

The arthritic patients' perspective of measuring treatment efficacy: Patient Reported Experience Measures (PREMs) as a quality tool

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Abstract

Objective

We aimed to assess the validity and reliability of a Patient Reported Experience Measures (PREMs) questionnaire which can be used in standard clinical practice to measure self-defined important experiences of inflammatory arthritis patients.

Methods

The Patient Reported Experience Measures (PREMs) questionnaire was conceptualised based on frameworks used by the WHO Quality of Life tool, as well as the PRO measurement information system (PROMIS). Cognitive interviews were conducted with 94 inflammatory arthritis patients (diagnosed according to EULAR/ACR criteria 2010), with a range of severity and disease activity to identify item pool of questions. Item selection and reduction was achieved based on patients as well as an interdisciplinary group of physicians, nurses, health educators and occupational therapy (OTs) feedback, in addition to clinometric and psychometric methods. The latter included Rasch and internal consistency reliability analyses. The PREMs questionnaire was developed centered around 5 categories: 1. Journey to diagnosis, 2. Impact of the disease on the patients' everyday life, 3. knowledge about the disease, 4. the care in the hospital, and 5. patient education and aftercare (including what to do in case of exacerbation). After analysis for ordered response options, content analysis and semi structured group discussion to cover these 5 categories, 32 questions were identified as the final item set. The routine clinic was used as a setting for the questionnaire evaluation. 183 patients were asked to complete the PROMs as well as PREMs questionnaires whilst sitting in the waiting area before being examined by the treating physician. Reliability and comprehensibility was assessed using the Test-retest reliability (reproducibility).

Results

The tool was derived from RA patients, therefore establishing its face validity. The PREMs questionnaire showed a high degree of comprehensibility (9.3). It demonstrated a relatively high-standardised alpha (0.892). The questionnaire items correlated significantly ($p < 0.01$) with clinical parameters of disease activity, PROMs, self-helplessness and DAS-28 score supporting its construct validity. The domain of impact of arthritis correlated significantly ($p < 0.01$) with health related quality of life (HRQOL) score as well as disease activity and damage measures, establishing its criterion validity. Patient education and aftercare correlated significantly ($p < 0.01$) with adherence to therapy.

Conclusion

The studied PREMs questionnaire had fair psychometric properties as it was valid, reliable and comprehensible. The patients were able to comprehend varying response options on a categorical scale, and could accurately respond to items using a 7-day recall period. It provides informative measure for the patients' experience with their disease, and in the meantime, facilitates incorporating the patients' feedback into the patients' management algorithm.

Key words

PREMs, inflammatory arthritis, questionnaire

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Introduction

Patients have an important role to play in communicating the impact of their diseases and the effectiveness of healthcare. In recent years, much attention has been paid to the assessment of the quality of health care provided to the patients suffering from chronic conditions. Understanding the views of RA patients, their perceptions of the disease and its treatment, could provide valuable insight to the design of novel therapeutic strategies and the designation of therapeutic priorities (1). The patients' experience about health care provided came to focus following the suggestions to link payments to hospitals conditional to the quality of care the patients receive (2). This would be based on a range of quality measures, including clinical outcomes, patient experience with their diagnosis and management journey as well as the patients' views regarding the success of their treatment. Unfortunately, data sets available describing the patients perspectives and expectations toward their disease and management are either nonspecific or have a limited scope (3). Patient Reported Experience Measures (PREMs) has been proposed as a measure of patients' perception of and satisfaction with care. This may include treatment, participation, information, confidence in the caregiver and availability. Therefore, the development of a PREMs for inflammatory arthritis patients is a move away from the traditional medical model and patient satisfaction questionnaires, to look at the long term health care and the patient's journey starting with joint pains to diagnosis and management. The aim is to identify the principle determinants of quality of care and experience which will then make it possible to benchmark future service provision (4).

In contrast with the patient reported outcome measures (PROMs) which focus mainly on outcomes and disease activity, PREMs addresses key areas such as structure, process, impact on the patient's life as well as outcome, recorded from the patient's perspective (5). Therefore, if care plans are designed tailored to the patient's own needs, this will enable the treating health care

professional to know whether the treatment targets have been met. This can be achieved by fully involving patients in developing and evaluating their own care plans. Thus PREMs may become an essential part of quality assessment in day to day practice (6).

The concept of both patient satisfaction and patient experience is considered to be a multidimensional process that requires a more comprehensive instrument than an individual question to give good feedback of the patients' satisfaction or experiences. Unfortunately, this concept of patient satisfaction and its measurement has been overlooked by researchers. Therefore, the currently available generic tools of measuring the patients' satisfaction and experience may not be adequate to assess quality of health care in inflammatory arthritis patients. The aim of this work was to develop a valid and reliable Patient Reported Experience Measure questionnaire for patients with inflammatory arthritis/ spondyloarthritis, which can be used in standard clinical practice as a metrics for quality improvement in healthcare.

Methods

The PREMs questionnaire was conceptualised based on frameworks used by the WHO Quality of Life tool, as well as the PRO measurement information system (PROMIS).

Participants

The patients cohort included RA diagnosed according to the EULAR/ACR 2010 diagnostic criteria (7), spondyloarthritis diagnosed according to ASAS diagnostic criteria (8), and psoriatic arthritis patients diagnosed according to CASPAR classification criteria (9).

Phase 1:

Item identification

The first phase of the study involved qualitative interviews with a sample of patients requiring long term health care for inflammatory arthritis. Cognitive interviews were conducted with 94 patients suffering from inflammatory arthritis / spondyloarthritis, with a range of severity and disease activity to identify item pool of questions. The sample

Competing interests: none declared.

comprised 72.3% (68) females with a mean age of 51 years and 27.7% (26) males with a mean age of 53 years.

The resulting analysis of these interviews had two layers. The first layer relates to content and the second layer relates to the affective responses. Item selection and reduction was achieved based on patients as well as an interdisciplinary group of physicians, nurses, health educators and Occupational therapists feedback, in addition to clinometric and psychometric methods. The latter included Rasch and internal consistency reliability analyses.

Phase 2:

Questionnaire development

The PREMs questionnaire was developed centered around 5 categories: 1. Journey to diagnosis: onset of disease – duration till diagnosis – treatment-control of disease activity; 2. Arthritis and life: Impact of the disease on the patients' life and ability to carry out their daily activities; 3. Knowledge of the disease, 4. The care in the hospital; and 5. Patient education and aftercare: including instructions in case of exacerbation. After analysis for ordered response options, content analysis and semi structured group discussion to cover these 5 categories, 32 questions were identified as the final item set.

Phase 3:

Validation of the developed questionnaire

The routine rheumatology clinics were used as a setting for the questionnaire evaluation. 183 patients were asked to complete the PROMs (10, 11) as well as PREMs questionnaires whilst sitting in the waiting area before being examined by the treating physician. To assess the validity of the PREMs questionnaire items were compared to parameters of disease activity. Patients' answers for their journey to diagnosis were compared to time of referral, time to confirm the diagnosis and onset of treatment. Impact of the disease on the patients' everyday life was compared to the patients' functional disability score. Knowledge about the disease was compared to the patients' adherence to therapy and patient global assessment score. Care experience was compared

to waiting times for clinical assessment, x-ray or US/MRI scans and laboratory tests. Patient education and after care were compared to number of missed hospital appointments and number of contact to the rheumatology helpline, as well as number of the patients' visits to their GP in between hospital appointments for new complaints.

Phase 4:

Comprehensibility and reliability

After completing the questionnaire for the first time, every patient was asked to rate the questionnaire out of a score of 10 to assess for its comprehensibility. Every patient was asked to complete a second copy of the questionnaire one week after completing the first copy.

Local ethical and methodological protocols' approval for study conduction were obtained. All patients who shared in the study signed an informed consent according to the Declaration of Helsinki.

Statistical analysis

Rasch analysis: the Rasch computer programme Winsteps was used in this work (12, 17). The fit of the data to the model is expressed in 2 ways. First the mean square information-weighted statistic (INFIT) provides information about responses given to items around the same concept. Second, the outlier-sensitive statistic (OUTFIT) refers to non-related items. Taken together, INFIT and OUTFIT allow to construct a detailed picture of the working of items within a scale. It is usual to see an INFIT/OUTFIT range of 0.7–1.3 to denote adequate fit of the data to the model (32). However, the magnitude of the fit statistics is affected by sample size and, in the case of un-weighted fit statistic (OUTFIT), by the number of items being summated. To have a consistent Type I error rate of approximately 0.05, a critical value for the upper limit of OUTFIT would be 1.3 with 150 persons, 1.2 with 500 persons and 1.1 with 1000 persons samples (33). A poor item fit statistic can indicate poorly constructed or understood items or, when a scale score is assigned by a professional lack of reliability in assignment. Otherwise, poor fit may indicate

problems with uni-dimensionality, that is, the item does not “belong” to the construct or attribute being measured. In the Rasch model of Impact of the disease on the patients' everyday life and disability, functional ability is considered to lie upon a linear “ruler,” similar to an ordinary ruler, where no disability is the anchor at one end and maximum disability is the anchor at the other end. The range of disability is expressed in logits, a completely linear measure. An item (question) threshold represents the position in logits that the item occupies on the linear scale. By plotting the item thresholds for each measure, it was possible to determine the width of the construct covered by each measure and the manner in which the thresholds mark that construct. Finally, the floor and ceiling percent was calculated for each item.

Descriptive statistical measures are presented as frequency distribution for categorical variables and mean and standard deviation in case of normally distributed continuous variables. Median and interquartile range was used to describe skewed data including their minimum and maximum values. Spearman correlation was used to test correlation and estimate validity of the PREMs items to clinical parameters. Paired student-*t* or Wilcoxon Signed rank tests were used for reliability testing taking into consideration the normality of the variable distribution. For all inferential statistics *p*-value was always set at 0.05.

Results

Questionnaire analysis

The PREMs questionnaire: The items of the questionnaire (Appendix 1) displayed adequate fit to the Rasch model. This is denoted by 2 fit statistics, INFIT and OUTFIT. For the number of cases in this study, INFIT and OUTFIT values within the range 0.71 to 1.29 represent adequate fit to the model (INFIT ranged from 0.81-1.02, OUTFIT range 0.80–1.09).

Results of the validation study

One hundred and eighty-three (183) consecutive patients treated in the rheumatology outpatient clinic were included in this phase. They were

97 with rheumatoid arthritis and 86 Spondyloarthritis. Table I shows the baseline characteristics of the patients who participated in this work including their demographics, disease duration and type of treatment. The tool was derived from patients suffering from inflammatory arthritis, therefore ensuring its face validity. The questionnaire items correlated significantly ($p < 0.01$) with clinical parameters of disease activity (Table II), PROMs, self-helplessness and DAS-28 score (for rheumatoid arthritis patients) as well as ASDAS score (for spondyloarthritis patients) supporting its construct validity. The score of "Arthritis and life" domain assessing the impact of arthritis on the patients' lives correlated significantly ($p < 0.01$) with HRQoL score as well as disease activity and damage measures, establishing its criterion validity. Patient education and aftercare correlated significantly ($p < 0.01$) with adherence to therapy. Table III shows the significant correlation of the PREM questionnaire items to the total score of the 5 main categories. The PREMs questionnaire showed internal consistency as demonstrated by a relatively high-standardised Cronbach alpha (0.892).

Comprehensibility and reliability

There was no significant difference in responses on comparing the first to the second run of the questionnaire (Table IV) thus showing an accepted reproducibility (reliability). Similarly, there was no significant difference on comparing patients' answers to "Managing Illness with Patient" and "Willingness to Complete Arthritis Questionnaire" Domains in the 1st to the 2nd run. The PREMs questionnaire also showed a high degree of comprehensibility (9.3).

Discussion

The optimal management of chronic diseases such as inflammatory arthritis relies on a high degree of patient concordance with lifestyle measures, medications and therapeutic intervention. Concordance is more likely if patients understand their condition and have confidence in the health care providers as well as the treatment they receive. The process of asking the patients to re-

port their views on a service, can guide service improvement and redesign modification of management (18-20). For these reasons, assessing patient-related experiences with clinical services became a legitimate outcome for a professional health care service (21, 22). Results of this study revealed that integrating PREMs into standard clinical practice is feasible and applicable. This PREMs questionnaire was found to be valid and reliable. It provided an informative measure for the patients' experience with their disease, and in the meantime, facilitates incorporating the patients' feedback into the patients' management algorithm. Similar findings were reported on assessing PREMs for COPD, cancer and pediatrics (23-26). In another rheumatology study, a survey was conducted on Rheumatology Monitoring Clinics, to ensure that stable patients with rheumatoid arthritis and spondyloarthritis on disease modifying anti-rheumatic drugs were monitored regularly and appropriately for drug toxicity, showed that the survey received positive feedback from patients, with an overall high degree of satisfaction (27). Questionnaires about people's health status are not new; PROMs has been used for many years as a means of seeking patients' views on their disease activity, the impact of the disease on their lives or the intervention being studied (28, 29). PREMs expands the scope of the care provided to the patients to give an extra focus on the potential links between health-related quality of life and patient satisfaction. PREMs can be used, on a less frequent basis, to understand patients' views on their experience whilst receiving the care, rather than the outcome of that care (30). Results of this work revealed a significant correlation between satisfaction and experience of care provided to the patient and patient-reported health outcome measures. Measurements of patients' experiences of care are important for the caregiver to be able to improve care in areas where patients feel that there are gaps. Therefore, choosing a PREMs tool is a crucial step. With the non-applicability of a general PREMs instrument that

Table I. Demographics, disease duration and type of treatment.

Variable	Statistic
Age	
Mean (SD)	57.8 (15.9)
Min - Max	30 - 90
Sex: n (%)	
Male	43 (23.5)
Female	140 (76.5)
Disease duration in years	
Median (IQR)	6 (5)
Min - Max	0.25 - 26.0
DMARD intake: n (%)	176 (96.2)
Biologic therapy: n (%)	118 (64.5)

Table II. Correlation of the "Arthritis and Life" domain with other clinically assessed disease activity parameters.

Clinical Parameters	Spearman Coefficient
Functional disability	0.902*
Quality of life	0.911*
Pain score	0.869*
PGA	0.892*
Fatigue	0.889*
DAS 28	0.857*
ASDAS	0.874*

* $p < 0.01$.

Table III. Correlation of the PREM questionnaire items to the total score of the 5 main categories.

PREMs Questionnaire Item	Correlation
Functional ability	0.338*
Severity of arthritis	0.411*
Changing lifestyle	0.297*
Time to clinic refer	0.536*
Time to be seen in hospital	0.688*
Helpline facility	0.517*
Waiting in waiting area	0.434*
Waiting in exam room	0.326*
Procedures explanation	0.188 NS
After care	0.323*

* $p < 0.01$.

works in all situations, it is important to develop a specific tool with deeper knowledge of the patients' needs and expected outcomes. This might differentiate PREMs from PROMs, where both general instruments like the SF-36 and EQ-5D or specific questionnaires (10, 11, 31) can be used for all the patients. Advice for identifying a good PREMs questionnaire includes: 1. Choose an instrument that covers several dimensions of the concept of

Table IV. Test-retest reliability between averages of different items of the questionnaire.

	1 st Run Mean (SD)	2 nd Run Mean (SD)	p-value
Arthritis and life	1.7 (1.0)	1.7 (1.0)	0.323 NS
Managing illness with patient			NS
Access to care	3.1 (1.1)	3.2 (1.1)	0.057 NS
Attitude to the patient (waiting)	4.3 (0.6)	4.4 (0.5)	0.291 NS
Doctor performance	4.9 (0.2)	4.9 (0.1)	0.291 NS
Nurse performance	4.7 (0.4)	4.8 (0.3)	0.023*
Other staff performance	4.3 (1.0)	4.4 (1.1)	0.025*
Willingness to complete arthritis questionnaire	98.7%	98.5%	NS
Procedural explanation	4.8 (0.4)	4.9 (0.3)	0.160 NS
After care	3.8 (1.0)	3.85 (0.7)	0.071 NS

patient satisfaction or patient experience. 2. Also to choose an instrument that has been tested for validity and reliability. However, it is important to remember that sometimes patient's expectations are unrealistic which is another hurdle that health care provider should deal with (28).

As healthcare is a multi-dimensional service, measuring satisfaction has become an important for public policy analysts, healthcare managers, practitioners and users. Despite problems with establishing a tangible definition of "satisfaction" and difficulties with its measurement, the concept continues to be widely used. Satisfaction can be measured in several ways. Displays can be measured by asking users to rate the quality of services they have received, or report their experiences. Selection (or de-selection) of providers is an objective behavioral indicator of satisfaction in health care System (27). Using paper format versus online surveys has been also studied by Lagha *et al.*, 2012 (32). A total of 121 patients were asked to rate their experience with the treatment they received for their congestive heart failure. 73 patients completed a questionnaire which was posted to them, whereas, 48 patients completed an online survey. The online cohort' participants were younger, had less contact with the specialist nurse and seemed less satisfied with the quality of clinical services. On the other hand, the postal cohort returned fewer negative comments (20 [27.4%] vs. 28 [58.3%]; $p < 0.0001$). In conclusion, integrating PREMs into standard clinical practice is feasible and applicable. The studied PREMs questionnaire was valid, reliable and

comprehensible. The patients were able to comprehend varying response options on a categorical scale, and could accurately respond to items using a 7-day recall period. It provides informative measures for the patients' experience with their disease, and in the meantime, facilitates incorporating the patients' feedback into the patients' management algorithm.

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Appendix I

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.

<p>Your Age:years.</p> <p>Your Sex: Male: <input type="checkbox"/> Female: <input type="checkbox"/></p> <p>Your Diagnosis:</p> <p>I. Arthritis & your life:</p> <p>-How does your Arthritis affect ability to carry out your daily tasks?</p> <p>Always: <input type="checkbox"/> Usually <input type="checkbox"/> At times: <input type="checkbox"/> occasionally: <input type="checkbox"/> Not at all: <input type="checkbox"/></p> <p>-How would you rate the severity of your Arthritis?</p> <p>Very Severe: <input type="checkbox"/> Severe: <input type="checkbox"/> Moderate: <input type="checkbox"/> Mild: <input type="checkbox"/></p> <p>-Have you changed your life style to address your Arthritis? I have made:</p> <p>No change: <input type="checkbox"/> Few changes: <input type="checkbox"/> Some changes: <input type="checkbox"/> Many changes: <input type="checkbox"/> Altered my lifestyle: <input type="checkbox"/></p> <p>II. Your Arthritis Management:</p> <p>-Were you given the opportunity to discuss your health concerns, preferences of management & potential consequences?</p> <p>Yes: <input type="checkbox"/> No: <input type="checkbox"/></p> <p>-Were you given the opportunity to choose, accept or decline medical treatment?</p> <p>Yes: <input type="checkbox"/> No: <input type="checkbox"/></p> <p>-Have you been treated with respect, dignity and compassion?</p> <p>Yes: <input type="checkbox"/> No: <input type="checkbox"/></p> <p>In the next section, Please circle the number which reflects your experience in the following areas, please note that: 1= Poor, 2= Fair, 3= OK, 4= Good, 5= Excellent</p> <p>III. Journey to Diagnosis:</p> <p>• Diagnosis & Ease of getting care:</p> <p>How would you rate your experience with</p> <p>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: <input type="checkbox"/></p> <p>• Waiting: How would you rate your experience with</p> <p>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</p>	<p>IV: care in the hospital: Staff:</p> <p>Has the treating Dr. / Rheumatology Nurse</p> <p>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 You advice and treatment: 1 2 3 4 5 Answered your questions: 1 2 3 4 5</p> <p>Clinic Nurse: Was the Nurse</p> <p>Friendly and helpful to you: 1 2 3 4 5 Answered your questions: 1 2 3 4 5</p> <p>Others (e.g. receptionists/ Assistants): Were they</p> <p>Friendly and helpful to you: 1 2 3 4 5 Answered your questions: 1 2 3 4 5</p> <p>• Questionnaire regarding your Arthritis:</p> <p>-No Questionnaire was given: <input type="checkbox"/></p> <p>-Did you find the questionnaire given to you today of relevance to your condition?</p> <p>Yes: <input type="checkbox"/> No: <input type="checkbox"/></p> <p>-To enable us to monitor your disease activity & provide appropriate treatment are you happy to complete the arthritis questionnaire in your next clinic visit?</p> <p>Yes: <input type="checkbox"/> No: <input type="checkbox"/></p> <p>• How would you rate the explanation of any procedures carried out & their findings:</p> <p>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 <input type="checkbox"/></p> <p>V: Patient Education and Aftercare:</p> <p>• Aftercare: Please rate your satisfaction with</p> <p>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</p> <p>• Patient education: Information leaflets</p> <p>Not given: <input type="checkbox"/></p> <p>If given, it was:</p> <p>-Clear and informative: 1 2 3 4 5 -Answer your queries: 1 2 3 4 5 -Patient friendly: 1 2 3 4 5</p>
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You are welcome to put any further comments / suggestions on the back of the page. Thank you.