

One size does not fit all

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SUMMARY OF THE MAIN FINDINGS

Chapter 1 constitutes an extensive introduction to the relationship between health literacy, health inequities and health potential, definitions and conceptual models of health literacy, health literacy measurement, the known impact of health literacy on outcomes (in general and within the field of RMDs), ways to address health literacy needs, and an organisational perspective on health literacy. These concepts are considered integral background information to the work presented in the subsequent chapters. They show how health literacy is ultimately an issue of health equity, and how addressing health literacy needs is necessary, and may help reduce the socio-economic health gap by maximising health potential. In the introduction, I also articulated the three main aims that guided this work. First, to identify health literacy needs of patients with RMDs. Second, to co-design solutions to better align rheumatology care with the health literacy needs of patients. Third, to explore current awareness of health literacy needs in rheumatology care from an organisational perspective. The subsequent chapters included in this thesis all correspond to one of the three research aims, and together contribute to advancing research and practice of health literacy within the field of rheumatology. The thesis is structured in three parts, each one primarily corresponding to one of the thesis aims.

Part I: Identifying health literacy needs

The first part of this thesis concerns the identification of health literacy needs of patients with RMDs. In **Chapter 2**, we studied patterns of health literacy strengths and weaknesses in a population of patients with RMDs. In this quantitative observational cross-sectional study, patients with rheumatoid arthritis (RA), spondyloarthritis (SpA), or gout filled out the Health Literacy Questionnaire (HLQ). Between the three participating geographically and socio-demographically diverse rheumatology clinics (South: Maastricht University Medical Center in Maastricht, West: Maasstad Hospital in Rotterdam, and East: Medisch Spectrum Twente in Enschede), 895 patients participated. HLQ scores in each of the nine domains were largely independent of hospital or type of rheumatic disease, although patients in one of the centres tended to score slightly better for domains 4 (social support), 6 (engaging with providers), 7 (navigating the health care system), and 9 (understanding health information), and patients with gout tended to score worse for domains 1 (feeling supported by providers), 3 (actively managing health), 8 (finding health information), and 9 (understanding health information).

Next, we used hierarchical clustering analysis to identify 'health literacy profiles' based on strengths and weaknesses, as reflected by higher and lower scores across the nine domains of the HLQ. We described 10 distinct 'health literacy profiles'. Two of those profiles represented 42% of patients who experienced little to no difficulty on all nine HLQ domains (profiles 1 and 3, high to very high scores on all domains). Another 42% of patients clearly struggled with 1 or several aspects of health literacy (profiles 2, 4, 5 and 6). The remaining profiles, representing

16% of our sample exhibited difficulties across a majority of health literacy domains (profiles 7-10). We described the strengths and weaknesses of the different 'health literacy profiles', by combining HLQ scores with sociodemographic data of the participants. Of note, patients with 'health literacy profiles' representing more health literacy difficulties self-reported worse health status than patients with higher health literacy scores. This showed the relevance of health literacy profiles in relation to health outcomes. Moreover, people with lower education and people with a migrant background are overrepresented in the more complex profiles, which relates to the social gradient that exists in the relationship between health literacy and health outcomes.

Using a multinomial regression model with health literacy profiles as the dependent variable, we assessed whether the 'health literacy profiles' were dependent on the clinic the patient attended, or the disease the patient had been diagnosed with. While some profiles occurred more often in one of the hospitals or one of the disease groups, we found that these differences were not statistically significant. Thus, the general lessons are potentially generalisable to a broader Dutch rheumatology context.

Chapter 3 constitutes a follow-up study of patients with RA who participated in the study described in Chapter 2 in one centre (East: Medisch Spectrum Twente). In a retrospective quantitative observational longitudinal design, we explored the association between the previously identified 'health literacy profiles' and disease activity and medication prescription, by extracting these data from the electronic patient files. Of the 122 patients with RA at this centre included in the original study, data on disease activity and medication prescription (biological disease-modifying anti-rheumatic drugs (bDMARDs), conventional DMARDs (csDMARDs) and prednisolone) was available for 108 of them. To enable between-groups comparisons, we further aggregated the 'health literacy profiles' into three groups, based on similarities between profile characteristics. In a slight diversion from the description in Chapter 2, the three groups were separated and labelled as follows: 1) 'several health literacy limitations' (profiles 6-10); 2) 'some health literacy limitations' (profiles 2, 4 and 5); and 3) 'good health literacy' (profiles 1 and 3).

We used linear mixed modelling with routinely collected 28-joint disease activity scores-erythrocyte sedimentation rate (DAS28-ESR) scores as the dependent variable to assess the relationship between health literacy group and disease activity over the course of 1 year, and Chi-square tests and logistic regression models to assess the relationship between health literacy group and medication prescription. We found that patients in the 'good health literacy' group had significantly ($p=0.01$) lower disease activity over time (mean DAS28-ESR: 2.4) than patients in the 'several health literacy limitations' group (mean DAS28-ESR: 3.1). This association was independent of education level. In addition, we found that fifty percent of the 'good health literacy' group was prescribed a bDMARD, compared to 18.2% and 38.1% in the 'some health literacy limitations' (adjusted OR 0.22 [0.08-0.65] and 'several health literacy limitations' (adjusted OR 0.81 [0.27-3.27], not significant) groups, respectively. Patients with

'some health literacy limitations' were more often prescribed a csDMARD only (OR 4.24 [1.57-11.51]) than patients with 'good health literacy', and patients in the 'several health literacy limitations' group were prescribed prednisolone significantly more often (52.4%, OR 3.56 [1.13-11.15] compared with 'good health literacy') than patients in the 'some health literacy limitations' (21.2%) and 'good health literacy' groups (22.2%). This difference suggests that the disease is insufficiently under control in these patients, which led to prednisolone initially being prescribed as a practical (short-term) solution, but continued as a long-term maintenance dose.

The study described in this chapter further confirmed the relevance of health literacy in clinical care. The results suggested that health literacy is an independent determinant of disease outcomes, meaning that education level is not an adequate proxy to understand health literacy needs. This study showed that the health literacy needs of patients are related to their disease activity, as well as the type of medication prescribed and used, independent of the education level of the patient. While we are not claiming to have established a causal link between health literacy and these health indicators, we do believe this study suggests that better recognition of and attention for patients' health literacy needs by health professionals is imperative to optimise disease management and patient understanding.

Part II: Opportunities for improvement

While quantitative data can help us define the magnitude of an issue, in the case of health literacy, we need qualitative data to understand the dynamics of the issue in the local context, to ensure the fit of interventions and solutions when moving from clinical studies to clinical care. Therefore, whereas Chapters 2 and 3 related to identifying health literacy needs from a quantitative perspective, Part II of this thesis provides further qualitative depth to these needs, while also discussing ways to address these needs. In **Chapter 4**, we describe further steps taken in the process towards health literacy responsive care, making recommendations for further research on and potential implementation of health literacy responsiveness in rheumatology care. Building upon the health literacy profiles described in Chapter 2, and using previously written field notes and additionally conducted semi-structured interviews, we developed six 'health literacy vignettes'; anonymised but recognisable patient stories reflecting their health literacy-related challenges. These vignettes were used as input for co-design consultations (focus groups and individual interviews) with patients (n=14) and health professionals (n=38). These consultations revolved around four questions: 1) Do you recognise this patient? 2) What are the challenges for this patient, or what challenges do you face in caring for this patient? 3) How could we better support this patient? 4) What should our clinic look like if there were 100 patients like this patient? Qualitative analysis was used to structure the outputs of the consultations, to describe challenges and potential solutions to these challenges in the shape of 'health literacy actions' (i.e. small changes on any level

in the process of healthcare delivery, or integration of existing tools or strategies into daily practices of healthcare organisations and professionals)

We identified eleven health literacy-related challenges that patients with RMDs face. Health professionals and patients suggested a wide range of possible solutions to these challenges, as well as solutions that could be considered generic or universal. Solutions were grouped into three categories, with seven subcategories: 1) responsive professional-patient interaction, subdivided into a) clarifying the patient's responsibilities, and b) applying communication strategies; 2) training programmes for health professionals or patients; and 3) organisational actions, subdivided in a) changes in how care delivery is organised, b) involvement of another health professional or organisation, and c) development and/or provision of materials to support clinical care. We provided a matrix that linked each of the individual health literacy challenges to the health literacy actions that could address the challenge. Further work is necessary to prioritise and further develop the proposed health literacy actions, and evaluate and integrate them into daily practice. Introduction of these health literacy actions, suggested by patients and health professionals, could enhance the health literacy responsiveness of our rheumatology clinics and potentially improve health outcomes.

In **Chapter 5**, we show that the work being done in rheumatology care is not a stand-alone project. Rather, it is embedded in an international network of researchers and practitioners supported by the World Health Organization (WHO), through the establishment of National Health Literacy Demonstration Projects (NHLDPs). In this report, we presented a common mission to reduce the burden of NCDs, described the methodological approach used to help achieve this, described the aims and context of each of the seven NHLDPs being conducted in the WHO European Region as of April 2019, and discussed how this work can help advance health and equity. We showed that an exchange of knowledge and practices can support work in the local context, while the outcomes of these projects together will help with the generalisability of health literacy practices, much more than an individual project could.

Part III: Organisational perspectives

The long-term aim of the work presented in this thesis is to contribute to health literacy responsive care in rheumatology clinics. This will require that organisations and professionals recognise patients' needs and deliver care and services in a way that matches those needs. Therefore, the final aim of this thesis was to investigate whether there is currently adequate awareness of health literacy among professionals and organisations to meet these expectations. Therefore, in **Chapter 6**, we explored discordance between the HLQ scores of patients with RMDs, and the intuitive assessment by their treating healthcare professional. For all patients who participated in the study described in Chapter 2, their treating health professional was asked to fill out a short questionnaire. They were asked to assess their patient's health literacy level on each of the nine domains of the HLQ on a 0-10 scale. In

addition, professionals reported how well they knew that patient, and scored their view on the impact of the disease on the functioning and health of that patient. To enable comparisons with the patients' HLQ scores, the patients' domain scores were also converted to a 0-10 scale. We collected data from 778 patient-professional pairs.

For analysis, we defined discordance per domain as a ≥ 2 -point difference in either direction on the 0-10 scale, which led to three categories: 1) 'negative discordance' (i.e. professional scored lower than the patient); 2) both scores are 'probably the same'; and 3) 'positive discordance' (i.e. professional scored higher the patient). If both the patient and the professional scored below three or above seven, despite a ≥ 2 -point difference, this was an indication that they agreed the score was either 'very high' or 'very low'. Therefore, these cases were classified as 'probably the same'. Because there is no gold standard for objective health literacy measurement, we do not know if discordance means that professionals over- or underestimate their patients, patients over- or underestimate themselves, or if the truth is somewhere in the middle. Nevertheless, significant discordance in the data still means that patients and health professionals are not on the same page about the patient's health literacy.

Depending on the HLQ domain, we found discordance in 20.7 to 40.5% of all cases. Moreover, health professionals indicated they did not know the patient's level of social support for health (HLQ domain 4) in one out of five (19.4%) cases, indicating this may not receive sufficient attention in clinical interactions. In addition, we used multilevel multinomial regression models to test the role of socioeconomic factors in negative and positive discordance in each of the nine HLQ domains. We found that particularly negative discordance was associated with socioeconomic factors, specifically lower education level and non-Western migration background (in five HLQ domains). We concluded that accurate estimation of patients' health literacy by professionals in rheumatology is not a given. Our results indicate that there may be hidden challenges in communication and care, and suggest these risks are not equal across socioeconomic groups and HLQ domains. This highlights both the multidimensional nature of health literacy, and that challenges in addressing health literacy needs may also be unequal between socioeconomic groups. Above all, these results teach us that addressing health literacy needs will require measurement and dialogue.

Lastly, in **Chapter 7**, we explored the consideration of health literacy in crisis communication. While work on this thesis was ongoing, the Coronavirus Disease 2019 (COVID-19) pandemic provided a unique opportunity to learn about the way rheumatology organisations already consider patients' health literacy needs in practice. We conducted a convergent, qualitatively driven mixed-methods study to explore key aspects of crisis communication and the explicit consideration of people's health literacy needs in communication with people with RMDs during the first wave of COVID-19 in the Netherlands. The study combined findings from seven qualitative interviews with (professional) representatives of organisations responsible for information provision to people with RMDs, and quantitative analysis of 15 patient information materials distributed by these organisations.

While analysing the qualitative data using common coding techniques, a thematic structure emerged. This led us to create a framework comprising four pillars of crisis communication; 1) preparedness; 2) strategy; 3) reach, and 4) content of communication. Health literacy was described and evaluated as a separate recurring theme. The quantitative analyses of patient information materials constituted an assessment of language difficulty using the 'Klinkende Taal' (English language version: SonalIng) online application, and an assessment of actionability and understandability using the 'Voorlichtingsmateriaal BeoordelingsInstrument' (VBI), the Dutch version of the Patient Education Materials Assessment Tool (PEMAT). 'Klinkende Taal' assesses the use of difficult words, jargon, passive, complex and long sentences, and long paragraphs, and assigns each text with a difficulty level inspired by the Common European Framework of Reference for Languages (CEFR), which ranges from A1 (basic) to C2 (proficient). It is widely believed that patient information materials should not exceed a B1-level in order for the majority of the population to understand what is meant. The 'VBI' is a checklist which results in a percentage of quality criteria adhered to, separately for actionability and understandability.

Despite extensive efforts by organisations as soon as the threat of the pandemic emerged, participants in our study reported a lack of preparedness for crisis communication, challenges related to scientific uncertainty and reaching the target group. Organisations also had difficulty simplifying information, and were uncertain whether their communication approach was adequate. Patient information materials varied greatly in actionability (quality score range 60–100%) and understandability (quality score range 58–100%), and we found that 69% of written materials were too difficult, mostly due to the use of long sentences and difficult words. The quantitative findings were in coherence with the qualitative findings, and we formulated several 'lessons learned' as opportunities for improvement. We argue that despite the best efforts of rheumatology organisations and healthcare providers, patients' health literacy needs were insufficiently considered and patient information materials were too difficult.

These final two empirical chapters show that a 'business as usual, with a little bit of health literacy in mind'-approach is insufficient to address people's health literacy needs. To make an impact through health literacy in rheumatology, we are going to need a conscious, integrated approach, which involves health professionals as well as rheumatology organisations. The work presented in this thesis can serve as a valuable starting point for these future efforts.