

SHORT REPORT

Evaluating quality of care in rheumatoid arthritis: the patient perspective

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INTRODUCTION

As rheumatoid arthritis (RA) is a potentially disabling disease, affecting up to 1% of the population, structural monitoring of standardised outcomes to identify best healthcare practices is vital to quality improvement.^{1 2} Seven sets of RA standardised outcomes or 'quality indicators' have been described in the literature.³ However, only one group involved patients.⁴

This lack of patient representation in the current indicator sets might be due to the common methodology of indicator selection: indicators are determined through systematic searches of evidence-based literature and consultation of experts, usually defined as clinicians or researchers, rather than patients.

Studies have shown that patients and healthcare providers have different perspectives regarding quality of care.^{5 6} As the patient is the customer in the business called 'health care', the quality of the product should meet the costumers' needs. Therefore, we have studied the patient's perspective on quality of care in order to incorporate this together with the clinician's perspective into quality indicators.

METHODS

Patients were consulted using focus group methodology in combination with an online survey. The focus group method is a well-established research technique, gathering rich, descriptive data from participants in a small and homogeneous group, who focus on a specific topic, while guided by a neutral moderator.⁷

Study sample and procedure

Phase I: focus group discussion

Nine patients of the established patient partner network of the Dutch Arthritis

Foundation were invited to the focus group discussion (FGD).

Participants received an invitation and written information on the topic of the study by email. Prior to the meeting all patients gave oral consent to record the meeting and to use the results of this meeting for research purposes. Transcripts of the recording were analysed by one researcher (SM).

The moderator (MvO) explained the purpose of the discussion, created a 'safe environment' and ensured that participants did not deviate too much from the topic. Participants had the opportunity to give extensive answers to questions.

In the first part of the FGD, patients were asked for their positive and negative experiences with rheumatology care and were asked to prioritise three elements that were considered most important for their rheumatology care. The top three answers of each of the participants were then discussed and clustered in similar groups, if possible, resulting in domains. Finally patients were asked to vote for the domains that were most important to them.

In the second part of the FGD, a set of nine domains, defined by Dutch rheumatologists in a separate, parallel process, was introduced (figure 1). These domains were discussed, compared with the domains chosen by the participants and missing domains were added.

Phase II: survey

All unique domains were presented to a panel of 1132 Dutch patients with RA. This established panel can be consulted by the Dutch Arthritis Foundation in case of healthcare-related questions or for research purposes. Patients are invited to participate for each study separately. Also, patients are free to leave the panel without explanation regarding their decision. Due to the voluntary and



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anonymous participation in this panel and the low burden for participants, the consultancy of these patients was not reviewed by the medical ethical committee (as per Dutch law).

The electronic survey was filled out in April 2015. Panellists were asked to score the domains on a 7-point Likert scale ranging from 'totally unimportant' to 'very important', or not applicable. Panellists were subsequently asked to prioritise five domains that were considered most important in the evaluation of rheumatology care.

RESULTS

Phase 1: focus group discussion

Six out of nine invitees agreed to participate in the FGD (five women; age range: 46–70; disease duration: 7–50 years).

Six main domains were considered as important according to the FGD patients after prioritising. Patients concluded that an important domain 'an overview of joints giving limitations' was missing in the physician's domains. This item was added to the list of important

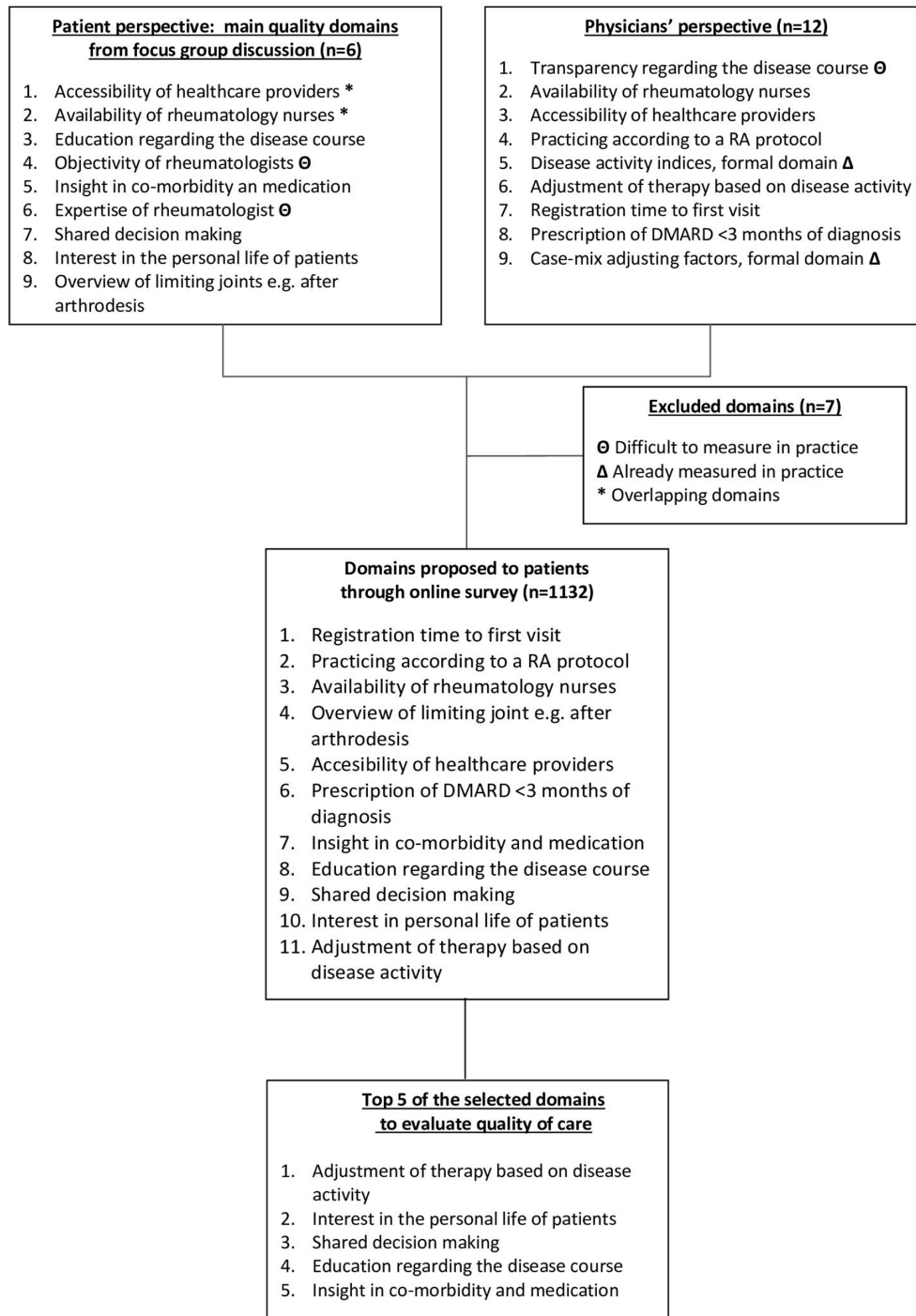


Figure 1 Selection of quality domains by patients from the focus group.

Table 1 Domains formed from the patients' perspectives with their supporting quotations

Clearness regarding the disease course	
MOD: "What is most important for you in rheumatology care?"	P1: "I have had two rheumatologists, one was very vague, when I left his office I thought I still know nothing. Now I have one who's very clear, I leave his office in seven min and I just love that. I don't like endless stories, I want to know where I stand."
MOD: "Clearness about the treatment you mean?"	P1: "just being specific. I like that very much."
Accessibility of healthcare providers	
MOD: "What is most important for you in rheumatology care?"	P2: "there are possibilities of evening consultations." P3: "and e-mailing or telephoning the doctor personally?" P2: "I have never done it, but it is possible."
MOD: "so accessibility is expressed by the possibility to e-mail or call the healthcare provider?"	P1: "yes and that you are called back the same day and you have an appointment within just two days." P3: "I experienced the same with my previous rheumatologist, it was very pleasant... Even during the Christmas holidays I could call her if needed." P4: "someone who can be reached in the evening and by e-mail"
Availability of rheumatology nurses	
MOD: "What is most important for you in rheumatology care?"	P1: "I know that if I didn't have my rheumatology nurse, I would not be satisfied with my rheumatology care." P4: "I see my rheumatologist for seven min and my rheumatology nurse for one hour...She explains everything and has enough time for it"
Shared decision making	
MOD: "What is most important for you in rheumatology care?"	P6: "I have RA for years, at the beginning of my disease I found the attention of the doctor pleasant. Now I want efficiency, that's better for me. If I have something to declare, I do it, otherwise I have a regular checkup." P5: "I'm my own doctor, I'm there for regular checkups and I don't ask him anything else... You know your own body so well"
Interest in patient's personal life	
MOD: "What is most important for you in rheumatology care?"	P1: "I have three people at home who can help me, but if I was alone, my situation would be a lot different. That's for a doctor important to assess how things are going with me."
Insight in comorbidity and comedication	
MOD: "What is most important for you in rheumatology care?"	P6: "patient who have other chronic diseases besides RA have to be taken into account" P1: "a very important issue. There are a lot of RA patients who are getting older"
An overview of joints limiting the patient	
MOD: "What is most important for you in rheumatology care?"	P2: "it is remarkable that only the tender and swollen joints are being considered. In my case I'm being restricted by other joints." P5: joints with prosthesis, what about them?
MOD: "those won't be taken into account"	P1: " that's odd, those joints are limiting...there are also stiff joints without inflammation. Those are not always tender."

MOD, Moderator.

domains from the patient's perspective. Domains with their supporting quotations are displayed in [table 1](#). This process is described in [figure 1](#).

Phase 2: survey

In order to avoid overlap we decided to merge domains that were already included in the set of

indicators of the physicians (education regarding the disease course, accessibility of healthcare providers, availability of rheumatology nurses). A total of 11 domains were proposed to a panel of 1132 Dutch patients with RA. The response rate was 57% (640 patients). The mean age was 58 years, ranging from 24 to 68 years (data available of 612/1132 patients)

and 78% were women (data available of 640/1132 patients).

In figure 2 an overview of the proposed domains is given, along with the frequency of patients who ranked a domain as important/very important for rheumatology care. When asked to provide a top five of important aspects of rheumatology care, the majority of patients choose (1) adjusting therapy based on disease activity (78%); (2) interest in the personal lives of patients (70%); (3) shared decision making (70%); (4) education about the expected disease course (63%); and (5) insight into comorbidity and comedication (61%).

DISCUSSION

This is the first study that has incorporated patients' perspectives on quality of RA care in the development of a national quality indicator set. Five domains, reflecting patients' perspectives on quality of RA care, have been identified by the patients. Remarkably, the top five of the patient-relevant quality indicators are all process measures.

Although the current opinion has shifted from process measurement towards outcome measurement, recent insights again highlight the importance of process indicators that are pivotal to change outcomes. Since process measures are easier to identify and change, they have been suggested to be more appropriate for quality improvement than outcome measures.^{8,9}

The preference of patients for process measures rather than outcome measures in our study has been reported before by Brown *et al* and Schröder *et al*.^{10,11} Healthcare providers tend to rely more on outcome measurements when evaluating quality of care, while patient satisfaction is often not associated with outcomes of care (high satisfaction can be reported even if the desired health outcome has not been obtained).¹⁰

The developed indicators from the perspectives of rheumatologists (outcome indicators) and patients (process indicators) complement each other well. The effects of the process measures (effect of interest of a rheumatologist in the personal life of a patient) can be seen in the outcomes (disease activity score) measured by the rheumatologist. Further research is needed to determine whether patient-reported outcomes are needed.

Another interesting finding is the value that patients attribute to treat-to-target (T2T) methodology in clinical practice matches well with international recommendations for clinicians.¹² This agreement was examined by Haraoui *et al* by means of a survey among 959 Canadian patients. Patients agreed on a high level with the reworded European League Against Rheumatism 2010 recommendations on T2T varying from 8.6 to 9.5 and reported being highly satisfied by the received care.¹³ The beneficial effects of the T2T strategy are probably the reason for the high satisfaction of patients; achieving lower disease activity leads to less comorbidity and higher levels of work productivity.¹⁴

Our study had some limitations. We did not seek saturation of data collection in the FGD (due to a limited time frame), which is considered the preferred methodology.⁷ As our objective was to find the top five of patient important domains, we chose to consult one group of patient experts and proposed results from this focus group to a panel of 1132 patients with RA, increasing support for the resulting measures. Furthermore, patients from the panel were 'self reported' patients with RA, making it possible that not every patient was a true patient with RA. However, based on the fact that educated patients are more likely to participate in research and surveys of any kind and have a better understanding of their diagnosis, we can assume that the majority of patients from this patient panel have reported their

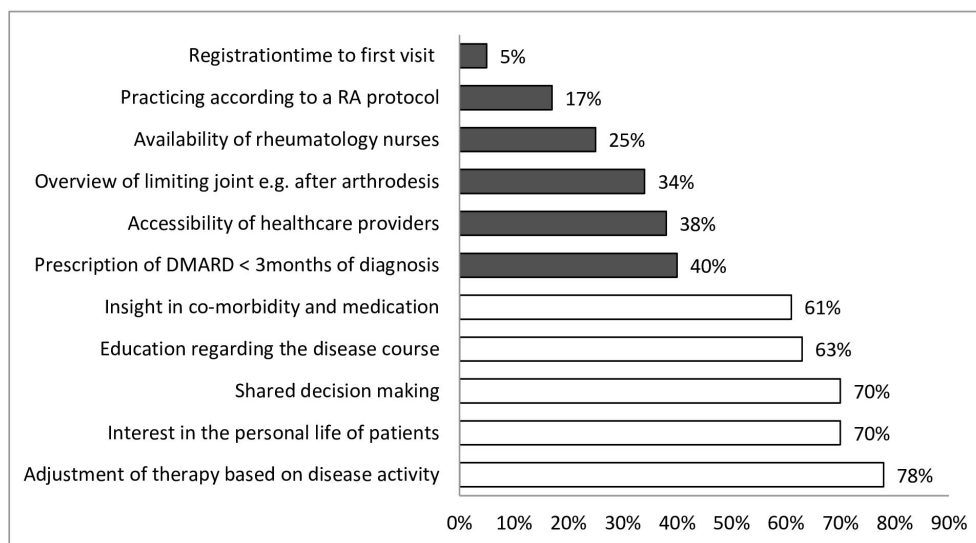


Figure 2 The proposed domains to Dutch patients with rheumatoid arthritis (RA). The percentages display the frequencies of patients who ranked a domain as important/very important for rheumatology care. The white bars display the five key measures, identified by patients to reflect their perspectives on quality of care.

disease correctly.¹⁵ Finally, neither disease duration nor the severity for each panellist is documented, making it impossible to analyse in subgroups (early and established RA; severe and mild disease). A strength of our study is that, to our knowledge, it is the first on quality of care that has consulted patients in such an extensive way. We were able to identify five domains that are considered to be important to patients in evaluating the quality of RA care. While other studies focused on existing Patient Reported Outcomes (PROs) that are valued by clinicians, such as the Health Assessment Questionnaire (HAQ) or visual analogue scale, we have consulted patients in order to form a limited set of domains to evaluate rheumatology care.

In conclusion, patients identified five key process measures to reflect their perception on quality of RA care. Research to capture patients' perspectives into a questionnaire for use in quality registries is ongoing.

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Contributors SM, MvO, SdJ and LHDvT designed the study, and performed the analyses, literature review and preparation of the text. RL and PvR advised and reviewed the manuscript.

Competing interests RL declares to have the following disclosures: Consultation or participation in advisory boards: Abbott/AbbVie, Ablynx, AmGen, AstraZeneca, Bristol-Myers Squibb, Celgene, Janssen (formerly Centocor), Galapagos, GlaxoSmithKline, Novartis, Novo Nordisk, Merck, Pfizer, Roche, Schering-Plough, TiGenix, UCB and Wyeth; Research grants: Abbott, AmGen, Centocor, Novartis, Pfizer, Roche, Schering-Plough, UCB and Wyeth; Speaker fees: Abbott/AbbVie, AmGen, Bristol-Myers Squibb, Janssen (formerly Centocor), Merck, Pfizer, Roche, Schering-Plough, UCB and Wyeth. RL is Director of Rheumatology Consultancy BV, which is a registered company under Dutch law. PvR declares to have the following disclosures: Grants: AbbVie, Roche, Pfizer, MSD and UCB. SdJ and MvO are employees of one of the main funders of this project, Reumafonds (the Dutch Arthritis Foundation).

Patient consent Patients who participated in this study are members of an established panel, consulted by the Dutch Arthritis Foundation in case of healthcare-related questions or for research purposes. Formation of this panel was promoted through the website of the Arthritis Foundation and through social media. Subsequently a newsletter was sent to approximately 100 000 patients with arthritis and associates of the Arthritis Foundation. Patients were asked for each study separately whether they want to participate or not. Also, patients were free to leave the panel without explanation regarding their decision. Due to the voluntary and anonymous participation in this panel and the low burden for participants, the consultancy of these patients was not reviewed by the medical ethical committee (as per Dutch law).

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Data sharing statement All data regarding this study have been used for this manuscript only. No other unpublished data from this study are available. These data are available only for the project group (eg, the authors of this manuscript).

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