Quality of rheumatic care

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With this thesis, we aimed to improve the quality of healthcare for patients with rheumatic and musculoskeletal disease (RMDs). When we initiated this thesis, some improvements and innovations were necessary to optimize these aspects in clinical practice. We therefore responded to encountered challenges in clinical practice related to monitoring of outcomes and providing patient-centered care. These challenges are not specific for rheumatology, but apply to all disciplines when considering the role and position of medical specialists in the near future. The Dutch Federation of Medical Specialists (FMS) formulated the aspiration that by 2025 Dutch medical specialist healthcare is among the most innovative, efficient and best-quality healthcare worldwide[1]. In this final chapter, the main findings of all studies part of this thesis are summarized, followed by a discussion of the main results with respect to used methodology and the implementations of results into clinical practice. These studies resulted in new insights into an existing body of evidence, but also identified knowledge gaps and prompted new research questions.

Summary of main findings

In **chapter 2** of this thesis, we described the need for a web-based tool for systematic monitoring of patients with SpA in clinical practice in the Netherlands and our efforts to develop and implement such a system, called SpA-Net. This tool follows the patient journey in daily practice and summarizes all relevant aspects for clinical decision making, including comorbidities, prescribed medication, adverse events and patient- and physician-reported outcome measures for disease activity, physical functioning and overall health status. For the design and content of SpA-Net, we consulted rheumatologists (including experts in the field of SpA), nurses and experienced patient research partners. The technical development and infrastructure were performed by an external firm specialised in the development of software for collecting and monitoring clinical and patient-reported outcomes. After the initial development phase, SpA-Net was evaluated during multiple rounds of internal and external testing with all stakeholders after which encountered errors were solved and the last version was optimized. Finally, in 2016, we used a multifaceted strategy to successfully implement SpA-Net as an electronic medical record (EMR) as part of the standard workflow in five rheumatology centres in the Netherlands. In 2017, its usability and acceptability was evaluated and confirmed by both patients and healthcare providers (HCPs) and barriers against use were identified. Since its launch more than 1300 patients with SpA have been enrolled.

In **chapter 3**, we described the need for a composite score to assess disease activity in patients with peripheral SpA in clinical practice. We therefore evaluated the performance of the Disease Activity Index for Psoriatic Arthritis (DAPSA), the Psoriatic Arthritis Disease Activity Score (PASDAS) and ASDAS in patients with peripheral SpA. We assessed the concurrent validity, discrimination across available thresholds of disease activity and the concordance in

classification of patients in DAPSA, PASDAS, and ASDAS disease activity states. Our findings showed that the concurrent validity and discrimination across thresholds of disease activity for the DAPSA, PASDAS and ASDAS were acceptable in patients with peripheral SpA with, on average, low degree of peripheral joint involvement. Classifying patients in the pre-defined disease activity states of the composite scores showed remarkable discordance in the high disease activity states (DAPSA 22%, PASDAS 56% and ASDAS 48%). In patients with and without psoriasis some differences in the performance of the measures were found, however this might be caused by the small proportion of patients without psoriasis included in this study. Of interest, the performance of the ASDAS was comparable in patients with axial SpA and peripheral SpA.

In **chapter 4**, we evaluated the extent to which extent treat-to-target (T2T) recommendations (i.e. frequency of measurement, target-based treatment intensification) were applied in clinical practice in a setting where HCPs were supported by SpA-Net. During a 1-year study period, disease activity was assessed at least once with the Ankylosing Spondylitis Disease activity Score (ASDAS) in 185 out of 219 patients (84%). The frequency of measurement varied from 0 (34 patients) to 6 (1 patient), while the majority (158 patients, 73%) had 1 or 2 measurements during the 1-year follow-up. At the first measurement, 114 (62%) did not meet low disease activity. Interestingly, in only 26 (23%) of these patients, disease activity was re-evaluated within the recommended 3 months and after 12 months, still in 31 (27%) of the patients, disease activity was not re-evaluated. We also investigated whether treatment adaptation occurred based on the ASDAS state. In 19 out of 114 (17%) patients with high disease activity, treatment was changed within 6 weeks after ASDAS measurement. At re-evaluation after 3 months in those with persistent high disease activity, only 2 more treatment adaptations occurred. From this study, we can conclude that, even with access to a web-based tool for monitoring patients and supporting HCPs, T2T is applied to only a limited extent in daily practice in patients with axial SpA. The scores seemed not to be driving re-evaluation nor treatment adaptation.

In **chapter 5**, we aimed to further specify the knowledge gap related to managing fatigue, a major concern for patients with RMDs in clinical practice. A patient panel formulated 15 research questions that were subsequently summarised in five research areas including: (i) the definitions of fatigue; (ii) measurement instruments to quantify and diagnose fatigue; (iii) determinants of fatigue; (iv) consequences of fatigue; and (v) the effect of interventions on fatigue. We performed a scoping review of published literature reviews addressing the five pre-identified research areas on fatigue in patients with rheumatoid arthritis (RA), SpA, osteoarthritis and fibromyalgia.
Overall, 134 reviews were included (19 Cochrane reviews, 44 non-Cochrane systematic reviews and 71 narrative reviews). Of these, 34% of the reviews considered fatigue in RA and only 4% of the reviews considered fatigue in osteoarthritis. Although no consensus definition exists for fatigue in RMDs, the reviews were in agreement that patients with RMDs can experience several types of fatigue that can occur simultanously or alternatingly in patients' lives.

Numerous unidimensional nor multidimensional patient-reported measurement instruments to assess fatigue were summarized in reviews. It was noted that only a small proportion of these instruments were developed and/or validated for use in clinical care and include cut-off values to identify persons with excessive fatigue. Further, a large number of health-related and contextual factors were identifed to be associated with fatigue as either a determinant or a consequence, but overall the strength of assocations was small, pointing to the complexity of fatigue. Regarding interventions, pharmacological interventions had a small to moderate effect on fatigue in RA, improved fatigue in SpA (no effect sizes available), but had no to a small positive effect on fatigue in fibromyalgia. Non-pharmacological interventions had generally no to a small positive effect on fatigue across RMDs.

In **chapter 6**, we deliberated on the need to fully inform patients on their current medical situation and on the expected effect of treatment options on disease outcomes and their personal lives. In this chapter, we developed an evidence-based decision aid to support patients who face a treatment decision to initiate or switch a b/tsDMARD and introduced this in clinical practice. The development process was based on a Dutch guidance document of the Dutch Health Care Institute for the development of patient information and decision aids in accordance with quality standards, and on the internationally accepted process development model of the International Patient Decision Aid Standards (IPDAS) collaboration[2,3]. The systematic development process consisted of state of the art consecutive phases, including explorative needs assessment interviews, development of a prototype, and usability and feasibility testing among patients and healthcare providers. Experts on axial SpA and professionals on patient information from the Dutch Arthritis Society were involved throughout all phases of the development process. The final version of the decision aid provides consultation support instructions in the context of disease control and treatment needs, informs on all available treatment options for axial SpA, provides detailed information on b/tsDMARDs, facilitates comparison of characteristics, and supports patients to deliberate on the decision to initiate or switch a b/tsDMARD. The pilot testing phases revealed that the usability and feasibility of the decision aid were acceptable. The final decision aid was introduced to patients and healthcare providers in several Dutch rheumatology settings.

In **chapter 7**, we described the need for a Dutch patient-reported experience measure (PREM) to assess the patient perspective on the structure and processes of healthcare in rheumatology settings in the Netherlands. The English Commissioning for Quality in Rheumatoid Arthritis PREM (CQRA-PREM) was found to be useful for this purpose in patients with RA and other rheumatic conditions[4,5]. We drafted a Dutch version of the CQRA-PREM using a forward-background translation procedure and tested its face-validity during focus group interviews with patients with RMDs. The Dutch version of the CQRA-PREM was piloted by patients with SpA and RA in clinical practice using SpA-Net and DREAM-RA, respectively. Ceiling effects were found in three out of seven domains, internal consistency of nearly all domains was considered good (0.65 ≤ Cronbach's α coefficients), thresholds for homogeneity were exceeded within

three domains (corrected item-total correlations >0.7) suggesting item redundancy and divergent validity showed that nearly all domains of the CQRA-PREM were at most weakly correlated with outcomes measures (− 0.3 ≤ spearman's rank correlation coefficients ≤ 0.3). It was concluded that the performance of the Dutch version of the CQRA-PREM has acceptable measurement properties for evaluating quality of healthcare from the patients' perspective in the Netherlands.

Next, the CQRA-PREM was implemented in clinical practice in two rheumatology settings and results were evaluated through repeated Plan-Do-Check-Act (PDCA) quality improvement cycles. During these cycles, the results from the CQRA-PREM were evaluated at several occasions with rheumatologists and rheumatology nurses from both medical centres after which action plans were formulated and executed in clinical practice to improve the structure and processes of healthcare where possible. For example, every new patient with SpA or RA now receives a business card with contact information from his/her treating rheumatologist and is referred to a rheumatology nurse for education. Also, the awareness about patient organizations, patient groups and self-management programs was further increased by providing leaflets and projecting information on screens in the waiting room. We concluded that the Dutch version of the CQRA-PREM is a useful tool for assessing patient experiences with healthcare in Dutch rheumatology settings.