often is it difficult for you to learn more about your health because you do not understand written information?*
Never/very much	83.9	46.7	64.2
Now and then/fairly	9.4	46.7	26.6
Sometimes/a bit	4.9	5.6	8.8
Often/a little bit	1.7	0.9	0.4
Always/not at all	0.0	0.2	0.0

* SBSQ is the Set of Brief Screening Questions to measure health literacy.

** General Practitioner.

DCE results

Two classes were identified in the panel latent class model (Table 7.4). All attributes were significant and influenced parental preferences for rotavirus vaccination as expected. In both classes, parents were more willing to vaccinate if vaccine effectiveness increased. Moreover, parents preferred the lowest frequency of severe side effects, a protection duration of three years, vaccine administration via a child welfare center and lowest out-of-pocket costs.

The average class probabilities were 0.58 and 0.42 for class 1 and 2 respectively. The probability of belonging to either class 1 or 2, was also dependent upon health literacy score and educational level (Table 7.5). Respondents with a higher educational level or a higher health literacy score were more likely to belong to class 2, while the probability to belong to class 1 increased when the health literacy score or educational level decreased. Therefore, respondents with a lower health literacy score or educational level were more likely to belong to class 1. The probability of respondents with a lower health literacy to belong to class 1 increased if those respondents also attained a lower educational level and decreased if those respondents attained a

higher educational level.

Table 7.4 The influence of health literacy on parental preferences for rotavirus vaccination

		Class 1		*Class 2*	
		Estimate	*SE*	*Estimate*	*SE*
Constant		-1.91***	0.26	-6.02***	0.36
Vaccine effectiveness		0.53***	0.03	0.54***	0.04
Frequency of severe side effects	1 in 1,000,000 (ref)	0.42***	0.08	0.80***	0.09
	1 in 100,000	-0.08	0.06	-0.16*	0.09
	1 in 10,000	-0.34***	0.09	-0.64***	0.11
Protection duration	1 year (ref)	-0.83***	0.06	-0.64***	0.09
	3 years	0.72***	0.09	0.40***	0.09
	6 years	0.11	0.07	0.24**	0.11
Healthcare facility	General Practitioner (ref)	-0.05	0.04	-0.12**	0.06
	Child Welfare Center	0.05	0.04	0.12**	0.06
Out-of-pocket costs	€0 (ref)	0.59***	0.06	1.12***	0.10
	€30	0.53***	0.07	0.18*	0.11
	€140	-1.12***	0.06	-1.30***	0.10
Class probability model					
Constant		2.82***	0.95	-	-
Health literacy score		-0.57**	0.28	-	-
Higher education		-0.76***	0.26	-	-
Average class probability		0.58		0.42	

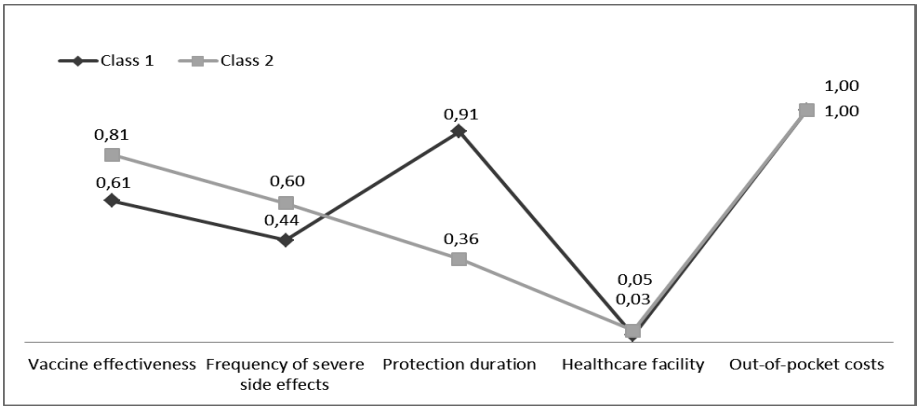
*** P<0.01, ** P<0.05, * P<0.10.

*Table 7.5 Probabilities of respondents belonging to either class 1 or 2 of the latent class model based on their educational level and health literacy score**

	Probability to belong to class 1	*Probability to belong to class 2*
High educational level		
Health literacy score=4	0.45	0.55
Health literacy score=3	0.58	0.41
Health literacy score=2	0.71	0.28
Health literacy score=1	0.81	0.18
Health literacy score=0	0.88	0.11
Lower educational level		
Health literacy score=4	0.63	0.37
Health literacy score=3	0.75	0.24
Health literacy score=2	0.84	0.16
Health literacy score=1	0.90	0.10
Health literacy score=0	0.94	0.06

* High education was defined as tertiary education, while all other education levels were conceptualized as lower educational level. Health literacy mean scores range between 0-4, a score between 0-2 indicates poor health literacy whereas a score ≥2 indicates adequate health literacy.

Respondents that belong to either class 1 or 2 reported different preferences with respect to rotavirus vaccination, indicating considerable preference heterogeneity (Figure 7.1). Respondents in both class 1 and 2 value out-of-pocket costs as most important (importance weight of 1) and healthcare facility as least important (lowest importance weight). Respondents in class 1 value protection duration as relatively more important compared to respondents belonging to class 2, while respondents in class 2 value vaccine effectiveness and frequency of severe side effects to be more important compared to respondents in class 1. Thus, respondents with a lower educational level and respondents with lower health literacy skills considered protection duration to be more important and vaccine effectiveness and frequency of severe side-effects to be less important compared to respondents with a high education and respondents with higher health literacy skills.



* Importance weights reflect the relative distance of all attributes to the most important attribute on a scale from 0-1 (1 indicating the most important attribute).

*Figure 7.1 Importance weights of the attributes stratified by class**

Vaccine specific utility scores

The utility scores for a realistic rotavirus vaccine (i.e., a 95% effectiveness, a frequency of severe side effects of 1 in 100,000 and a protection duration of 3 years) implemented within a NIP (i.e., free of charge and administered at the CWC) were 4.1 for class 1 (lower educated and lower health literacy skills) and 0.1 for class 2 (high educated and higher health literacy skills). These scores implicate that respondents in both classes would vaccinate their newborn against the rotavirus in this particular scenario (i.e., utility scores are larger than 0). However, if the same vaccine would be implemented on the free market (i.e., €140 out-of-pocket costs and administered at the GP), the utility scores of class 1 (lower educated and lower health literacy skills) and class 2 (high educated and higher health literacy skills) would be 2.3 and -2.6, respectively. In this situation, respondents belonging to class 1 (lower educated and lower health literacy skills) would still prefer to vaccinate their newborn against rotavirus, while respondents in class 2 (high educated and higher health literacy skills) would not.

Discussion

Health literacy is associated with parental preferences concerning rotavirus vaccination. Current study results indicate that parents with lower health literacy skills and parents with a lower educational level value the protection duration of a vaccine as more important compared to parents with higher health

literacy skills and parents with a higher education. Moreover, vaccine effectiveness and the frequency of severe side effects were perceived more important by parents with higher health literacy skills and educational level compared to parents with lower health literacy skills and educational level. Irrespective of health literacy and educational level, out-of-pocket costs were revealed to be the most important characteristic in the decision about rotavirus vaccination, while the healthcare facility were the vaccine would be administrated was least important in this decision making process.

Of particular interest is the finding that lower health literate parents valued vaccine effectiveness and the frequency of severe side effects as less important compared to higher health literate parents when deciding about vaccinating their newborn against rotavirus. Both these vaccine characteristics were included in the DCE as a numerical value and depicted as a percentage and absolute frequency respectively. Such information is difficult to interpret, especially for parents with lower health literacy skills.[30,31,46-48] If parents had difficulties interpreting and understanding these risk attributes, they might deem those attributes as less important. This is in line with previous research indicating that if information is less well understood it is more likely to be neglected[32], or otherwise undervalued. Therefore, the difference in preference concerning vaccine effectiveness and the frequency of severe side effects between respondents with lower and higher health literacy skills might not be caused by actual differences in preference structures, but rather reflect a lack of understanding. By means of newly designed research methods, it should be explored if preferences of respondents with lower and higher health literacy skills still differ if respondents interpret the numerical value of risks as similar as possible. Such research will reveal to what extent a decision-making process is influenced by understanding certain vaccine characteristics. In addition, future research is required to explore if DCEs that are conducted online with the use of verbal support or in face-to-face settings might overcome issues with the understanding of vaccine characteristics. These considerations raise the question to what extent a DCE is a valid method to obtain insight into vaccination preferences among individuals with lower health literacy skills. However, in real life situations people with lower health literacy skills have to deal with complex information as well and may base their preferences on information that is not well understood.

Our findings showed that parents with higher health literacy were less likely to participate in the tested vaccination scenarios. The limited knowledge base with respect to health literacy and participation in vaccination programs suggests

the opposite (i.e., lower health literacy is associated with lower participation rates).[24-26] Besides differences in preferences for vaccine characteristics or differences in how well these characteristics were understood or how they were perceived, a possible interpretation of this finding may be derived from literature on the association between socio-economic position and vaccination participation. Although the concept of health literacy is not equal to socio-economic position, they are closely related. Literature suggests that individuals with a higher socio-economic position are more critical towards childhood vaccination, which could lead to higher vaccination hesitance and lower participation rates.[1,10] It might therefore be that parents with higher health literacy are less likely to vaccinate their newborn against rotavirus because of more critical thoughts about rotavirus vaccination.

The present study showed that health literacy influenced study outcomes irrespective of educational level. Both factors influenced the results in a similar direction and they independently contributed to the class assignment models and all subsequent results. Health literacy can therefore not be adjusted for by only including educational level in future research on vaccination decisions. Health literacy should be measured and reported as a sample characteristic in all future research investigating vaccination decisions. This will lead to a more accurate interpretation of study results.

This study is subject to some limitations. Firstly, although a response rate of 37.4% is relatively high for a postal questionnaire without reminders, selective non-response seems plausible. Our sample shows relative many highly educated parents compared to Dutch national figures.[49] Furthermore, the number of non-Dutch parents in our study population is relatively low compared to the general population of the Netherlands.[49] Generalizability of our results to preferences of non-Dutch parents therefore may be limited. Secondly, although the applied measure of health literacy, the SBSQ, currently is the only short questionnaire validated in Dutch that can be assessed in writing, it provides a limited and subjective measure of functional health literacy. Compared to other (objective) measures of health literacy, the SBSQ may lead to an underestimation of the number of parents with lower health literacy.[42] Moreover, using a more comprehensive measure of health literacy, assessing the ability to critically judge information and apply it in various circumstances, may help explain differences in preferences based on difficulty with judging information. Therefore, our study may underestimate the true effect of health literacy on parental preferences and vaccination decisions. Thirdly, within a DCE respondents are asked to interpret and value attributes by comparing two or more options, while in real life, people

are presented with only one option. Therefore, the interpretation and weighing of attributes in real life might be more complicated. Subsequently, a DCE can provide insight into conditions under which people are likely to choose for rotavirus vaccination, but in real life decisions are being affected by factors such as previous experiences and social influences as well.[2,3,12,50,51] Although DCEs provide an indication under what conditions people are likely to choose for a certain product, in this case vaccination, it remains unsure what decisions are made in real life.

Conclusion

This study shows that health literacy is associated parents' preferences for rotavirus vaccination. When offered on the free market, parents with higher health literacy may be less likely to vaccinate their newborn against rotavirus than parents with lower health literacy. The results of this study call for more attention for health literacy as an important factor to take into account when studying vaccination behaviour. Whether differences in vaccination decisions are actually due to varying preference structures or might be better explained by varying levels of understanding should be further investigated. Altogether, it seems advisable that researchers measure and report health literacy when studying vaccination decision behaviour.

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Chapter 8

General discussion

Introduction

In the Netherlands, citizens are expected to fulfil a more autonomous and responsible role with respect to their health and healthcare.[1,2] This has been motivated by various societal developments, such as more attention for the position of patients, the increase in people who suffer from a chronic condition (resulting in a call for self-management), and reforms directed at transforming the Dutch healthcare system from supply to demands regulated. The focus on individual responsibility for health and care has raised some concerns. Not every individual may be sufficiently equipped to fulfil an autonomous and responsible role, which implies for instance that individuals are expected to make well-considered decisions and to manage their disease or organize their care. In this respect, health literacy skills are considered an important factor that can contribute to individuals' abilities to fulfil an autonomous and responsible role regarding their health and care. However, health literacy is a relatively new concept in Europe and most studies on the determinants, allied psychosocial processes and health-related consequences have been done in the USA. The overall aim of the present thesis was to provide insight into the health literacy skills of the Dutch adult population in relation to socio-economic and demographic characteristics, psychological factors, health actions and health. The research questions described in this thesis were placed in Von Wagner's conceptual framework, in which three principal types of health actions are outlined, namely access and utilization of healthcare, patient-provider interactions and management of health and illness.[3] The three research questions that were addressed in this thesis were as follows:

1 *To what extent is health literacy associated with socio-economic and demographic characteristics and with health status?*
2 *To what extent is health literacy associated with (psychological determinants of) use of primary care, patient-provider interaction and self-management in the context of chronic care?*
3 *To what extent is health literacy associated with psychological determinants of participation in prevention programs?*

In this general discussion, first the main findings of each part of this thesis are described and discussed, followed by a reflection on methodological issues. Thereafter, implications of the findings for theory development, future research, policy and practice are discussed. This chapter is round off by a general conclusion.

Main findings

Part I – Health literacy in the Dutch adult population

Research from outside of Europe indicates that health literacy is related to health outcomes and socio-economic and demographic determinants of health.[4] In the first part of this thesis, we aimed to explore to what extent this applies to the Dutch population. ***Chapter 2*** provided insight into the health literacy skills of the Dutch general population in relation to socio-economic and demographic characteristics based on data obtained from the 2012 European Health Literacy Survey (HLS-EU).[5] The HLS-EU provided the first Dutch health literacy measure from a broad perspective on health literacy (conceptualizing health literacy as a multidimensional concept). The instrument that was developed and used for the purpose of the HLS-EU draws a distinction between four health literacy skills: accessing, understanding, appraising and applying. The instrument measures to what extent individuals perceive difficulties with these skills with respect to the domains of healthcare, disease prevention and health promotion. Across all domains, on a scale from 1 (lowest score) to 4, mean scores ranged from 3.1 for perceived difficulties with appraising information to 3.4 for perceived difficulties with understanding information.

However, the difficulties respondents perceived with the four health literacy skills, varied to some extent per health domain. For instance, accessing information was perceived as more difficult in the domain of healthcare (mean 2.6) than in the domain of disease prevention (mean 3.4). In general, individuals with a lower level of education and a lower self-reported social status perceived more difficulties regarding all four skills than those who had a higher level of education and reported a higher social status. In addition, males perceived more difficulties than females regarding all four skills. Age was negatively associated with accessing and understanding health-related information, but was not associated with either appraising or applying health-related information. Thus elderly do not seem to differ from younger adults regarding their ability to judge and use health-related information, but they do differ from younger adults regarding their ability to access and understand health-related information. These associations varied according to the domain that was addressed. The results imply that when health literacy is measured as a set of skills to be used in various contexts, associations with socio-economic and demographic characteristics can vary according to these skills and contexts.

Literature suggests that health literacy may be an explaining mechanism in the association between educational attainment and health, since health literacy

is found to be associated with both level of education as well as health outcomes.[6] However, few studies have actually examined this. Therefore, in ***Chapter 3***, it was explored to what extent health literacy constitutes a pathway in the association between education on one hand and perceived general, physical and mental health on the other. For this purpose, data from the 2008 Adult Literacy and Life Skills Survey (ALL) were used including the Health Activities and Literacy Scale (HALS).[7] The HALS is based on a selection of health-related reading and problem-solving tasks developed according to measurement methods that stem from the educational field, to measure individuals' performances. A relatively high percentage of the respondents demonstrated poor (43.4%) or very poor health literacy (10.6%), which was associated with their level of education; those who were more highly educated had higher health literacy scores. Furthermore, it was found that those with higher health literacy reported better self-reported general, physical and mental health. Having completed a lower level of education was also associated with lower perceived general, physical and mental health. Mediation analyses indicated that health literacy mediated the association between education and self-reported general, physical and mental health. This means that having lower health literacy skills partly explains the association that was found between having a lower level of education and reporting poorer health.

Regardless of the differences in the conceptualization of health literacy, in line with literature, both studies indicate that health literacy is associated with indicators of socio-economic status and demographic characteristics[8-13] and in part accounts for the association between educational attainment and perceived health.[14-16]

Part II – Health literacy in the context of chronic care

Adults who suffer from a chronic condition are likely to be more frequently involved with healthcare and self-care activities than adults who do not suffer from a chronic condition. This means that relatively often, a demand is made on the health literacy skills of this population. The aim of the second part of this thesis was to obtain insight into the extent to which health literacy is associated with (psychological determinants of) use of primary care, patient-provider interaction and self-management among adults with a chronic condition. In this respect, we focused in Chapter 4 on diabetes self-management and in Chapter 5 on control over care among Dutch adults with various chronic conditions. Self-management and control over care are explicitly stimulated by Dutch healthcare standards for chronically ill patients.[17]

In the conceptual model of Von Wagner and colleagues, it is described that health literacy relates to the management of disease via psychological determinants like knowledge.[3] Therefore, in ***Chapter 4***, a study was described that examined whether diabetes knowledge constitutes a pathway between health literacy and diabetes self-management. Self-management encompasses various behaviours related to the monitoring and care for one's condition. These behaviours can be used as indicators of self-management. In the study as described in Chapter 4 smoking behaviour, physical activity, self-control of glucose levels, monitoring of glucose levels and HbA1c level, were included as diabetes self-management indicators. HbA1c level is not a behaviour but was perceived as an indication of the extent to which a person manages his or her diabetes. Higher HbA1c levels may indicate poorer self-management.

Analyses were performed on a cross-sectional sample of patients with predominantly type 2 diabetes obtained from patient registrations and questionnaires completed in 2010.[18] Health literacy was assessed by the Set of Brief Screening Questions (SBSQ).[19-21] The mean score on this short indicator of health literacy, was found to be related to knowledge of diabetes and certain indicators of self-management behaviour. No significant association was found between health literacy and self-reported monitoring of glucose levels and between health literacy and smoking. However, lower health literacy was associated with a higher HbA1c level, less physical activity and lower odds for performing self-control of glucose levels than those with higher health literacy.

With respect to the association between diabetes knowledge and self-management indicators, the study showed that patients with more knowledge were more likely to control their glucose levels themselves and were less likely to smoke, compared to those with less knowledge. No associations were found between diabetes knowledge and the other self-management indicators. Finally, diabetes knowledge mediated the association between health literacy and glucose self-control and between health literacy and smoking. This indicates that those who have lower health literacy skills are less likely to control their glucose levels themselves, partly because they have less knowledge of diabetes. With respect to smoking this implies that respondents with lower health literacy are more likely to smoke when they have less diabetes knowledge.

The results of the study described in Chapter 4 indicate that the association between health literacy and self-management of diabetes is not straightforward and depends on the type of self-management behaviour. For instance, no association between health literacy and monitoring of glucose levels was found, but health literacy was associated with physical activity. This nuances the

theoretical model of Von Wagner and colleagues.[3] Namely, the findings imply that the presence of an association between health literacy and disease self-management, depends on the type of actions that are preformed to manage a disease. The results also imply that knowledge is more important for certain self-management tasks than for others. Efforts to increase diabetes knowledge may therefore not always lead to better outcomes among those with lower health literacy. Thus, both diabetes knowledge as well as health literacy skills seem important targets for interventions to promote diabetes self-management, since targeting both is likely to lead to improvements on more self-management aspects than targeting only health literacy or knowledge.

Where Chapter 4 focussed on health literacy and disease specific self-management activities, ***Chapter 5*** reflected on health literacy in relation to perceived control over care. Chapter 5 also described the relation between health literacy and frequency of general practitioner (GP) visits. The study in which this was explored, was based on a sample of disabled adults and chronically ill (including individuals with diabetes, cardiovascular disease, lung disease and musculoskeletal disease). Thereby, a distinction was made between functional, interactive and critical health literacy as assessed by the Functional, Communicative, Critical Health Literacy scale (FCCHL).[22] Functional health literacy reflects basic skills in reading and writing to be able to function effectively in everyday situations. Communicative/interactive health literacy reflects more advanced cognitive, literacy and social skills, that can be used to actively participate in everyday activities, extract information and derive meaning from different forms of communication and to apply new information to changing circumstances. Critical health literacy refers to more advanced cognitive skills, which together with social skills, can be applied to critically analyse information, and to use this information to exert greater control over life events and situations.[23]

Perceived control over care (i.e., the ability to steer the care process to some extent) was indicated by perceived ability to organize care, interact with healthcare providers and perform self-care. The study showed that after controlling for various patient characteristics, higher interactive health literacy appeared to be the type of health literacy that was most strongly associated with less perceived ability to exert control over care compared to the other two types of health literacy. Critical health literacy was not associated with patients' perceived ability to exert control over care when adjusting for functional and interactive health literacy. Furthermore, functional health literacy was the only type of health literacy that was associated with the use of primary care; patients

with lower functional health literacy visited their GP more often than patients with higher functional health literacy (after controlling for perceived health status). This suggests that patients with lower functional health literacy may need more support from their GP in caring for their condition than patients with higher functional health literacy. Patients with lower health literacy skills may be less able to discern between more serious symptoms that require the attention of their GP and lighter health problems which they should be able to handle themselves.

This study reflected on various components of the conceptual model of Von Wagner.[3] Namely, on the ability to organize care (an aspect of the volitional phase), on the management of disease, on interaction with healthcare providers and on use of care (three types of health actions). The associations as proposed by Von Wagner, between health literacy and health actions as well as organizing care, were confirmed in this study. However, the associations varied per type of health literacy; functional, interactive and critical health literacy seem to be relevant for distinct health actions/aspects of exerting control over care.

To summarize, the findings presented in this part of the thesis indicate that adults with a chronic condition that have higher health literacy skills seem better capable of organizing care, interacting with their healthcare provider and managing their disease. However, the study described in Chapter 5 shows that specific aspects of health literacy relate distinctly to perceived control over care.[24,25] The skills needed to find, understand and apply relevant information and express ones thoughts are especially important in this respect (interactive health literacy). This means that initiatives to strengthen individuals' position in the care of their condition may be more effective when they are directed at interactive health literacy skills.

In the studies that were described in this part of the thesis, knowledge concerning a chronic condition was included as a determinant of health actions (Chapter 4) as well as a determinant of health literacy (Chapter 5). The relation between health literacy and knowledge is complex since there is yet not an univocal theory on how both concepts relate to each other. Knowledge is considered by some scholars to be part of health literacy, whereas others consider it to be a unique construct. According to Von Wagner's conceptual model,[3] previous knowledge about a specific health-related topic, like a chronic condition, can strengthen health literacy skills. In this respect, knowledge is a determinant of health literacy, which is the way it was conceptualized in the study described in Chapter 5. On the other hand, Von Wagner's model suggests that health literacy skills can also increase knowledge; someone with higher

health literacy skills may be more likely to incorporate information on certain health-related issues than someone with lower health literacy skills. In the study described in Chapter 4, knowledge was related to health literacy in line with this view. Although health literacy and knowledge are related constructs, the studies described in Chapter 4 and Chapter 5 indicate that health literacy and knowledge provide unique contributions in explaining variance in self-management, perceived control over care and frequency of GP visits.

Part III – Health literacy in the context of prevention

The aim of the third part of this thesis was to obtain insight into the extent to which health literacy is associated with psychological determinants of participation in prevention programs. Specifically, the extent to which health literacy relates to decision-making with respect to colorectal cancer (CRC) screening and childhood vaccination was studied. According to Von Wagner's conceptual model, lower health literacy is related to lower participation in prevention programs via psychological processes.[3] This includes factors that are related to decision-making regarding preventive behaviour (e.g., attitude, knowledge, perceived barriers and benefits and decision-making skills). In the two chapters included in the third part of this thesis, it was described how health literacy relates to these psychological processes.

In ***Chapter 6***, a systematic review was presented on the relation between health literacy and informed decision-making concerning CRC screening. Informed decision-making can be interpreted as a process, including various stages of decision making (from the awareness of the decision problem (like the possibility to participate in screening) to the actual decision that is made).[26] Informed decision-making can also be interpreted as an outcome of sufficient knowledge combined with a decision that is consistent with a person's attitude toward a decision problem.[27] For the purpose of this review, a broad approach to the concept informed decision-making was adopted, including factors related to various stages of the decision-making process (awareness, risk perception, perceived barriers and benefits, knowledge, attitude, deliberation) as well as an informed decision as the outcome of this process (sufficient knowledge in combination with deliberation and attitude-uptake consistency).[26,27] Studies were considered relevant for inclusion when (an aspect of) informed decision-making (awareness, risk perception, perceived barriers and benefits, knowledge, attitude, deliberation) was studied in relation to (an aspect of) health literacy (accessing, understanding, appraising, applying) in the context of CRC screening. Eight studies were considered relevant for inclusion. Seven of these studies focused on

knowledge concerning CRC (screening), four on attitudes or beliefs concerning CRC (screening) and one on the perception of risk information in relation to health literacy. All studies showed either no association between health literacy and aspects of informed decision-making, or a positive association. Namely, in some studies higher health literacy was associated with higher scores on a knowledge test and a more positive attitude towards screening. But the body of literature on the association between health literacy and informed decision-making concerning CRC screening is limited. Therefore, more research is needed to determine whether there is indeed a positive association between health literacy and informed decision-making concerning CRC screening. Additionally, an important topic for further research would be what knowledge would be essential for people with higher and lower health literacy skills to make informed decisions for participation in screening programs.

Vaccination is, next to screening, an important action to prevent disease. In the Netherlands, individuals generally receive various vaccinations during childhood, offered in the National Immunization Program (NIP). In ***Chapter 7***, it was explored whether parents with higher health literacy differed from parents with lower health literacy concerning their preferences for the characteristics of rotavirus vaccination. The rotavirus vaccine may become part of the Dutch NIP. Following Von Wagner's conceptual model, preferences could be interpreted as a form of attitude. A person can have positive or negative feelings towards characteristics of rotavirus vaccination. These preferences could influence individuals' decisions to participate in prevention services such as vaccination.[3]

Chew's Set of Brief Screening Questions (SBSQ) was used to asses health literacy.[19-21] Parents preferences were obtained by a discrete choice experiment (DCE). The DCE assessed parents' preferences regarding out-of-pocket payment, vaccination location, likelihood of severe side effects, protection duration and vaccine effectiveness. The results of the study show that respondents with lower health literacy skills perceived vaccine effectiveness and the likelihood of severe side effects to be less important and protection duration to be more important than respondents with higher health literacy skills. It was also found that parents with higher health literacy were less willing to participate in rotavirus vaccination when the vaccine was offered outside the NIP, while this was not the case for parents with lower health literacy skills.

What this study implies is that given the same information (i.e., information presented in the same format and with the same content), the characteristics of rotavirus vaccination that parents with lower health literacy skills considered as important differed from those considered important by parents with higher

health literacy. Whether this is due to differences in the understanding of information or to distinct preferences remains unclear. Nevertheless, this study calls for attention on health literacy as a factor to consider when studying vaccination behaviour and developing education materials. Regardless the cause for differences in preferences, parents with lower health literacy may decide differently when rotavirus vaccination is offered based on certain characteristics than parents with higher health literacy.

Methodological considerations

Health literacy measurements

Reliable, valid, and feasible measurement of the concepts under study is one of the most challenging aspects of research. In the present thesis, various instruments to measure health literacy were applied including the European Health Literacy Survey Questionnaire (HLS-EU-Q); the Health Activities and Literacy Scale (HALS); the Set of Brief Screening Questions (the SBSQ); and the Functional Communicative and Critical Health Literacy questionnaire (the FCCHL). All of these instruments can be considered reliable based on their psychometric properties, but the instruments differ in *how* they measure health literacy and in what *aspects* of health literacy are measured. In this paragraph, these two characteristics of the health literacy instruments that were used in the current thesis will be elaborated. In addition, considerations concerning the interpretation of health literacy scores will be described.

Subjective versus objective health literacy

The first distinction between health literacy instruments can be made based on how health literacy is measured: subjectively or objectively. The HALS is an objective assessment of health literacy, based on scores on a range of tasks that measure health-related prose and document literacy, numeracy and problem-solving skills. On the other hand, the HLS-EU-Q, the SBSQ and the FCCHL measure self-reported difficulties with health-related information. Both methods of measuring health literacy have their strengths and limitations. Subjective measures of health literacy may reflect an overestimation of peoples' health literacy skills, since generally people tend to overestimate their skills.[28-30] However, a limitation of objective health literacy measures is that it remains unclear to what extent individuals' assessed performances on health-literacy tasks can be considered a problem in their daily life. Namely, when systems and

information are poorly accessible, those with high health literacy scores may still perceive difficulties in their daily life. For example, someone who easily fulfils reading tasks, may perceive difficulties with finding the right information on treatment options. On the other hand, those with lower health literacy might find ways to circumvent difficult demands of the system, e.g. by mobilizing social support from relatives or friends. Another limitation is that objective health literacy measures should be administered in person and therefore they are more difficult to include in questionnaire-based survey research.

Objective health literacy measures, such as the HALS, are especially useful to determine differences in performances between individuals, groups or countries or to measure changes in health literacy skills over time on a population level. In addition, subjective health literacy measures, such as the HLS-EU-Q, provide insight into perceived problems in daily life and health domains that may need special attention. Measures like the HLS-EU-Q include items that are more considerate of the context in which health literacy skills need to be applied and thereby provide more insight into actions that could be taken to improve health literacy, opposed to objective health literacy measures. It can be concluded that objective and subjective health literacy measures provide insight into health literacy in different ways and therefore complement each other.

Aspects of health literacy

The instruments as used in the present thesis not only measure health literacy in multiple ways, but also measure distinct aspects of health literacy. The HLS-EU-Q covers three domains of health (healthcare, disease prevention and health promotion) and addresses four types of skills (assessing, understanding, appraising and applying). The FCCHL is less extensive than the HLS-EU, but also provides insight into specific aspects of health literacy by measuring functional, interactive and critical health literacy skills. On the other hand, the SBSQ provides a relatively limited measure of health literacy, since it makes no distinction between skills or health literacy types and is merely directed at the context of healthcare. The HALS includes a broad range of tasks over various health domains, but is directed only at written health-related information. Although various aspects of health literacy are measured (and some health literacy instruments are broader than others), most studies on health literacy show results in a similar direction, including the ones as described in this thesis. That is, lower health literacy tends to be associated with poorer health-related outcomes, such as poorer perceived health. This could imply that the various health literacy instruments measure aspects of a similar latent construct.

Although a multidimensional concept can be difficult to study, because it complicates the comparability of findings, it is important that health literacy instruments aim to draw a distinction between multiple aspects. This will provide insight into which specific aspects of health literacy affect certain outcomes. Instruments that measure multiple aspects of health literacy (like the FCCHL and the HLS-EU-Q) can provide insight into the relative scores of people on these aspects (for instance some people may score low on functional health literacy, but higher on interactive health literacy). This can help determine the specific health literacy aspect that should be addressed when aiming to improve the use of health information. Furthermore, insight into various aspects of health literacy may help researchers and healthcare providers to think in terms of health literacy profiles instead of high versus low health literacy. This is useful for healthcare organizations to get a grasp on how they can best serve particular groups.

Interpretation of health literacy scores

Since many conceptualizations of health literacy and various health literacy instruments are available, health literacy scores can be complex to interpret. For instance, both the HLS-EU-Q and the HALS provide insight into the health literacy skills of the Dutch adult population. However, because there is no golden standard for the measurement of health literacy, it is difficult to determine what percentage of the Dutch adult population actually has lower health literacy skills. The HLS-EU-Q was assessed in eight European countries and based on the cut-off points that were chosen in the context of the HLS-EU project, the Netherlands performed relatively favourable compared to the other countries.[31] Nonetheless, the HLS-EU implied that 26.9% of the Dutch population aged 16 years or older has problematic and 1.8% inadequate health literacy skills. This total percentage of 28.7 differs remarkably from the more than 50% that are expected to have poor to very poor health literacy based on the HALS results. This implies that the conceptualization and measurement of health literacy determines the indication of the amount of people who have lower health literacy skills.

The cut-off points for lower and higher health literacy skills are more established for the HALS scores than for the HLS-EU-Q, the SBSQ and the FCCHL scores. However, whether a person has sufficient health literacy skills, regardless the type of instrument that has been used, depends highly on the context, the social environment and demands of the healthcare system. For instance, when people find themselves in a stressful or otherwise uncomfortable

situation and experience fear, distress or pain, it may be more difficult to understand, appraise or use information than in a comfortable situation. Furthermore, as indicated by the study described in Chapter 2, some health domains may be more complex than others and the extent to which people have sufficient health literacy skills may differ according to domain or content. In addition, in daily life, individuals may receive help from their family and friends when managing the understanding and application of health-related information.[32] This could temper the adverse effects of lower health literacy in practice. Furthermore, the demands of the healthcare system may determine the meaning of health literacy scores. When health information is poorly accessible or difficult to understand, health literacy scores have different implications in daily life than when information is highly accessible and easily understood. Namely, in both scenarios, certain levels of health literacy could be sufficient to function in daily life. Additionally, it has been suggested that someone's health literacy skills may vary throughout the life course. For instance, health literacy skills may increase through certain (disease-related) experiences, or health literacy skills may decrease due to age-related cognitive decline.[3] Taking all these issues into consideration, one should be cautious about categorising people as having high or low health literacy. A person can have higher health literacy skills in a particular situation or point in time and lower health literacy skills in another situation or another point in time.

Limitations

The studies described in this thesis have limitations. The study samples used in the separate chapters are likely to be subject to selection bias. First, ethnic minorities were underrepresented in the samples in which information on ethnicity was available, ranging from 8% (in Chapter 7), 9% (in Chapter 5) to 13% (in Chapter 3 and Chapter 4). The percentage of ethnic minorities in the Dutch adult population aged 20-65 was approximately 22.5% in 2013 (10.2% of Western origin and 12.3% non-Western).[33] Studies from North America imply that members of minority populations show lower health literacy skills than adults from the majority population (for example[8]). However, if ethnic minorities participate in health literacy research, their scores on health literacy instruments may be influenced by difficulties filling in questionnaires or misinterpreting the questions due to difficulties with the native language. Therefore, lower scores may reflect language difficulties. It is questionable whether this can be considered a reflection of lower health literacy.

In addition to ethnic minorities, Dutch adults with low literacy skills are also

likely to be underrepresented in the studies that were included in the present thesis. It was estimated that in 2008, 10% of the Dutch population between 16 and 65 years of age had low literacy skills.[34] This does not include those who are close to illiteracy (2,5%), but it may include individuals with disorders like dyslexia or dyscalculia. Basic arithmetic and reading skills are considered to be the foundation of health literacy as suggested by Von Wagner and colleagues.[3] Since those who have poor basic arithmetic and reading skills seem likely to be underrepresented in the studies described in the present thesis, the estimations of the number of people who are likely to have lower health literacy skills may be higher in real life.

Another limitation of the present thesis is that the included studies focused on socio-economic and demographic characteristics and various (psychological determinants of) health actions in relation to health literacy, in line with the conceptual model of Von Wagner. What was not included in this model and also not described in the present thesis, is how health literacy relates more intuitive or routine driven behaviour. Namely, health-related behaviour can be based on routines rather than for instance attitude, knowledge or the weighing of pros and cons [26,35] Furthermore, emotions like fear and distress could affect the use of health literacy skills. How health literacy relates to these types of emotions was not part of the present thesis, but would be relevant to address in future research. Furthermore, the theoretical embedment of health literacy in relation to psychological factors as well as health actions remains limited. Although the theoretical model of Von Wagner and colleagues is very valuable for the guidance of research, the theoretical distinction or overlap between the included concepts remains unclear.[3]

Another limitation of the studies as described in the present thesis, is that the studies were based on cross-sectional data. Therefore no inferences could be made on the direction of the associations that were found.

Discussion of main findings

The studies described in this thesis underline that health literacy could be regarded a multidimensional concept of which various aspects can be measured. This includes the ability to read and understand different types of health-related texts in print, but also the ability to understand verbal and digital health-related information, the ability find this information and to judge and use it. Based on the studies as described in this thesis, these can be considered key-aspects of

health literacy.

The findings also imply that aspects of health literacy can differ in their complexity. For instance, the study described in Chapter 2 implies that Dutch adults perceive more difficulties with appraising health-related information compared to accessing, understanding and using information. Health literacy skills also depend on the context in which they need to be applied: information in the context of healthcare seems more easy to access, understand, judge and use than information in the context of prevention. In addition, the findings indicate that specific aspects of health literacy can be relevant for specific health actions. Interactive health literacy seems for instance more relevant for people's ability to organize care than critical health literacy.

In the present thesis, the scores on the health literacy instruments were mainly interpreted as an indication of personal skills. However, the subjective health literacy measures that were applied may not only provide an indication of personal skills, but can also be interpreted as the complexity of a healthcare system. For instance, if respondents state to perceive difficulties with understanding what their doctor says to them, this could imply that the information is unclear or too complex. Furthermore, health literacy scores can be interpreted as an indication of the balance between individuals' skills and demands of a healthcare system or demands of society at large. For instance, when comparing health literacy scores between countries, as was done in the European Health Literacy Survey, health literacy scores can be informative about individuals' skills in light of the functioning or demands of healthcare systems or societies, or the other way around. Health literacy as the balance between individuals' skills and demands of a system/society should receive more attention in future research. This approach implies that solutions for lower health literacy should come from two sides: the side of individuals as well as the side of systems (information providers).

Based on the findings of the studies as described in this thesis, health literacy can be considered an asset for public health in multiple ways. In the first place, it can be considered an asset in the way Nutbeam proposed: health literacy skills help people to exert control over their health and care.[23] Namely, those with higher health literacy skills were found to be better able of performing certain self-management tasks in the care for their chronic condition, interact with health-care providers, and to organize care. Health literacy can be considered an asset for public health researchers and healthcare providers. Namely, health literacy was found to provide a unique contribution to explaining variation in health actions and in perceived health. Furthermore, health literacy is a factor

that may be modifiable through interventions, unlike factors such as age and sex. Health literacy therefore offers new opportunities for the development of interventions to reduce disparities in health or to strengthen the autonomy of individuals regarding their health and care.

Implications

Based on the findings of the present thesis and in light of the current knowledge base concerning health literacy, implications were formulated with respect to theory development, research, practice and policy.

Implications for theory development

Conceptualization of health literacy

The studies that were described in this thesis illustrate that health literacy can be conceptualized in various ways. The debate on the definition and measurement of health literacy continues. Given the variety in definitions of health literacy from several points of view and the discussion on whether to speak of one or multiple health literacies, it is questionable whether one definition is feasible or useful. Perhaps a general conceptualization would be more suitable to enhance the research field on health literacy instead of striving for a single definition. A general concept represents a characterization of a generally agreed-upon direction in which to look, whereas a definition implies set boundaries and a precise meaning.[36] This approach was adopted by Machteld Huber in her search for a new conceptualization of health.[36] Instead of adopting a precise definition of health, she proposed formulating health as the ability to adapt and self-manage.[36] This formulation was not labelled as a definition, but as a general conceptualization. In an era in which knowledge is generated at a high speed, talking about a general concept of health literacy seems suitable since it leaves room for multiple interpretations or operationalizations. Nevertheless, studies that measure health literacy should clearly state what aspect of health literacy is being measured, but all can contribute to insight into the general concept health literacy.

Theoretical embedment of health literacy

According to the model of Von Wagner, health literacy is related to various psychological processes, as well as to basic skills in reading and writing.[3] But how health literacy exactly differs from these concepts remains largely unclear. It is

recommended that more efforts are undertaken to stronger embed health literacy theoretically, thereby clearly describing how health literacy relates to concepts such as knowledge, attitude/beliefs, motivation and informed decision-making.

Implications for research

Health literacy as sample characteristic

In line with literature, the studies that are combined in the present thesis imply that health literacy is related to individual characteristics such as level of education, age and sex, but that it provides a unique contribution in explaining differences in behaviour and health-outcomes. Therefore, it is recommended to include health literacy measures in research that aims to explain differences in health or health-related behaviour, such as self-management or screening participation, and to report it as a sample characteristic in addition to education, ethnicity, sex and age. Currently, this is not common as illustrated by the review on health literacy and CRC screening described in Chapter 6.

Developing and retaining health literacy skills

Health literacy seems to a certain extent learnable and by some considered an outcome of health education.[37] Von Wagner and colleagues suggest that basic skills in reading and arithmetic as well as cognitive abilities are important determinants of health literacy skills.[3] However, health literacy can also be modified by experiences throughout people's life course (experiential learning).[3] This implies that individuals' health literacy skills could be modified through interventions. The review of Berkman and colleagues (including English literature) reveals that a number of interventions have a positive impact on health literacy skills.[38] However, there are hardly European studies that examined the effects of interventions on health literacy.

Furthermore, research on how to retain health literacy skills is currently lacking. Some state that health literacy can be considered as a 'use it or lose it' phenomenon, implying that skills should be practiced in order to be retained. In this context it has been suggested that frequent reading may have a positive effect on health literacy skills, i.e., on functional health literacy skills.[6] Based on the data we had at our disposal, higher health literacy was found to be associated with a higher frequency of reading (not reported). However, the drawback of cross-sectional data is that it is not possible to determine the direction of associations. It is possible that reading behaviour does not influence health literacy, but reading frequently is a characteristic of those who have higher health literacy skills. Longitudinal research is needed to study how health

literacy can be retained and whether reading behaviour is a relevant determinant in this regard. Another expected determinant of retaining health literacy skills is age-related cognitive decline. Von Wagner and colleagues suggest in their model that age-related cognitive decline can negatively affect the procession of information.[39] It would be relevant to examine what aspects of health literacy may be affected by cognitive decline. Since the Dutch population is aging, which will lead to an increase in the number of people who suffer from a chronic condition, this is a relevant topic for future research.

Health literacy and decision-making

In the current thesis, attention was paid to the relation between health literacy and elements of decision-making, although not in great depth. It would be relevant to obtain a better understanding of the relation between health literacy and decision-making, especially informed decision-making. Informed decision-making is increasingly regarded the goal of information on prevention such as cancer screening. The study described in Chapter 7 implies that adults with lower health literacy skills have different preferences when deciding on rotavirus vaccination for their newborn than parents with higher health literacy. Whether this reflects real differences in preferences or rather differences in how information is understood should be studied in more depth. Future studies may also address whether people with lower and higher health literacy differ in their decision-making strategies and in their information needs. For instance, topics could include whether certain types of information like numerical information or more abstract information are perceived or used distinctly by individuals with higher and lower health literacy skills. Another topic might be to what extent individuals with higher and lower health literacy differ in basing decisions on the deliberation of the pros and cons of a decision option, on emotions or on social influences. Furthermore, more insight is needed in what information is required by individuals when they have to make health-related decision, such as participation in cancer screening, and whether these information needs differ according to someone's health literacy skills. Insights in this regard could help when developing education materials.

Enhancing the research field of health literacy

Health literacy is a relatively new research topic, that has received little attention, especially in Europe. But in the past decennia, the research field of health literacy has expanded. There has been many discussion on how to define and measure health literacy. Most studies on health literacy so far, are based on

cross-sectional data. In order to advance the research field, there is a need for research on the effectiveness of interventions to enhance health literacy. Research on interventions could support healthcare providers in determining how they could serve patients with lower health literacy skills. It could also enhance theory development regarding health literacy (for instance how health literacy skills can be obtained or enhanced). Furthermore, longitudinal research designs are needed, in order to study the development of health literacy skills throughout the life course.

Implications for practice

Maintaining or increasing health literacy skills

Efforts to strengthen or to maintain individuals' health literacy skills are relevant for public health, since this thesis indicates that having higher health literacy is related to better health-related outcomes. Based on theory concerning skill development in general, investments early in life, even before formal education, are considered to be an important contributor to skill formation.[40] Furthermore, skills can be obtained during a person's life course by experiences and formal or informal learning opportunities, which are also incorporated in the conceptual framework of Von Wagner and colleagues.[3] This implies that efforts to maintain or to increase health literacy skills may be needed at several points in time during one's life course. For instance, basic skills in reading and arithmetic, the foundation of health literacy, can be addressed during formal education and by informal educational opportunities early in life. Health literacy as measured by the HALS may relate to these types of entrances to skill development. The skills to interact with the healthcare system, obtain relevant information and use information for the benefit of one's health may be addressed later in life. These are the type of skills that go beyond the ability to correctly interpret and use information in print.

In this regard, it may be helpful to draw a comparison with the concept of intelligence. In psychology, a distinction is often made between fluid intelligence and crystallized intelligence.[41] The first form of intelligence refers to one's working memory and the capacity to obtain new information. This type of intelligence is thought to increase until approximately the age of 20, and thereafter decreases gradually with age.[41] Crystallized intelligence refers to long-term memory and is thought to reflect problem-solving skills that are gained through knowledge and experience.[41] Researchers may want to draw a similar distinction between health literacy skills: skills that are fluid (e.g., the capacity to understand and learn) and skills that are crystallized (e.g., the capacity to

correctly monitor blood glucose levels). When aiming to increase functional health literacy skills among the general population, fluid skills may need to be addressed early in life, for instance by addressing them in school curriculum. In order to increase interactive and critical health literacy skills, more crystallized skills may be needed, for example, by teaching patients how to monitor their glucose levels.

Efforts from healthcare organizations and providers

In addition to focusing on individuals' skills, it is important to address the healthcare system as well. Health literacy can be considered as a balance between individuals' skills and healthcare system demands. From this perspective, efforts to increase or maintain individuals' skills should be counterbalanced by efforts to make health-related information accessible and understandable. Demands of a healthcare institution can increase or decrease the barrier for individuals with lower health literacy to access relevant health information, as is suggested by the model of Von Wagner.[3] Organizations that make it easier for people to navigate, understand, and use information and services to take care of their health are referred to as 'health literate organizations' in the literature.[41]

Given the increasing amount of health information that is available today, healthcare professionals should assume the task of informing their patients about information sources, including webpages that contain useful information on health and healthcare. The study described in Chapter 2 implies that Dutch adults relatively frequently perceive difficulty appraising health-related information compared to accessing, understanding and using information. Appraising information can be interpreted in two ways: judging whether information is reliable or judging whether information is relevant for one's personal goals. Appraisal in the first interpretation can be very complex given the amount of health-related information that is available to date and whose reliability is often hard to determine. Therefore, healthcare professionals may need to take an advising role and inform patients about trustworthy (online) information.

The second interpretation of appraising information is addressed by decision aids. Decision aids can help people make decisions that are in line with their preferences. It is important that the usability of future decision aids for individuals with lower health literacy is taken into consideration.[43] In order to judge whether information is personally relevant, information should be understandable. With respect to health information accessibility, it may be

fruitful to invest in applications that enable people to choose the level of complexity of a given (web) text.

Implications for policy

Currently, Dutch health policy lays great emphasis on personal responsibilities and citizen autonomy. Some scholars state that a unilateral emphasis on citizens' autonomy could enhance polarization in society and health outcomes.[2] Therefore, it is suggested that emphasis on personal autonomy, which has positive aspects, is counterbalanced with initiatives to support those who find it difficult to exert autonomy with respect to their health and care. More specifically, efforts need to be undertaken to ensure that information on health-related issues (like information on health insurances or information on cancer screening) is accessible and understandable for all. Currently, there are a number of laws in the context of health and care, in which clear information provision is made explicit. The Dutch Law of Agreement to Medical Treatment (WGBO) says that all clients have the right to receive *understandable* information regarding their disease and treatment.[44] And the European law on the provision of food information to consumers (EU Regulation 1169/2011) was called into being to improve the information (including the legibility) that is provided on food labels.[43]

Thus, there seems to be attention for individuals' needs for understandable information. Nevertheless, the act on individuals' right to understandable information could be generalized to other health-related contexts. For instance to the insurance sector where consumers have to decide what type of insurance would fit their needs. In order for people to make well-considered decisions, accessible and understandable information is essential. This also yields for national screening programs. Invitations for screening should be understandable, also for those who have lower health literacy skills. Individuals tent to neglect information that is too complex to understand[45], which is a barrier for informed decision-making.[26] Therefore, it is recommended to invest in the development of guidelines regarding the type of characteristics on which accessible and understandable information should comply, for fields that relate to public health. If healthcare policy presumes that individuals make informed decisions regarding their health and care, policymakers should make assure that individuals are provided information that can be used to make informed decisions.

General conclusion

Health literacy is a multidimensional construct that can be operationalized in multiple ways. About a third to half of the Dutch adult population is expected to have relatively low health literacy skills, based on two distinct health literacy surveys. These individuals are likely to face difficulties in fulfilling the autonomous and responsible role with respect to their health and care that is nowadays expected of Dutch citizens. This thesis indicates that regardless of the operationalization, lower health literacy is related to indictors of a lower socio-economic position, older age and poorer perceived health status. Lower health literacy is also related to indicators of lower self-management abilities and a higher use of primary care. Subsequently, this thesis implies that health literacy is related to psychological factors underpinning informed decision-making with respect to screening and vaccination. Efforts that can increase or maintain people's opportunities as well as their abilities to access, understand, appraise and apply health-related information may be beneficial for people's health outcomes as well as for their ability to exert control over their health and care. Health literacy can be considered a balance between individual skills on the one side and system demands on the other side. Therefore, it seems most effective to offer interventions to increase or maintain health literacy from both angles. It can be concluded that health literacy is an important asset for individuals to exert control over their health and care. Health literacy is also an asset for researchers, healthcare providers and policy makers, since it provides a unique contribution to explaining differences in health actions and health outcomes.

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Summary

Introduction

In the Netherlands, citizens are expected to fulfil an autonomous and responsible role when it comes to their health and healthcare. This is induced by various social developments, such as: legal reforms to strengthen the patient's position, more attention for patient-centred care, pressure on the healthcare system due to an aging population, and reforms to transform the Dutch healthcare system from supply regulated to demands regulated. The focus on individual responsibility with respect to health and care, places an increased emphasis on peoples' health literacy skills. Health literacy can be defined as an individual's skills to access, understand, appraise and apply health related information. In contemporary society, people with higher health literacy skills may be advanced over those who have lower health literacy skills, when it comes to health. Several studies show an association between lower health literacy and adverse health-related outcomes, such as a poorer ability to follow medical instructions, more hospitalizations, less use of preventive care and a lower level of self-care. Thus, health literacy seems an important determinant of public health. However, health literacy is a relative new concept and most studies on the determinants of health literacy, allied psychological processes and health-related consequences have been performed in the USA. Therefore, the research in this thesis aimed to obtain insight into the health literacy skills of Dutch adult in relation to socio-economic and demographic characteristics, psychological factors, health actions and health. Health actions refer to healthcare access and use, management of health and illness and patient-provider interaction. Particularly with respect to chronic care and prevention (i.e., screening and vaccination), an increased attempt is being made to individuals' responsibility. Therefore it is especially relevant to study the role of health literacy in these areas.

Health literacy in the Dutch adult population

In the first part of this thesis two studies were described that aimed to explore to what extent health literacy among Dutch adults related to socio-economic and demographic characteristics and to perceived health. This was in the first place done based on data that was obtained in the 2012 European Health Literacy Survey (HLS-EU) (Chapter 2). The instrument that was developed and used in the HLS-EU to measure health literacy, measured perceived difficulties with accessing, understanding, appraising and applying health-related information over three domains: healthcare, disease prevention and health promotion. Given the range from 1 (the lowest score) to 4 mean scores ranged from 3.1 for appraising information to 3.4 for understanding information across all domains.

However, perceived difficulties varied to some extent per health domain. For instance, accessing information was perceived as more difficult in the healthcare domain (mean 2.6) than in the disease prevention domain (mean 3.4). Individuals with a lower level of education and a lower perceived social status perceived more difficulties with all four skills than those who had a higher education and a higher perceived social status. In addition, males perceived more difficulties than females with all four skills. Furthermore, age was negatively associated with accessing and understanding health-related information, but was not associated with appraising and applying health-related information. The results of this study imply that perceived difficulty with health-related information may differ according to the type of health literacy skill and the context in which health literacy skills are addressed. In addition, associations with socio-economic and demographic characteristics vary according to the type of skill and domain.

A second study examined whether health literacy constitutes a pathway in the association between education on the one side and perceived general health, perceived physical health and perceived mental health on the other (Chapter 3). For this purpose, data from the 2008 Adult Literacy and Life Skills Survey (ALL), including the Health Activities and Literacy Scale (HALS) were used. In contrast to the HLS-EU, in which health literacy is operationalized as perceived difficulties with health-related information, the HALS operationalizes health literacy as the score on a set of reading and problem-solving tasks. Based on this operationalization, in this study, lower health literacy was associated with the person's level of education; those with a higher education showed higher health literacy scores.

Furthermore, it was found that those with lower health literacy reported worse self-reported general, physical and mental health than those with higher health literacy. Having completed a lower level of education was also associated with lower perceived general, physical and mental health. Mediation analyses indicated that health literacy mediated the association between education and self-reported general, physical and mental health. This finding indicated that part of the association between lower level of education and lower perceived health could be attributed to lower health literacy. Based on both studies, it could be concluded that lower health literacy is more often prevalent among those who have attained a lower level of education, have a lower perceived social status, or who are elderly or male. Subsequently, health literacy provides a contribution to explaining education-related variation in perceived health.

Health literacy in the context of chronic care

The aim of the second part of this thesis was to obtain insight into the extent to which health literacy is associated with (psychological determinants of) the use of primary care, patient-provider interaction and self-management in the context of chronic care. Firstly, it was examined to what extent health literacy relates to indicators of diabetes self-management and whether diabetes knowledge constitutes a pathway between health literacy and diabetes self-management indicators (Chapter 4). This study included a secondary data analysis based on a cross-sectional sample of patients with predominantly type 2 diabetes obtained from patient registrations and questionnaires completed in 2010. Perceived health literacy was assessed using the Set of Brief Screening Questions (SBSQ). The study showed that lower health literacy was associated with a higher HbA1c level, less physical activity and lower odds for performing self-control of glucose levels than those with higher health literacy. No significant association was found between health literacy and self-reported monitoring of glucose levels or between health literacy and smoking. With respect to the association between diabetes knowledge and self-management indicators, the study showed that patients with more knowledge were more likely to control their glucose levels themselves and less likely to smoke, compared to patients with less knowledge. No association was found between diabetes knowledge and the other indicators. Finally, diabetes knowledge mediated the association between health literacy and glucose self-control and between health literacy and smoking.

The results of this study indicate that the association between health literacy and self-management is not straightforward and depends on the type of self-management behaviour. The results also imply that knowledge is more important for certain self-management tasks than for others; therefore, efforts to increase diabetes knowledge may not always lead to better outcomes among those with lower health literacy. Knowledge as well as health literacy skills seem to be important for self-management. Interventions directed at increasing both are expected to have a positive effect on more aspects of self-management than interventions directed at enhancing only knowledge or health literacy skills.

In another study, it was examined to what extent health literacy relates to perceived control over care and the frequency of GP visits (Chapter 5). This study was based on a sample of chronically ill and disabled adults. Thereby, a distinction was made between functional, communicative/interactive and critical health literacy as assessed by the Functional, Communicative, Critical Health Literacy scale (FCCHL). Functional health literacy refers to basic literacy skills. Communicative or interactive health literacy refers to the more advanced

(cognitive and social) skills needed to obtain and apply health-related information. Critical health literacy refers to even more advanced (cognitive and social) skills that are needed to critically analyse information. Perceived control over care was indicated by perceived ability to organize care, interact with healthcare providers and perform self-care. After controlling for various patient characteristics, interactive health literacy was most strongly associated with perceived ability to exert control over healthcare compared to the other two types of health literacy. Functional health literacy was the only type of health literacy that was associated with the use of healthcare; patients with lower health literacy visited their GP more often than patients with higher health literacy. The results imply that the three types of health literacy may be relevant for various aspects of self-management. Based on both studies it could be concluded that when chronically ill are expected to be more autonomous and responsible in respect to caring for their condition, those with lower health literacy skills may need additional support in some respects.

Health literacy in the context of prevention

The aim of the third part of this thesis was to obtain insight into the extent to which health literacy is associated with psychological determinants of participation in prevention programs. Specifically, it was studied to what extent health literacy relates to psychological factors underlying informed decision-making with respect to colorectal cancer (CRC) screening and decision-making with respect to childhood vaccination. First a systematic review was presented on the relation between health literacy and informed decision-making concerning CRC screening (Chapter 6). Studies were considered relevant for inclusion if (an aspect of) informed decision-making was studied in relation to (an aspect of) health literacy in the context of CRC screening. Eight studies in which various aspects of informed decision-making regarding CRC screening were related to health literacy were considered relevant for inclusion. Seven of these studies focused on knowledge concerning CRC (screening), four on attitudes or beliefs concerning CRC (screening) and one on the perception of risk information. All studies showed either no association between health literacy and aspects of informed decision-making, or a positive association. In some studies, higher health literacy was associated with higher scores on a knowledge test and a more positive attitude towards screening. The results imply that the body of literature on the association between health literacy and informed decision-making concerning CRC screening is limited and that the heterogeneity in operationalization of both health literacy and concepts underpinning

informed decision-making make it difficult to draw conclusions.

From screening, a shift was made to childhood vaccination (Chapter 7). It was explored whether parents with higher health literacy differed from parents with lower health literacy in their preferences for characteristics of rotavirus vaccination. Chew's Set of Brief Screening Questions (SBSQ) was used to assess health literacy. Parents' preferences were obtained by a discrete choice experiment. The discrete choice experiment assessed parents' preferences for out-of-pocket payment, vaccination location, the likelihood of severe side effects, protection duration and vaccine effectiveness. The results of the study showed that respondents with lower health literacy skills perceived that the vaccine's effectiveness and the likelihood of severe side effects was less important and protection duration was more important than respondents with higher health literacy skills.

It was also found that parents with higher health literacy were less willing to participate in rotavirus vaccination when the vaccine would be offered outside the National Immunization Program; this was not the case for parents with lower health literacy skills. What this study implies is that, given the same information, parents with lower health literacy skills consider other characteristics of rotavirus vaccination as important than parents with higher health literacy. Whether this is due to differences in the understanding of information or to differences in preferences remains unclear. Nevertheless, this study calls for attention to health literacy as an important factor to consider when studying vaccination behaviour and when developing education materials. Based on both studies it was concluded that a stronger theoretical embedment of the relation between health literacy and informed decision-making would be valuable, since the extent to which both concepts overlap and differ from each other it remains vague. Additionally, more empirical research on the relation between health literacy and informed decision-making would be valuable, to examine the extent to which both concepts relate to each other.

Discussion and conclusion

The studies that were described in this thesis imply that various aspects of health literacy can be distinguished and that individuals may perceive more difficulties with certain health literacy aspects than with others. The context in which health literacy skills need to be applied is influential as well; someone can have higher health literacy skills in the context of healthcare than in the context of prevention. When researchers study various aspects of health literacy and measure these aspects in distinct ways (for instance perceived difficulties versus

test scores), this leads to variation in study outcomes. Namely, in the HLS-EU project it was estimated that approximately a third of the Dutch population has health literacy skills that are problematic to inadequate. Based on the outcomes of the ALL, approximately half of the Dutch population can be expected to have poor to very poor health literacy skills. The studies that were combined in the present thesis show that health literacy, regardless of operationalization, provides a unique contribution to explaining differences in disease self-management, use of healthcare, interaction with healthcare providers, preferences with respect to vaccination, and perceived health. This in addition to determinants such as level of education, age and sex.

For researchers and healthcare providers, health literacy can be considered as an asset because it contributes to explaining variation in health-related behaviour and health. As opposed to factors such as sex, education and ethnicity, health literacy skills may be learned to some extent. This provides new opportunities for interventions that aim to strengthen Dutch citizens' autonomy with respect to their health and care or for interventions that aim to reduce disparities in health. The concept of health literacy offers a very specific goal that can be anticipated by healthcare institutions or providers. Namely, health literacy is constituted by the interaction of individual skills and demands of the healthcare system. Therefore, it is important that healthcare organizations and healthcare providers offer information that is accessible, understandable and usable for all. The research as described in this thesis showed that health literacy is also an asset for individuals in order to exert control over their health and care.

Samenvatting

Inleiding

In Nederland wordt van burgers verwacht dat zij een zelfstandige en verantwoordelijke rol vervullen met betrekking tot hun gezondheid en zorg. Dit is het gevolg van verschillende sociale ontwikkelingen, zoals wetswijzigingen om de positie van patiënten te versterken, meer aandacht voor patiëntgerichte zorg, de druk op het zorgsysteem door de vergrijzende populatie, en hervormingen van het Nederlandse zorgsysteem van aanbod gestuurd naar vraag gestuurd. De focus op individuele verantwoordelijkheid met betrekking tot gezondheid en zorg, gaat gepaard met een sterk beroep op de gezondheidsvaardigheden van mensen. Gezondheidsvaardigheden kunnen gedefinieerd worden als de vaardigheden die nodig zijn om informatie omtrent gezondheid en ziekte te kunnen verkrijgen, begrijpen, beoordelen en toe te passen. Bijvoorbeeld een uitnodiging om deel te nemen aan darmkankerscreening, uitleg van de huisarts over de zorg voor een chronische aandoening of berichten in de media over gezonde voeding.

In de huidige samenleving hebben mensen met hogere gezondheidsvaardigheden mogelijk een voordeel ten aanzien van mensen met lagere gezondheidsvaardigheden, wanneer het op hun gezondheid aankomt. Dit wordt bevestigd door studies die aantonen dat lagere gezondheidsvaardigheden gerelateerd zijn aan indicatoren van een slechtere gezondheid, zoals meer moeite met het opvolgen van instructies van zorgverleners, meer ziekenhuisopnamen, en minder gebruik van preventieve zorg. Gezondheidsvaardigheden is echter een relatief nieuw concept en de meeste studies over de determinanten van gezondheidsvaardigheden, verwante psychologische processen en gezondheidsgerelateerde consequenties zijn uitgevoerd in de VS. Het doel van onderhavig onderzoek was inzicht te krijgen in de gezondheidsvaardigheden van Nederlandse volwassen in relatie tot sociaaleconomische en demografische kenmerken, psychologische factoren, gezondheidsgerelateerd gedrag en gezondheid. Gezondheidsgerelateerd gedrag verwijst in dit onderzoek naar toegang tot en gebruik van gezondheidszorg, het managen van gezondheid en ziekte, en interactie tussen patiënt en zorgverlener. Vooral met betrekking tot chronische zorg en preventie (d.w.z., screening en vaccinatie) wordt in toenemende mate een beroep gedaan op de verantwoordelijkheid en autonomie van individuen. Daarom is het met name interessant om de rol van gezondheidsvaardigheden binnen deze domeinen te onderzoeken.

Gezondheidsvaardigheden in de Nederlandse volwassen bevolking

Het doel van het eerste deel van dit proefschrift, was te onderzoeken in hoeverre

gezondheidsvaardigheden onder Nederlandse volwassenen gerelateerd zijn aan sociaaleconomische en demografische kenmerken en aan ervaren gezondheid. Dit werd in de eerste plaats onderzocht op basis van data afkomstig van de in 2012 uitgevoerde European Health Literacy Survey (HLS-EU) (Hoofdstuk 2). Het instrument dat ten behoeve van deze survey is ontwikkeld voor het meten van gezondheidsvaardigheden, meet ervaren moeite met het kunnen verkrijgen, begrijpen, beoordelen en toepassen van gezondheidsgerelateerde informatie. Deze informatie heeft betrekking op één van de volgende drie domeinen, te weten gezondheidszorg, preventie van ziekte en gezondheidsbevordering. Op een schaal lopend van 1 (laagste score) tot 4, scoorden respondenten gemiddelde 3.1 voor het beoordelen van informatie tot 3.4 voor het begrijpen van informatie, over alle domeinen heen. Echter, gezondheidsvaardigheden verschilden tot op zekere hoogte per domein: het verkrijgen van informatie werd als moeilijker ervaren binnen het domein van gezondheidszorg (gemiddeld 2.6) dan binnen het domein van ziektepreventie (gemiddeld 3.4). Individuen met een lager opleidingsniveau en een lagere ervaren sociale status ervoeren meer moeite met alle vier de vaardigheden dan individuen met een hoger opleidingsniveau en een hogere ervaren sociale status. Daarnaast ervoeren mannen meer moeite dan vrouwen. Ook was leeftijd negatief geassocieerd met het verkrijgen en het begrijpen van informatie, maar niet met het beoordelen en toepassen van informatie. De resultaten van deze studie impliceren dat ervaren moeite met gezondheidsgerelateerde informatie kan verschillen naar type gezondheidsvaardigheid en naar domein. Daarnaast kunnen associaties tussen gezondheidsvaardigheden en sociaalconomische en demografische kenmerken in sterkte verschillen naar type vaardigheid en naar domein.

In een tweede studie werd onderzocht in hoeverre gezondheidsvaardigheden een mediërende rol vervullen in de associatie tussen opleidingsniveau aan de ene kant en ervaren algemene, fysieke en mentale gezondheid aan de andere kant (Hoofdstuk 3). Hiervoor werden data afkomstig van de in 2008 uitgevoerde Adult Literacy and Life Skills Survey (ALL) gebruikt, inclusief de Health Activities and Literacy Scale (HALS). Op basis van de HALS werden gezondheidsvaardigheden geoperationaliseerd als de score op een set vragen om leesvaardigheid en probleemoplossend vermogen te meten in the context van gezondheid en zorg. Op basis hiervan bleken lagere gezondheidsvaardigheden geassocieerd te zijn met opleidingsniveau: hoger opgeleiden hadden hogere gezondheidsvaardigheden. Daarnaast liet de studie zien dat mensen met lagere gezondheidsvaardigheden, een slechtere ervaren algemene, fysieke en mentale gezondheid hadden in vergelijking tot mensen met hogere gezondheidsvaardigheden. Ook gaven

mensen met een lager opleidingsniveau aan een slechtere algemene, fysieke en mentale gezondheid te ervaren dan mensen met een hoger opleidingsniveau. Een mediatie analyse liet zien dat gezondheidsvaardigheden de associatie tussen opleidingsniveau en ervaren algemene, fysieke en mentale gezondheid medieert. Dit betekent dat een deel van de associatie tussen een lager opleidingsniveau en een slechtere ervaren gezondheid, verklaard kan worden door lagere gezondheidsvaardigheden. Op basis van beide studies werd geconcludeerd dat onder lager opgeleiden, onder mensen met een lagere ervaren sociale status, onder ouderen en onder mannen, lagere gezondheidsvaardigheden vaker voorkomen. Daarnaast dragen gezondheidsvaardigheden bij aan het verklaren van opleidingsniveau gerelateerde variatie in ervaren gezondheid.

Gezondheidsvaardigheden in de context van chronische zorg

Het doel van het tweede deel van dit proefschrift was inzicht krijgen in hoeverre gezondheidsvaardigheden geassocieerd zijn met (psychologische determinanten van) gebruik van huisartsenzorg, patiënt-zorgverlener interactie en zelfmanagement, in de context van chronische zorg. In de eerste plaats werd onderzocht in welke mate gezondheidsvaardigheden gerelateerd zijn aan indicatoren van diabetes zelfmanagement en of kennis over diabetes een link is tussen gezondheidsvaardigheden en diabetes zelfmanagement (Hoofdstuk 4). Dit onderzoek betrof secundaire data-analyse op basis van dwarsdoorsnede onderzoek. Dit onderzoek omvatte een steekproef van patiënten met overwegend diabetes type 2, welke werden geworven op basis van patiëntenregistraties en vragenlijsten, ingevuld in 2010. Ervaren gezondheidsvaardigheden werd in dit onderzoek gemeten op basis van de Set of Brief Screening Questions (SBSQ). De studie liet zien dat lagere gezondheidsvaardigheden geassocieerd waren met hogere HbA1c waarden, minder fysieke activiteit en een minder hoge kans op het zelf controleren van glucose waarden. Geen significante associaties werden gevonden tussen gezondheidsvaardigheden en het zelf registreren van glucose waarden en tussen gezondheidsvaardigheden en roken. Met betrekking tot de relatie tussen diabetes kennis en zelfmanagement, liet de studie zien dat patiënten met meer kennis vaker hun glucosewaarden zelf controleerden en minder vaak rookten dan patiënten met minder kennis. Diabetes kennis bleek niet geassocieerd te zijn met andere zelfmanagement indicatoren. Een mediatieanalyse liet zien dat diabetes kennis de associatie tussen gezondheidsvaardigheden en het zelf controleren van glucose waarden lijkt te mediëren, evenals de associatie tussen gezondheidsvaardigheden een roken. De resultaten van het onderzoek laten zien

dat de associatie tussen gezondheidsvaardigheden en zelfmanagement afhangt van de specifieke zelfmanagement taak. Ook suggereren de resultaten dat inspanningen om kennis te vergroten onder diabetes patiënten met lagere gezondheidsvaardigheden mogelijk niet in alle gevallen zullen leiden tot betere gezondheidsuitkomsten. Zowel kennis als gezondheidsvaardigheden lijken belangrijk voor zelfmanagement. Interventies gericht op het versterken van beiden zullen naar verwachting op meer aspecten van zelfmanagement effect sorteren dan interventies gericht op het bevorderen van enkel kennis of gezondheidsvaardigheden.

In een tweede studie werd onderzocht in hoeverre gezondheidsvaardigheden gerelateerd zijn aan ervaren eigen regie over zorg en met het aantal huisartsbezoeken op jaarbasis (Hoofdstuk 5). Deze studie was gebaseerd op een steekproef van chronisch zieken en gehandicapten. In dit onderzoek werd een onderscheid gemaakt tussen functionele, communicatieve/interactieve en kritische gezondheidsvaardigheden, op basis van de Functional, Communicative, Critical Health Literacy scale (FCCHL). Functionele gezondheidsvaardigheden verwijst naar basisvaardigheden in lezen en schrijven. Communicatieve gezondheidsvaardigheden verwijst naar complexere (sociale en cognitieve) vaardigheden om informatie te verkrijgen en toe te passen. Kritische gezondheidsvaardigheden verwijst naar nog complexere (sociale en cognitieve) vaardigheden om informatie kritisch te analyseren. Ervaren eigen regie over zorg werd geoperationaliseerd als ervaren vermogen om zorg te organiseren, te communiceren met zorgverleners en om zelf zorgtaken uit te voeren. De studie liet zien dat interactieve gezondheidsvaardigheden in verhouding tot de andere twee typen, het sterkst geassocieerd was met ervaren vermogen om eigen regie te voeren. Functionele gezondheidsvaardigheden was als enige type geassocieerd met het gebruik van huisartsenzorg; patiënten met lagere functionele gezondheidsvaardigheden bezochten hun huisarts vaker dan patiënten met hogere functionele gezondheidsvaardigheden. De resultaten impliceren dat de drie typen gezondheidsvaardigheden mogelijk relevant zijn voor verschillende aspecten van zelfmanagement. Op basis van beide studies kan geconcludeerd worden dat wanneer mensen met een chronische ziekte meer op zichzelf worden aangewezen wat betreft de zorg voor hun ziekte, mensen met lagere gezondheidsvaardigheden mogelijk meer ondersteuning nodig zullen hebben.

Gezondheidsvaardigheden in de context van preventie

Het doel van het derde deel van dit proefschrift was te onderzoeken in hoeverre gezondheidsvaardigheden geassocieerd zijn met psychologische determinanten

van deelname aan preventieprogramma's. Specifiek werd onderzocht in hoeverre gezondheidsvaardigheden gerelateerd zijn aan geïnformeerde besluitvorming met betrekking tot darmkankerscreening en kindervaccinatie. In de eerste plaats is een systematische overzichtsstudie gepresenteerd over de associatie tussen gezondheidsvaardigheden en geïnformeerde besluitvorming met betrekking tot darmkankerscreening (Hoofdstuk 6). Studies werden geïncludeerd wanneer (een aspect van) geïnformeerde besluitvorming onderzocht werd in relatie tot (een aspect van) gezondheidsvaardigheden in de context van darmkankerscreening. Acht studies voldeden aan de inclusiecriteria. In deze studies werden verschillende aspecten van geïnformeerde besluitvorming onderzocht in relatie tot gezondheidsvaardigheden. Zeven studies onderzochten kennis over darmkankerscreening, vier onderzochten attitudes over darmkankerscreening en één onderzocht de perceptie van risico informatie. De studies vonden of geen associatie tussen gezondheidsvaardigheden en aspecten van geïnformeerde besluitvorming, of een positieve associatie: hogere gezondheidsvaardigheden bleken in een aantal studies geassocieerd te zijn met hogere scores op een kennistest en een positievere attitude ten aanzien van darmkankerscreening. De resultaten wijzen uit dat de associatie tussen gezondheidsvaardigheden en geïnformeerde besluitvorming rond darmkankerscreening beperkt is. Door de heterogeniteit in operationalisaties van zowel gezondheidsvaardigheden als factoren die ten grondslag liggen aan geïnformeerde besluitvorming, is het moeilijk om conclusies te verbinden aan de bevindingen van de studies.

Naast darmkankerscreening is kindervaccinatie een vorm van preventie. In een tweede studie is onderzocht of ouders met hogere gezondheidsvaardigheden verschilden van ouders met lagere gezondheidsvaardigheden wat betreft hun voorkeuren voor kenmerken van het rotavirus vaccine (Hoofdstuk 7). De Set of Brief Screening Questions (SBSQ) werd gebruikt om gezondheidsvaardigheden te meten. De voorkeuren van ouders werden gemeten aan de hand van een discrete keuze experiment. In het discrete keuze experiment werden de voorkeuren van ouders bevraagd ten aanzien van de beschermingsduur van het vaccine, de effectiviteit van het vaccine, de kans op ernstige bijwerkingen, de locatie van vaccinatie en het betalen van een eigen bijdrage. De studie liet zien dat respondenten met lagere gezondheidsvaardigheden de effectiviteit van het vaccine en de kans op ernstige bijwerkingen minder belangrijk en beschermingsduur belangrijker vonden dan respondenten met hogere gezondheidsvaardigheden. Ook werd gevonden dat ouders met hogere gezondheidsvaardigheden minder bereid waren om hun kind tegen het rotavirus te laten vaccineren wanneer het vaccine aangeboden zou worden buiten het

Rijksvaccinatieprogramma. Dit gold niet voor ouders met lagere gezondheidsvaardigheden. Wat deze studie heeft laten zien is dat, gegeven dezelfde informatie, ouders met lagere gezondheidsvaardigheden andere kenmerken van een vaccine belangrijker lijken te vinden dan ouders met hogere gezondheidsvaardigheden. Of dit verschil te wijten is aan verschillen in begrip van informatie of aan verschillen in preferenties is niet duidelijk. Wel geven deze bevindingen aanleiding om aandacht te hebben voor gezondheidsvaardigheden wanneer onderzoek verricht wordt naar vaccinatie gedrag en wanneer voorlichtingsmaterialen ontwikkeld worden. Op basis van beide studies werd geconcludeerd dat meer onderzoek wenselijk is naar de relatie tussen gezondheidsvaardigheden en keuzegedrag, omdat het grotendeels onduidelijk blijft hoe beide concepten zich tot elkaar verhouden. Het is belangrijk om deze relatie nader te onderzoeken, omdat zowel gezondheidsvaardigheden als keuzegedrag belangrijke concepten zijn bij het verklaren van verschillen in het gebruik van preventieve zorg en voor de ontwikkeling van voorlichtingsmaterialen.

Discussie en conclusie

De studies zoals beschreven in dit proefschrift hebben laten zien dat verschillende aspecten van gezondheidsvaardigheden te onderscheiden zijn en dat mensen meer moeite kunnen hebben met bepaalde aspecten dan met andere. Hierbij speelt de context waarbinnen gezondheidsvaardigheden moeten worden toegepast ook een rol; iemand kan hogere gezondheidsvaardigheden hebben met betrekking tot gezondheidszorg en lagere wanneer het over preventie gaat. Wanneer onderzoekers verschillende aspecten van gezondheidsvaardigheden onderzoeken en aspecten op verschillende manieren meten (bijvoorbeeld subjectief versus objectief), leidt dit tot variatie in uitkomsten. Namelijk, op basis van de uitkomsten van de HLS-EU werd geschat dat ongeveer een derde van de Nederlandse populatie problematische tot inadequate gezondheidsvaardigheden zou hebben (gebaseerd op de schatting gedaan binnen het HLS-EU project). Echter op basis van de ALL bleek ongeveer de helft van de Nederlandse populatie naar verwachting lage tot zeer lage gezondheidsvaardigheden te hebben. Ongeacht de verschillen in operationalisaties, heeft dit proefschrift laten zien dat gezondheidsvaardigheden een unieke bijdrage leveren aan het verklaren van verschillen in zelfmanagement, interactie met zorgverleners, preferenties voor vaccinatiekenmerken, huisartsbezoek, en ervaren gezondheid. Dit in aanvulling op determinanten zoals opleidingsniveau, leeftijd en geslacht.

Voor onderzoekers zijn gezondheidsvaardigheden dan ook een waardevolle

toevoeging omdat dit concept kan helpen bij het verklaren van verschillen in gezondheidsgerelateerd gedrag en gezondheid. In tegenstelling tot factoren als sekse, opleidingsniveau en etniciteit, kunnen gezondheidsvaardigheden tot op zekere hoogte geleerd worden. Dit biedt nieuwe mogelijkheden voor de ontwikkeling van interventies om de rol van Nederlandse burgers ten aanzien van hun gezondheid en zorg te versterken of interventies om verschillen in gezondheid te reduceren. Daarnaast bieden gezondheidsvaardigheden een heel specifiek doel waar organisaties en zorgverleners op kunnen inspelen. Namelijk, in de praktijk komen gezondheidsvaardigheden voort uit een interactie tussen individuele vaardigheden en de eisen die gesteld worden door het zorgsysteem. Het is daarom van belang dat organisaties of zorgverleners informatie over gezondheid en zorg op een voor iedereen toegankelijk en begrijpelijke manier aanbieden. Tot slot heeft het onderzoek in dit proefschrift laten zien dat gezondheidsvaardigheden ook een meerwaarde hebben voor individuen om de regie te kunnen houden over hun gezondheid en zorg.

Dankwoord

Nu het proefschrift is afgerond wil ik graag een aantal mensen bedanken. Jantine, Jany en Ellen, mijn grootste dank gaat uit naar jullie als mijn promotor en co-promotoren. Jullie hebben mij de kans gegeven om dit proefschrift te schrijven en zijn tot op het einde toe zeer betrokken geweest. Ieder op jullie eigen manier hebben jullie mij geïnspireerd, gemotiveerd en vertrouwen gegeven. Zonder jullie kritische blik en nuttige adviezen was het proefschrift niet geworden wat het nu is. Bedankt voor de leerzame en leuke jaren. Naast mijn (co-)promotoren wil ik iedereen bedanken die een bijdrage heeft geleverd aan de totstandkoming van dit proefschrift of zich op een andere manier onmisbaar heeft gemaakt. Natuurlijk alle co-auteurs, mijn leuke collega's van het RIVM en het NIVEL, mijn paranimfen, mijn dierbare vrienden en familie en tot slot mijn lieve Merijn. Vanuit de grond van mijn hart: bedankt allemaal. Zonder jullie had ik geen reden gehad om dit moment te vieren.

Curriculum Vitae

About the author

Iris van der Heide was born on the 24th of September 1986 in Leusden, the Netherlands. She studied Communication- and Information Science at Utrecht University, obtaining her Bachelor's degree and a minor in Interdisciplinary Social Science in 2009. During her Master Communication Studies, she followed an internship at the department of Social Sciences at Utrecht University, where she performed a study on interpersonal and intercultural patient-provider communication. This was the topic of her Master thesis. In 2010, Iris obtained cum laude her Master's degree. After graduation, she started working as a junior researcher at the Dutch National Institute for Public Health and the Environment (RIVM) on a health literacy research project, in collaboration with the Netherlands Institute for Health Services Research (NIVEL). Iris became involved in health literacy and wrote her PhD thesis on this topic, under supervision of dr. Ellen Uiters (RIVM), dr. Jany Rademakers (NIVEL) and prof.dr.ir. Jantine Schuit (RIVM). In the following years, she made contributions to various national and international projects at RIVM and NIVEL and wrote papers on diverse public health related topics. Currently, Iris is working at NIVEL on a European project concerning integrated care programs for people with multi-morbidity.

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2013	Health and Society Online course by Harvard University, edx.org
2013	Applied Statistics Netherlands Institute for Health Services Research (NIVEL), Utrecht (Netherlands)
2013	Presenting in English James Boswell Institute, Utrecht University, Utrecht (Netherlands)
2012	Academic English Writing James Boswell Institute, Utrecht University, Utrecht (Netherlands)
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