

Quality of rheumatic care

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Impact paragraph

The overarching aim of this thesis was to improve the quality of rheumatology healthcare by responding to challenges related to monitoring of disease outcomes and providing patient-centered care. When we initiated this thesis, some improvements and innovations were necessary to optimize these aspects in clinical practice. In this thesis, we addressed aspects related to monitoring of outcomes by using patient reported outcome- and experience measures (PROMs and PREMs, respectively). In addition, we responded to patient-initiated needs for improving the clinical management of fatigue and for supporting the decision making process for patients facing high-impact treatment decisions. Throughout this thesis, we paid explicit attention to the usability and feasibility of introducing new innovations and management recommendations in rheumatology care. In this chapter, we reflect on the scientific, clinical and societal relevance of this thesis. In addition, we describe how patients were involved in our research and in the dissemination of results.

Challenges related to monitoring of disease outcomes

To facilitate monitoring of disease outcomes in clinical practice, we developed and implemented a web-based tool for systematic monitoring of patients with spondyloarthritis (SpA) in clinical practice in the Netherlands, called SpA-Net (**chapter 2**). We consulted rheumatologists (including experts in the field of SpA), nurses and experienced research partners for the content and design of this tool in efforts to maximize the impact and usability of this tool. After the initial development phase, we consulted patients with SpA for multiple rounds of internal and external testing, for evaluating its usability and acceptability in practice and for identifying barriers against its use. Finally, we used a multifaceted strategy to successfully implement SpA-Net as an electronic monitoring record as part of the standard workflow in five rheumatology centres in the Netherlands.

This patient registry can follow the patient journey in daily practice and facilitates monitoring of various disease aspects, including comorbidities, prescribed medication, adverse events and patient- and physician-reported outcome measures for disease activity, physical functioning and overall health status. Such up-to-date complete overview of all relevant health and disease aspects support healthcare providers (HCPs) and patients with clinical decision making, which in turn can result in better outcomes of care. In addition, monitoring of disease outcomes using PROMs can support patients in understanding their disease and can stimulate engagement in their own care. In response, this may improve communication with their HCPs, which in turn enhances making shared treatment decisions and improves treatment adherence.

Besides, longitudinal observational data on relevant health outcomes in daily practice can be useful for research purposes, as these data come from a large heterogeneous real world patient population without focusing on specific interventions, which has better external validity compared to data collected in randomized control trials (RCTs). In addition, SpA-Net also enabled us to run a pragmatic multicentre RCT evaluating whether telemonitoring combined with patient-initiated follow-up can reduce the number of outpatient consultations compared

to routine care in patients with SpA. Such self-monitoring strategy with the use of SpA-Net can potentially lower the number of follow-up outpatient visits, which can optimize use of time and resources in clinical practice.

Furthermore, this patient registry has societal impact as the effectiveness and safety of (expensive) drugs are securely monitored for the total SpA population, including elderly and those with comorbidities. Moreover, this patient registry is linked to the Dutch pharmacovigilance centre (Lareb) for reporting (serious) adverse events on medication. Finally, the recorded outcomes can be used to provide accountability towards external stakeholders who have the right to be informed on the quality of provided healthcare, such as patients, policy makers and society.

Evaluation of monitoring axial SpA in clinical care

At the start of this thesis, no data existed on the question to what extent the recommended management strategy ‘treat-to-target’ (T2T) was applied in clinical practice in patients with axial SpA. This T2T strategy includes both regular monitoring of disease activity with validated outcome measures and adequate treatment of patients towards pre-identified targets to prevent long term structural damage. Moreover, there was no insight to what extent T2T approach is applied in clinical practice, where patient populations are more heterogeneous, variation in behaviours of HCPs exists and stronger restrictions are present in terms of time, costs and resources compared to RCTs. We therefore evaluated the extent to which T2T was implemented in axial SpA using SpA-Net during a 1-year study period. Our study showed that available information on disease activity scores did not result in re-evaluation of disease activity within the recommended period of 3 months, nor into changes and/or escalation in therapy when the predefined target of inactive disease or low disease activity was not achieved (**chapter 3**). These findings imply that HCPs and patients experience some scientific, clinical or practical barriers for implementing T2T in practice. Future studies should therefore explore all barriers and facilitators of T2T in an effort to optimize outcomes of care. This newly obtained knowledge can form a starting point to draft a multifaceted implementation strategy for successfully implementing T2T in clinical practice, or, if necessary, adapting the T2T recommendations.

Outcome measures for disease activity in peripheral SpA

As ‘peripheral SpA’ is a relative new disease concept, no specific disease activity measurements instruments exist for this disease. Notwithstanding, some available disease activity instruments in other types of SpA have sufficient face validity to perform well in peripheral SpA. Therefore, we assessed the comparative performance of the Disease Activity Index for Psoriatic Arthritis (DAPSA), the Psoriatic Arthritis Disease Activity Score (PASDAS) and the Ankylosing Spondylitis Disease activity Score (ASDAS) (**chapter 4**). We showed that these three composite scores had acceptable measurement properties in peripheral SpA, but more research is needed to select one of these composite scores, or any other score, for this purpose. In a response to our study, an editorial by experts on assessing psoriatic arthritis confirmed the clinical and scientific relevance of our study and emphasized the complexity of assessing disease activity in peripheral SpA.

Challenges related to providing patient-centered care

An important element of providing patient-centered care is that patients should not only be actively engaged in their clinical care, but also in scientific research. We therefore responded to the knowledge gap ‘fatigue and its treatment’, which has been prioritized by a discussion panel of patients with rheumatic and musculoskeletal diseases (RMDs) as the most important topic that should be addressed to improve the management of their rheumatic disease in daily life. As a first step to act towards this prioritized impactful topic, we performed an elaborated reviews of reviews on aspects of fatigue that are relevant for clinical practice for patients with rheumatoid arthritis (RA), SpA, osteoarthritis and fibromyalgia (**chapter 5**). Interpretation and usability of findings of this review were discussed with a patient discussion panel. The extensive amount of evidence summarised in our scoping review is highly relevant for both clinical and research settings.

We identified several important knowledge gaps and research areas that need further investigation. Our findings emphasize the need for an agreed research agenda for unravelling and ultimately improving fatigue in RMDs. This research agenda should be drafted in cooperation with patients to align research with their preferences and needs. Such research requires merging areas to efficiently develop more insights into and solutions for this complex symptom. All newly obtained knowledge should be incorporated in guidelines for research and practice as this can ultimately reduce the personal and societal burden of excessive fatigue in these patients.

From a clinical perspective, the retrieved information on (types of) fatigue can reduce patients’ struggles to communicate on their experiences with fatigue and can thereby also reduce patients’ feelings of being misunderstood or isolated. In addition, our complete overview of available measurement instrument for fatigue enables HCPs to select the preferred instrument for each condition in clinical or research settings. Moreover, using clinical reasoning, the information retrieved on determinants and consequences can be used to propose a tailored treatment plan for (excessive) fatigue in patients with RMDs.

Shared-decision making

Another key principle of patient-centered care is shared-decision making (SDM). SDM is defined as the process of HCPs and patients jointly participating in making decisions related to patients’ health after discussing the options, the benefits and harms, and considering the patients’ values, preferences, and personal circumstances. To support the SDM process in patients with axial SpA who face a treatment decision to initiate or switch a biologic or target synthetic Disease-Modifying AntiRheumatic Drug, we developed an up-to-date evidence-based decision aid and introduced this tool to patients and HCPs in several rheumatology settings across the Netherlands (**chapter 6**).

We involved all intended users in the development process to increase their trust in the content and to contribute to broad acceptance and use of this tool in clinical practice. With this decision aid, we enabled patients who face a treatment decision to make well-informed

value-based personal treatment decisions. In this way, patients can become less passive in decision-making and experience less decisional conflicts. In turn, this may ultimately result in increased long-term satisfaction with provided healthcare and improved behavioural and health outcomes, such as better treatment adherence, better clinical outcomes and reduced healthcare costs.

PREMs for rheumatology settings

When evaluating the quality of provided healthcare, it is also essential to include patients' perspectives on this matter as these may differ from the perspectives of HCPs and policy makers. We facilitated assessing patient perspectives on the quality of Dutch rheumatology services by evaluating the psychometric properties of the Dutch version of the widely used Commissioning for Quality in Rheumatoid Arthritis PREM for rheumatology settings (CQRA-PREM) in patients with RA and SpA and by implementing this instrument in two rheumatology settings in the Netherlands (**chapter 7**). We evaluated results from the CQRA-PREM through repeated Plan-Do-Check-Act quality improvement cycles at several occasions with rheumatologists and rheumatology nurses from both medical centres. Afterwards, action plans were formulated and executed in clinical practice to improve the structure and processes of healthcare where possible. With this accomplishment, we serve as an example for researchers and HCPs in other rheumatic centres that it is feasible to implement PREMs in practice. Besides, the CQRA-PREM can be used to study the effect of changes on the quality of healthcare, to identify best practices within or between settings and to inform stakeholders, including patients, on the quality of healthcare.

Dissemination of results

Findings from this thesis contribute to new scientific insights, evidence and tools to improve the quality of rheumatology care. Our studies identified knowledge gaps and prompted new research questions to which can be acted upon to further improve outcomes of care for patients with RMDs. We informed researchers and HCPs on our findings through scientific publications in peer-reviewed rheumatology journals and presentations at national and international conferences on rheumatology. We successfully created a video-abstract about our study on assessing disease activity in peripheral SpA to increase the dissemination of the results of our study. Furthermore, we aimed to increase the impact of our findings by accepting two interview invitations. The first interview also addressed our study on assessing disease activity in peripheral SpA and was published at DOQ.nl, an online knowledge platform for HCPs which reflect on visions, experiences and current developments in a variety of fields of expertise. The second interview addressed our scoping review on fatigue in RMDs and was published in the journal of the Dutch Society for Rheumatology which targets an audience of Dutch HCPs. Our decision aid is publically accessible on the website of the Dutch Arthritis Society, a comprehensive and credible source of information on rheumatic and musculoskeletal diseases and available treatment options (in Dutch: www.reumanederland.nl).

By addressing encountered challenges in rheumatology practice, we also contribute to the goals, ambitions and expectations of the Dutch Federation of Medical Specialists for the role and position of medical specialists in the near future. In their most recent vision document they formulated the aspiration that by 2025 Dutch medical specialist healthcare is among the most innovative, efficient and best-quality healthcare worldwide.