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REVIEW ARTICLE

PROMs in inflammatory arthritis: moving from static to dynamic

Yasser El Miedany

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Abstract There are several advantages in using patient-reported outcome measures (PROMs) in standard clinical practice, particularly if a questionnaire is distributed to each patient at each visit as a standard in the infrastructure usual care. The patients, being the most knowledgeable persons concerning their pain and global estimate, do most of the work by completing a questionnaire. Completion of the questionnaire helps the patients prepare for their visit as well as improving doctor–patient communication. Recently, the role of PROMs has expanded from the static phase of capturing and measuring outcomes at a single point of time to a more dynamic role. This dynamic role is aiming at driving improvement not only in the quality of inflammatory arthritis care but also in the patients' reported experience. Therefore, in addition to its value in tailoring treatment targets adapted to the patient's needs, PROMs also have the potential of modifying the disease impact through improving the patients' adherence to therapy and allowing the patients to monitor the changes in their condition. Though more attention has been given to the use of PROMs in routine clinical care, little was published regarding what could be done with the plethora of data gained from PROMs and how dynamic it can be enhancing the "patient-centered care" approach and improving patients' experience. This article highlights the value of adopting PROMs for arthritic patients in standard clinical practice and its impact on long-term patients' management.

Keywords Arthritis · Patient-reported outcome measures · PREMs · PROMs · Rheumatoid arthritis · Treat to target · US

Y. El Miedany (✉)
Darent Valley Hospital, Dartford DA2 8DA, Kent, England, UK
e-mail: drelmiedany@rheumatology4u.com

Introduction

Patients' experience of inflammatory arthritic conditions and their treatment is a core factor of their management. Using the patients' perspective of good or poor health status is not only an indicator of quality of care, but also the outcomes of the treatment approach adopted. Whilst quality of care is situated at the heart of arthritis management, in particular when it is assessed by the patients themselves, changes in health status self-reported by the patients reflect the healthcare delivered to the patient by the provider and the wider healthcare system. Patient-reported outcome measures (PROMs) are defined as measures of a patient's health status or health-related quality of life at a single point in time [1]. They provide a means of gaining an insight into the way patients perceive their health and the impact that treatment or adjustments to lifestyle has had on their quality of life and ability to carry out their activities of daily living. These instruments can be completed by patients or individuals about themselves, or by others on their behalf. Till recently, PROMs have been looked at as a research tool and not for use in everyday practice. Several published studies highlighted the value and possibility of using PROMs in the standard clinical practice [2–5]. The inclusion of PROMs in routine practice (Fig. 1) was reported to provide important and often otherwise overlooked information, revealing the impact of the disease or its treatment on the patient's physical, emotional, and social well-being. Past discussions about the challenges of using PROMs in clinical practice [6–10] included clinicians' skepticism, time and resources for the implementation, validity of the PROMs, unfamiliarity with PROMs interpretation, and costs of implementation. Though these points were handled in recently published studies, little was published regarding what could be done with the plethora of data gained from PROMs or

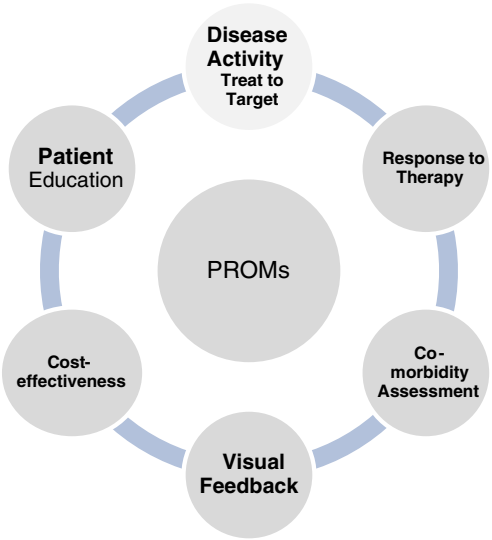


Fig. 1 PROMs' role in the management of inflammatory arthritis in the standard clinical practice

what is known as "what is after PROMs." This article highlights the value of adopting PROMs for arthritic patients in standard clinical practice and its impact on long-term patients' management.

Role of PROMs in monitoring the arthritis vital signs and response to therapy

The introduction of the early arthritis concept and the "window of opportunity" widened the scope to include disease parameters of help to identify the patient subgroup suffering from persistent inflammatory arthritis. The EPISA study [11], carried out to predict persistent inflammatory arthritis disease course, identified duration of morning stiffness, deterioration of functional disability over 3 months as well as anti-cyclic citrullinated peptide (CCP) antibodies as the three main poor prognostic manifestations in this subgroup of patients. This important role of functional disability was also highlighted by studies which linked increased mortality to greater functional disability in arthritis patients. [12]. Recently, the American College of Rheumatology guidelines (2012) [13] for management of inflammatory arthritis identified functional disability, sero-positivity for rheumatoid factor or anti-CCP, presence of bony erosions as well as the presence of extra-articular manifestations as poor prognostic features in arthritic patients.

It is not surprising that pain was recognized as the fifth vital sign whereas functional impairment was recognized as the sixth vital sign in arthritic patients. With the introduction of biologic agents and the significant good response of disease activity to therapy, quantitative clinical assessment as well as disease activity measures booked its place in the patients' management. The most widely used disease activity indices in RA are disease activity score (DAS-28) [14] and clinical disease activity index [15]. It should be noted that the patient global estimate is included in all these widely used indices of disease activity. Therefore, at least one PROM is measured in all RA clinical practice, although not always reported as an individual measure.

As only patients themselves can report their perspective on the outcomes of illness and its treatment effects, PROMs become a standard measure of disease activity parameters including pain, patient global assessment, duration of morning stiffness as well as functional disability which are included in the American College of Rheumatology/ EULAR core set variables for monitoring of disease activity as well as the Outcome Measures in Rheumatoid Arthritis Clinical Trials 6 conference [3]. Therefore, recording PROMs has both a diagnostic value in helping to identify those who might be suffering from early inflammatory and a therapeutic impact as it helps to monitor response to therapy over time.

The discrepancy between the clinicians and the patients can be attributed to the fact that both clinicians and patients have different perspectives on outcomes. Whilst clinicians focus on disease activity scores, patients prioritize treatment outcomes that are not routinely measured by the clinician, such as well-being, fatigue, work ability, and sleep [16–18]. Differences between what clinicians and patients believe might also be attributed to prioritizing treatment of disease over its consequences. On the other hand, an earlier study [19] carried out to assess the subjective patient self-reported painful joints in contrast to the objective physician-recorded tender joints revealed that patient-reported tender joint count was reliable and responsive to change in disease activity.

Role of PROMs in the assessment of co-morbidities

The relation of RA and comorbid conditions can be complex. This might be attributed to different types of co-morbidities and their pathogenesis. In type I comorbidity, there is no relation between RA and the comorbid condition that is detected. For example, trauma and certain cancers are unrelated to the presence of RA. Type II comorbidity occurs when the comorbid condition leads to an increase in an RA outcome: for example, persons with depression and RA are more likely to become work disabled than persons without depression. Type III comorbidity (RA consequences) occurs when an RA outcome leads to an increase in a comorbid condition, for example, gastrointestinal ulceration and herpes zoster. Type IV comorbidity (RA illness) occurs when RA causes (at least in part) the comorbid conditions, e.g., myocardial infarction and lymphoma. Type V comorbidity (RA treatment) occurs when RA treatment causes or

contributes to comorbidity development, e.g., steroids and infection. Finally, type VI comorbidity (common external factor) occurs when a common condition leads both to RA and the comorbidity, e.g., smoking, RA, and lung cancer [20]. The potential role of PROMs in the assessment of co-morbidities in arthritic patients is another example of the PROMs' dynamic nature. Recent PROMs questionnaires allow the treating clinician to assess for RA-associated co-morbidities at each visit. In its early stages, inflammatory arthritis patients may not have significant co-morbidities that warrant further management. However, as the disease progresses and becomes more active, the patient can be prone to one or more of these co-morbidities. Screening for these symptoms is highly recommended on a regular basis for every patient. Furthermore, this approach would also facilitate, on the spot, assessment for cardiovascular risk, falls risk, osteoporosis as well as depression [21]. This dynamic impact of PROMs plays an important role on the long-term patients' care.

Do PROMs have a potential disease-modifying role?

Recording PROMs has proved to be valuable; however, this has been looked at as a one-stop measure. In relation to the patient's ever-changing condition, recording PROMs at each visit adds to its dynamic plasticity. This leads to the important question of how to step forward to use these measures, obtained over several visits, to the best in the patients' management. A recent study [22] looked into sharing the patients' previous PROMs records with them either in a paper or electronic format. Electronic recording of the data obtained enables further analysis of PROMs which can be expressed as easy-to-read charts. This can be shared with the patients, helping them to visualize the progress of their disease activity course and outcome measures. Monitoring electronic data of real-time changes in disease activity provided patients with visual evidence of their responses to treatment at different time points. Following 1 year of management, statistically significant differences were seen in disease activity parameters and patients' willingness to remain on treatment ($p<0.01$) favoring the visual feedback approach. Results of this study revealed that viewing previous PROMs records (1) helped the patients understand the effect of treatment on disease activity, (2) helped in medication adherence, (3) improved trust in the treating physician, (4) alleviated concerns about the future, and (5) helped in coping with daily life and disease. Results of this study highlighted that not only is this approach politically correct, in that the patients were involved in the treatment, but the statistically significant differences suggest that this adjunctive therapy based on PROMs recordings may actually also be disease modifying.

Treat to target

Several clinical trials adopting the treat-to-target strategy have documented better clinical outcomes of a targeted approach compared with a routine approach for inflammatory arthritis patients [23–30]. The primary outcome in most of these trials was DAS-28 score. Interestingly, some studies included data for individual PROMs, including physical function, pain as well as patient global estimate of status. In the Tight Control for Rheumatoid Arthritis (TICORA) study, the strategy of intensive management led to significantly greater improvement in disease activity, radiographic progression, quality of life and scores for physical function, pain and patient global estimate of status compared to routine care [23]. In the Computer-Assisted Management in Early Rheumatoid Arthritis (CAMERA) study carried out in the Netherlands, the primary outcome for this study was the number of patients in DAS remission for at least 3 months. Scores for physical function were improved similarly from baseline to 2 years follow-up in both groups, but scores for pain and patient global estimate were improved at significantly higher levels in the intensive group (25). A meta-analysis was performed of combined results according to PROMs in five studies (TICORA, CAMERA, BeSt [31, 32], GUEPARD [25] and a study of two early arthritis inception cohorts in the Netherlands [33]. All measures in individual studies indicated better outcomes in the treat-to-target versus control groups. The overall weighted mean difference for physical function (0–3 scale) was 0.16 in favor of the treat-to-target strategy (range across all studies, 0.07–0.25; $p=0.01$ versus usual care), 15.34 (0–100 scale) for pain (range, 11.50–19.18; $p=0.02$), and 15.52 (0–100 scale) for patient global estimate (range, 11.61–19.42; $p=0.01$) [34]. Therefore, PROMs documented significantly better clinical outcomes with treat-to-target strategies. Another recent study [35] highlighted the value of patient self-report PROMs questionnaires in identifying which joints may be in need of further US assessment in standard clinical care. This had a positive impact in implementing the treat-to-target approach in patients with inflammatory arthritis.

Patient education

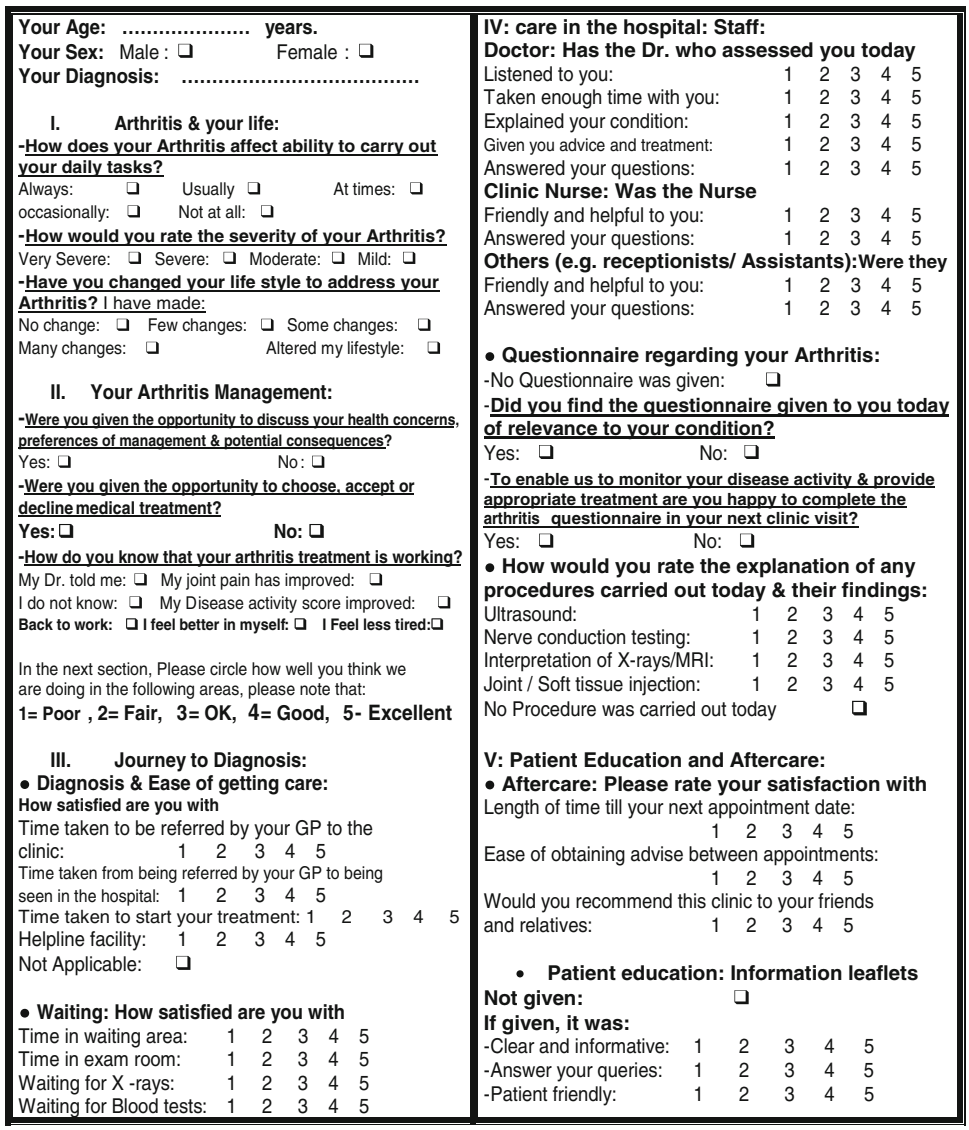
Over the past years, there have been some discrepancies between patient education approach in standard clinical practice and research studies. In standard clinical practice, patient education tended to focus on helping patients to understand their disease and to be given information regarding the interventions being used, whereas, in contrast, research studies targeted behavior changes and enhancement of a general sense of control as well as skill in coping with

Table 1 Change from baseline for patient-reported outcomes in four treat-to-target studies

Study	Target	Tender J. count	Pain score (VAS, 0–100)	Patient global assessment (VAS, 0–100)	Fatigue score (VAS, 0–100)	Morning Stiffness (min)	HAQ (0–3)
TICORA [23]	DAS<2.4	−12	−43	−52	NR	NR	−0.8
CAMERA [24]	ACR remission	−11	−36	−32	NR	−63	−0.4
ESPOIR-GUEPARD [25]	DAS-28<3.2	−10.1	−44.8	−46.6	−37.1	NR	−0.9
Schipper et al. [33]	DAS-29<2.6	−4	−30	−32	NR	NR	−0.5

Values are expressed as mean difference from baseline

NR not reported, *VAS* visual analog scale



Patient Reported Experience Measures

We would like to know how you feel about your experience and treatment that you received at the place where you were given this survey.Your views are very important to us to help find out how satisfied you are with the service provided. This would help us to continue providing an efficient service for our patients as well as how we can make them better. It is up to you whether you want to take part in this survey – you do not have to. All responses will be kept confidential. Thank you for your time.

Your Age: ..... years.
Your Sex: Male : ❑ Female : ❑
Your Diagnosis: .....

I. Arthritis & your life:
-How does your Arthritis affect ability to carry out your daily tasks?
Always: ❑ Usually ❑ At times: ❑
occasionally: ❑ Not at all: ❑
-How would you rate the severity of your Arthritis?
Very Severe: ❑ Severe: ❑ Moderate: ❑ Mild: ❑
-Have you changed your life style to address your Arthritis? I have made:
No change: ❑ Few changes: ❑ Some changes: ❑
Many changes: ❑ Altered my lifestyle: ❑

II. Your Arthritis Management:
-Were you given the opportunity to discuss your health concerns, preferences of management & potential consequences?
Yes: ❑ No : ❑
-Were you given the opportunity to choose, accept or decline medical treatment?
Yes: ❑ **No:** ❑
-How do you know that your arthritis treatment is working?
My Dr. told me: ❑ My joint pain has improved: ❑
I do not know: ❑ My Disease activity score improved: ❑
Back to work: ❑ **I feel better in myself:** ❑ **I Feel less tired:** ❑

In the next section, Please circle how well you think we are doing in the following areas, please note that:
1= Poor , 2= Fair, 3= OK, 4= Good, 5- Excellent

III. Journey to Diagnosis:
• Diagnosis & Ease of getting care:
How satisfied are you with
Time taken to be referred by your GP to the clinic: 1 2 3 4 5
Time taken from being referred by your GP to being seen in the hospital: 1 2 3 4 5
Time taken to start your treatment: 1 2 3 4 5
Helpline facility: 1 2 3 4 5
Not Applicable: ❑

• Waiting: How satisfied are you with
Time in waiting area: 1 2 3 4 5
Time in exam room: 1 2 3 4 5
Waiting for X -rays: 1 2 3 4 5
Waiting for Blood tests: 1 2 3 4 5

IV: care in the hospital: Staff:
Doctor: Has the Dr. who assessed you today
Listened to you: 1 2 3 4 5
Taken enough time with you: 1 2 3 4 5
Explained your condition: 1 2 3 4 5
Given you advice and treatment: 1 2 3 4 5
Answered your questions: 1 2 3 4 5
Clinic Nurse: Was the Nurse
Friendly and helpful to you: 1 2 3 4 5
Answered your questions: 1 2 3 4 5
Others (e.g. receptionists/ Assistants):Were they
Friendly and helpful to you: 1 2 3 4 5
Answered your questions: 1 2 3 4 5

• Questionnaire regarding your Arthritis:
-No Questionnaire was given: ❑
-Did you find the questionnaire given to you today of relevance to your condition?
Yes: ❑ No: ❑
-To enable us to monitor your disease activity & provide appropriate treatment are you happy to complete the arthritis questionnaire in your next clinic visit?
Yes: ❑ No: ❑
• How would you rate the explanation of any procedures carried out today & their findings:
Ultrasound: 1 2 3 4 5
Nerve conduction testing: 1 2 3 4 5
Interpretation of X-rays/MRI: 1 2 3 4 5
Joint / Soft tissue injection: 1 2 3 4 5
No Procedure was carried out today ❑

V: Patient Education and Aftercare:
• Aftercare: Please rate your satisfaction with
Length of time till your next appointment date: 1 2 3 4 5
Ease of obtaining advise between appointments: 1 2 3 4 5
Would you recommend this clinic to your friends and relatives: 1 2 3 4 5

• Patient education: Information leaflets
Not given: ❑
If given, it was:
-Clear and informative: 1 2 3 4 5
-Answer your queries: 1 2 3 4 5
-Patient friendly: 1 2 3 4 5

Fig. 2 Questionnaire developed to assess for patient reported experience measures

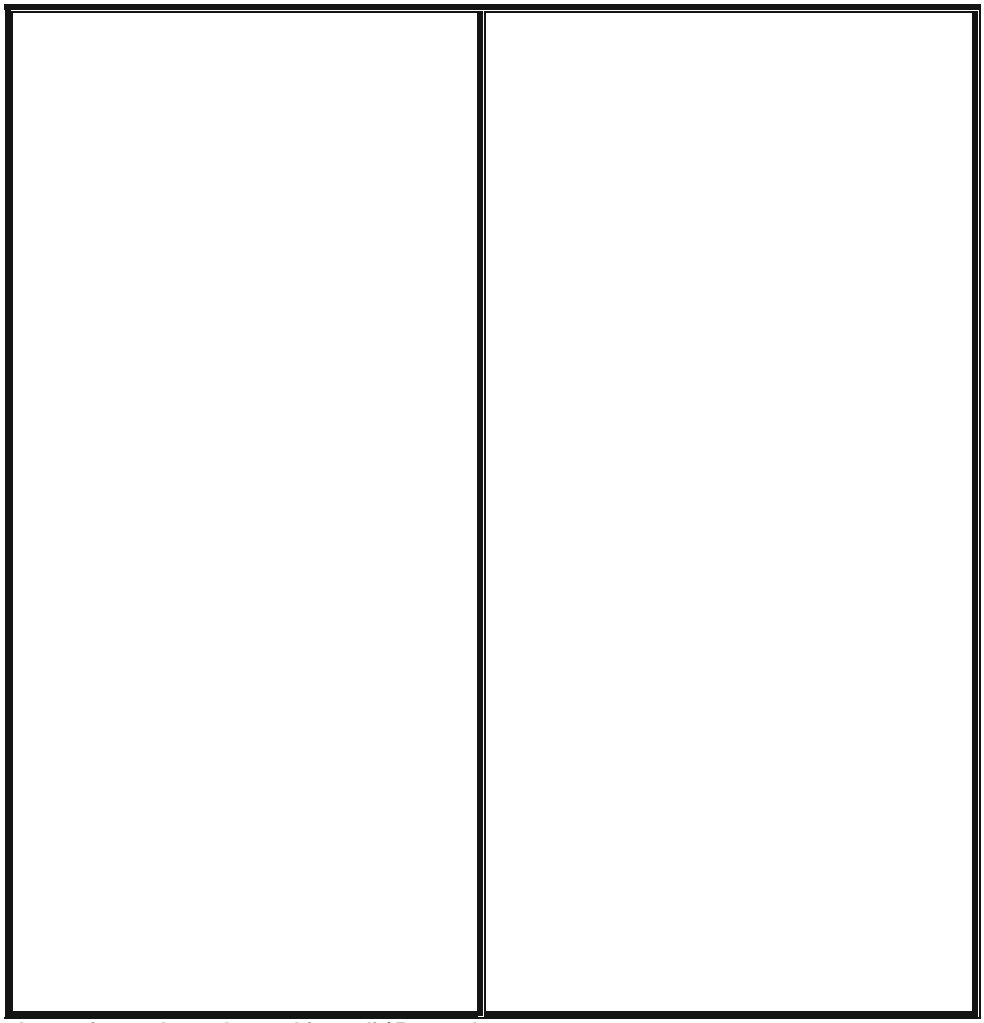


Fig. 2 (continued)

the disease and its sequelae [36, 37]. The Educational Needs Assessment Tool (ENAT) [38] was developed in the UK to systematically assess the educational needs of patients with arthritis. Its validity was assessed among arthritis patients, and its test–retest reliability demonstrated a good repeatability of the instrument (rs=0.82; ICC=0.87). However, the ENAT was criticized for being limited to research. The recently published guidelines from NICE [39] and EULAR [40] for inflammatory arthritis addressed other risk factors that are not included in the ENAT and may also account for increased mortality, poor quality of life and work disability, as well as co-morbidities, e.g., cardiovascular, falls, and osteoporosis/fracture risks. Recent studies showed that PROMs can be used as a link between the disease outcomes and patient education as it enables the treating physician and the patient to identify the main points that need tackling. The integration of the PROMs and patient education offered a new opportunity toward patient self-efficacy in disease management [41]. Some recently introduced patient education programs such as the "joint fitness program" adopted PROMs to identify the patient's educational needs [42].

Cost-effectiveness

Cost-effectiveness is not a straightforward concept because it encompasses elements not directly measurable in currency, such as morbidity, mortality, and reduction in quality of life. Recently, the American College of Physicians recommended the establishment of an organization for the generation and review of cost-effectiveness analyses [43]. In England and Wales, the National Institute for Health and Clinical Excellence (NICE) was established to balance the financial costs and clinical benefits of health technologies and evaluate their cost-effectiveness [44]. The health status information collected from patients by way of PROMs questionnaires before and after an

intervention provides an indication of the outcomes or quality of care delivered to the patients. The PROMs used to collect data from patients will comprise a condition-specific instrument, in addition to more general patient-specific information. There are intentions to link payments to PROMs data: "payments to hospitals will be conditional on the quality of care given to patients as well as the volume. A range of quality measures covering safety, clinical outcomes, patient experience and patient's views about the success of their treatment (known as Patient reported outcome measures or PROMs) will be used." [45]. However, as the patients' disease course improves, they tend to focus on their current health status, and the previous disease activity may fade into the background. A recent study [46] revealed how PROMs can be cost-effective. In this study, arthritic patients could achieve better control of their disease by showing them a comparison between previous PROMs taken when their disease activity was at its peak and their current PROMs. This was achieved by helping them to be more adherent to their medications and less likely to stop due to intolerance (Table 1). It also helped to give them the ability to cope with their activities of daily living, achieve less visits to their GPs, and become less concerned about their future. Medication compliance was significantly correlated with changes in all measured disease parameters as well as ability to work.

PROMs and PREMs

Current health policy emphasizes patient experience, together with effectiveness and safety, as key components of quality of care. As a consequence, PROMs and patient-reported experience measures (PREMs) are increasingly being seen as important assets for assessing quality of care, evaluating outcomes of specific interventions and for clinical assessment and decision support. In addition to PROMs, the PREMs will augment this approach by measuring how well a service is truly meeting the needs of patients. PREMs provide a 360° view of service quality from the clinical, commissioning, and patient perspective. These tools can be used to identify areas for improvement and areas of excellence for sharing of best practice, monitor service delivery, document service improvements, and improve quality of care and patient experience of care [47]. Figure 2 is a validated patient-reported experience measure questionnaire developed by the author (submitted for publication) that can be used for arthritis patients.

There is a difference between both PROMs as well as PREMs on the one hand and patient satisfaction scales on the other hand. In general, the focus of the patient satisfaction surveys is usually narrow. It essentially only deals with the interaction between the health care professional and service user in an outpatient setting [47]. As arthritis patients interact with a far greater range of people and systems as they move through a given care pathway, a broader perspective is needed to assess a patient's experience. Both PROMs and PREMs are pertinent to today's clinical practice. They provide richer information than patient satisfaction questionnaires, which are concerned with a relatively narrow (but also important) area. It is possible for a user to have a satisfactory experience of a service (and score a satisfaction questionnaire highly) but a poor clinical outcome (which would not be identified by a satisfaction scale). On the other hand, PROMs and PREMs will capture not only the patient experience/ satisfaction but also the outcome from the patient's perspective. These data complement the gathering of routine clinical outcome data, which pertain primarily to the quality of care provided [48, 49].

In conclusion, the collaboration between the rheumatologist and patients can considerably strengthen the effectiveness of the patients' management. This is achievable so long as the approach used is planned, has a goal, and is accountable. Integrating patient-reported outcome measures in the standard care of inflammatory arthritis patients is feasible and takes PROMs from a static to dynamic role. The current PROMs, including co-morbidities assessment, may lead to the deviation from single score numbers of disease activity into a holistic approach which are recommended as treatment targets. In fact, PROMs may help in tailoring treatment targets adapted to the patient's needs as agreed upon between the clinician and the patient.

Disclosures None.

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