

The History of Patient-Reported Outcomes in Rheumatology



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KEYWORDS

- Patient-reported outcomes • Health Assessment Questionnaire
- Arthritis Impact Measurement Scales • Rheumatic diseases • Rheumatology
- Health status assessment • Self-report measures

KEY POINTS

- Historically, rheumatology researchers and clinicians have been at the forefront of patient-reported outcomes assessment and changing the paradigm from a narrower biomedical model to a broader biopsychosocial model of health.
- The Health Assessment Questionnaire and the Arthritis Impact Measurement Scales were published in 1980 as the foundation patient-reported outcome scales in rheumatology.
- More than 250 instruments are available for measuring outcomes of importance to patients with rheumatic diseases, including functional incapacity, disability, pain, fatigue, depression, anxiety, perceived helplessness, self-efficacy, sleep disruptions, work limitations, and social role participation.
- The approach for patient-reported outcome measurement is moving from classic test theory to modern psychometric theory and the Patient Reported Outcome Measurement Information System offers opportunities for rheumatology.
- The initial use of patient-reported outcomes measures in rheumatology was in the research arena, but strong efforts were made over the last 15 to 20 years to promote their value in routine clinical care to assess, monitor, and predict outcomes, such as work disability, costs, and mortality and assess new therapies in clinical trials.

INTRODUCTION

Chronic diseases require measurement for diagnosis and management. As noted by Lord Kelvin in the 19th century, “When you cannot measure it, when you cannot express it in numbers, you have scarcely, in your thoughts, advanced to the stage of science, whatever the matter may be.” Measurement in arthritis and rheumatic

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diseases initially focused on radiographic changes, tender or swollen joints, erythrocyte sedimentation rate, grip strength, morning stiffness, and the subjective global assessment by a physician of a patient's status. In 1949, the American Rheumatism Association Functional Classification was proposed by Steinbrocker's committee to assess functional status in patients with rheumatoid arthritis (RA).¹ Physicians classified RA patients' function into 1 of 4 categories: (1) complete functional capacity, (2) functional capacity adequate to conduct normal activities, (3) functional capacity adequate to perform few or none, and (4) largely or wholly incapacitated.¹ This classification was the first attempt to quantify and measure functional incapacity or disability, the final common pathway of uncontrolled arthritis and many rheumatic and musculoskeletal conditions.²

In the 1970s, individuals interested in measuring health status outcomes noted that in chronic disease, outcome must be more sensitive and include physical, mental, and social functioning of the patient.^{3,4} In rheumatic diseases, many of the outcomes of importance to the patient are best assessed through self-report. In addition to functional incapacity or disability, these outcomes include pain, fatigue, depression, anxiety, perceived helplessness, self-efficacy, sleep disruptions, work limitations, and social role participation.^{5,6} As noted in the introductions to the 2003 and 2011 *Arthritis Care and Research* special issues on patient outcomes in rheumatology, historically, rheumatology researchers have been at the forefront of patient-reported outcomes assessment.^{5,7} This article reviews the beginnings of patient-reported outcome assessment in rheumatic diseases, the breadth of patient-reported outcome measures and instruments available today, refinements of the patient-reported outcomes measurement approach, and efforts that have been made to incorporate patient-reported measures as a standard of assessment in clinical research including clinical trials and in routine rheumatologic clinical care.

THE BEGINNING OF PATIENT-REPORTED OUTCOMES IN RHEUMATIC DISEASES

In the February 1980 issue of *Arthritis and Rheumatism*, 2 seminal articles were published back to back.^{8,9} Fries and colleagues⁸ published, Measurement of Patient Outcome in Arthritis, and Meenan and colleagues⁹ published Measuring Health Status in Arthritis: The Arthritis Impact Measurement Scales. Both articles described multidimensional self-report questionnaires designed to assess outcomes in patients with rheumatic disease. The article by Fries and colleagues⁸ presented a structure for the representation of patient outcome represented by 5 separate dimensions: death, discomfort, disability, drug (therapeutic) toxicity, and dollar cost. Each dimension represented an outcome directly related to patient welfare, and the dimensions could be performed at interview or by patient questionnaire.⁸ The patient-reported Health Assessment Questionnaire (HAQ) disability index, sometimes referred to as the *HAQ DI, original, or legacy HAQ*, evaluates difficulty in performing activities of daily living over the past week in 8 categories (dressing and grooming, arising, eating, walking, hygiene, reaching, gripping, and errands and chores). Twenty specific activities are assessed on a 4-point Likert scale from without difficulty to unable to do. Thirteen additional questions assess the use of assistive devices, and 8 additional questions assess help received from others.

The Arthritis Impact Measurement Scales (AIMS) assess physical, emotional, and social well-being.⁹ Mobility, physical activity, dexterity, social role, social activity, activities of daily living, pain, depression, and anxiety were all part of the original AIMS, which was a combination of previously studied and newly developed (at the time) health status scales. The 2 previously tested measures that the AIMS instrument

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