

One size does not fit all

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SCIENTIFIC AND SOCIAL IMPACT

What is the problem?

Health is not only determined by biological factors, but also by social determinants. Social determinants of health refer to the conditions in which people are born, grow, work, live, and age. Social determinants can lead to unfair and avoidable inequalities in health. The central topic of this dissertation is 'health literacy', which is increasingly seen as a concept that we can do something about, in order to reduce health inequalities. We studied health literacy among patients with rheumatic and musculoskeletal diseases (RMDs). RMDs are complex chronic diseases that require intensive interaction with healthcare services, as well as efforts from patients to self-manage their health in daily life.

In a narrow sense, health literacy refers to people's capacity to access, understand and apply health information. In a broader sense, health literacy refers to the personal capacity and resources people require to be able to manage their own health, beyond reading and using health information. It includes several dimensions, such as being able to communicate with health professionals, having the social support you need, and being able to navigate the health system. Health literacy is seen as an asset, relevant in clinical situations, but also helping people live healthy lives. If you have 'limited' health literacy, you might have more trouble following health advice, knowing what to do when experiencing health issues, understanding your doctor, or taking medication in the 'right' way. All these things (and more) could lead to health problems that could otherwise have been prevented. As people do not choose to have 'limited' health literacy, supporting patients with health literacy needs is simply 'the right thing to do'.

There are two main approaches to improving health through health literacy. The first is *improving people's* health literacy. This can be done through education programmes, often starting early in life, teaching people how to manage their own health. The second approach is to change the way (public) health services are *delivered by professionals and organisations*, so that having 'limited' health literacy does not create barriers to benefitting from these services. This is called 'health literacy responsiveness': the healthcare environment 'responds' to the health literacy needs of patients through 'health literacy actions'. Examples of actions include providing simpler information to people who have difficulty reading (using shorter sentences or pictures), supporting people in making appointments, and taking additional time to check if patients understand their treatment plan. While several examples of these 'health literacy actions' exist, we did not yet know how best to support our own patients with RMDs.

To find out what to do in our clinics, we followed the OPTimising HEalth Literacy and Access (Ophelia) approach, which was previously developed in Australia. Ophelia constitutes a guideline for health literacy development in the local context. It partly relies on quantitative data (numbers) from the Health Literacy Questionnaire (HLQ). A person fills out the questionnaire, which results in scores on nine distinct health literacy domains. Sometimes, a strength in one domain might compensate for weaknesses in others. For example, if you

have trouble understanding health information yourself, but have the support of a close friend or a trusted healthcare professional. Combinations of strengths and weaknesses differ between people, but previous research showed there may be common patterns in patients with similar conditions. Therefore, we need to think about how that affects the way we should deliver care. What are the needs of our patient population? What can we do to address them? To find answers to these questions, Ophelia relies on qualitative data (expression of views, experiences, needs and solutions) from patients and health professionals. This dissertation focused on the health literacy needs of our patients, and importantly, what 'health literacy actions' we could take in rheumatology care, so we can move away from the 'one size fits all' delivery of health information and services. Through this work, we contribute to fairer access to and outcomes of care for patients with RMDs.

What did we learn?

We focused on three main questions. First, we studied the health literacy needs of our patients. We identified 'common' patterns of strengths and weaknesses among patients with RMDs. They resulted in ten different 'health literacy profiles' of patients in our participating clinics, each representing different needs. We found that patients with more health literacy needs were more likely to have high disease activity over time. We also found differences in the medication they were prescribed. This emphasised the importance of addressing health literacy needs.

Second, we wanted to find out more about the specific health literacy challenges that patients experience, and what health professionals and organisations could do to address those challenges. We talked to patients and their health professionals, and learned that patients can face multiple challenges, such as difficulties remembering information or being able to balance their working life with their health condition. Luckily, patients and health professionals have many ideas and strategies to help solve these challenges! We described these as proposed 'health literacy actions'. These actions are required at different levels, from individual patient-provider interactions, to organisational change, to governmental social policies. Besides working locally, we collaborate with researchers in other European countries through the World Health Organization National Health Literacy Demonstration Projects (WHO NHDLPs). Through this collaboration, we can find out what strategies work in multiple places, and what strategies are unique to the local context.

Third, we wanted to explore whether healthcare professionals and organisations are well equipped to consider health literacy in their work. In order for healthcare professionals to improve care based on patients' health literacy, we need to know whether a doctor or nurse can identify patients' health literacy needs at the point of care. We found that 'educated guesses' are possible, but in 1 out of 4 patients, large differences between the health literacy scores of the patient and the professionals' estimations occurred. As the research in this dissertation took place during the COVID-19 pandemic, we were also able to study to what

extent rheumatology professionals and organisations adapted their crisis communication strategy during the first wave of the COVID-19 pandemic to the health literacy needs of their target audience. We learned that despite good intentions, health literacy was insufficiently considered. These findings show that we need to make explicit efforts to address health literacy needs in rheumatology care. This also means we will have to give health professionals the time and resources they need to do so.

Why is this relevant?

Our findings help to better understand the health literacy challenges of people with RMDs, their impact on health care and outcomes, and the potential approaches or 'health literacy actions' that could support healthcare professionals in providing better care to patients with different needs. We hypothesise that these actions can improve patients' health outcomes, improve patients' and professionals' experience and contain costs. More research is needed to further develop, integrate and evaluate the 'health literacy actions' in our clinics to ensure 'health literacy responsive care'. With this work, we hope to make access to and outcomes of rheumatology care more equal between (groups) of patients.

Who (potentially) benefits and how?

Both patients and health professionals benefit from the increased awareness and understanding of health literacy needs, through better health outcomes and improved experience. This dissertation should serve as a starting point in achieving 'health literacy responsive care'. In a future project, several of the identified 'health literacy actions' will be tried out and further developed in the rheumatology clinic at Maastricht UMC+. If this project shows the benefits of 'health literacy responsive care', we could scale up to other rheumatology clinics (nationally and internationally), and potentially to other clinical settings.

Lessons for (clinical) researchers include the need to use multidimensional tools to measure health literacy, and to include health literacy thinking in care (implementation) projects. Any programme or initiative aiming to improve the provision of health services should engage people with diverse health literacy needs. Otherwise, it is unlikely that the initiative will reach and benefit those patients who need it most.

Other stakeholders who benefit from this research include hospital management and health professionals outside our clinic. This project shows a way to act upon societal challenges (health inequalities and 'limited' health literacy) at a local level. We need actions on different levels, going much further than simplifying written information materials alone. Health literacy actions can support patients in managing their own health and navigating the health system, thereby improving adherence and making the best use of clinical appointments, for example. Lastly, through our work with the WHO NHLDP network, our lessons learned should serve as an example for health literacy action on both a local, national, and international level.

How were these stakeholders involved and informed?

The main stakeholders in this project, patients and health professionals (rheumatologists (in training), nurses, physician assistants & nurse practitioners), were involved in the study design and collection and interpretation of the data. We also asked a patient panel of 4 patients for feedback when setting up the study protocol and during data collection. Almost 900 patients and 39 health professionals completed our questionnaires. We also held 13 interviews with patients to capture patients' experiences, and then held focus groups and interviews with patients and professionals to discuss the health literacy data and patients' experiences. This engaged 38 professionals and 14 patients in thinking about health literacy challenges and solutions. In addition, three rheumatology organisations shared their experience with health literacy and crisis communication during the COVID-19 pandemic.

Several additional activities were performed to inform stakeholder groups and increase our impact. I shared our findings at two patient partner meetings organised by ReumaZorg Nederland (a national patient organisation), and as a keynote speaker at the EULAR PARE (Patient chapter of the European League Against Rheumatism) Conference 2022, where health literacy was a key theme. Patient representatives and professionals working for patient organisations from across Europe engaged with our findings and brainstormed how they could apply these lessons in their local context, thereby supporting patients across the continent. In addition, I delivered educational sessions for the Dutch Society for Rheumatology (NVR), Dutch Health Professionals in Rheumatology (NHPR), Nurses & Carers Netherlands (V&VN), medical students at Utrecht UMC, and Internal Medicine trainees at Maastricht UMC+, each attended by dozens of (future) health professionals. Furthermore, researchers and health professionals were informed through scientific publications and national and international conferences in health literacy and rheumatology. We successfully created a video abstract to increase the reach and impact of our paper. On two occasions, a medical journalist dedicated an article to our findings, once at DOQ.nl, and once in the EULAR Congress Report of 2020.

Where are we heading?

The findings of and thinking behind the research in this thesis have sparked conversations and increased awareness of the role of health literacy in rheumatology among patients, health professionals and researchers. We expect to see further impact of this work in the future. For example, in 2023, health literacy will be a key topic of a clinical science session at EULAR Congress (the leading conference for rheumatology in Europe) for the first time, and V&VN will organise further education on health literacy for nurses and nurse practitioners. Furthermore, we hope to receive funding to further develop and implement 'health literacy actions' in practice.

Developments are not limited to the field of rheumatology. Through our work with the NHLDPs and the Ophelia approach, our project is included in the important 2022 WHO report "Health literacy development for the prevention and control of non-communicable diseases".

The idea that patients' health literacy is key to health outcomes and healthy populations is also slowly gaining the attention of the Dutch Ministry of Health and research funders. Personally, I am affiliated with the Dutch Health Literacy Alliance, and an elected member of the Practice Standards Committee of the International Health Literacy Association. The lessons learned in this thesis could therefore impact healthcare access and outcomes in many different settings through improved 'health literacy responsiveness'. While there is a lot left unwritten, I hope that the work in this dissertation may indeed support this process.