

Patients and Clinicians Have Different Perspectives on Outcomes in Arthritis

SARAH A. HEWLETT

ABSTRACT. Outcome measurement in arthritis has undergone a major shift during the past 2 decades, moving from process measures (e.g., plasma viscosity) to patient-centered outcome measures (e.g., pain, function). However, while patients self-report many of these outcomes, it is clinicians who judge those reports to guide clinical decisions and define the efficacy of treatments in clinical trials. It is important to ascertain whether patient or professional views converge or diverge and also whether the outcomes being measured are those of importance to patients. This article reviews some of the available evidence on the congruence (or otherwise) of patient and professional views of outcome, and reports considerable variation between the 2 views. Reasons why views might differ are discussed (for example, disease activity might be assessed using different variables by patients and clinicians), and the possibility of the effect of the personal meaning or impact of an outcome for a patient is raised. Finally the significance of these discrepant views is addressed, posing the challenge of how we might incorporate a measure of the personal meaning of an outcome to a patient into our outcome measures. (*J Rheumatol* 2003;30:877-9)

Key Indexing Terms:

RHEUMATOID ARTHRITIS

PATIENTS

OUTCOME ASSESSMENT

Function, like love, is a many splendoured thing and very much in the eye of the beholder¹.

Outcome measurement in arthritis has undergone a major shift during the past few decades, moving from what was primarily the assessment of process measures (e.g., inflammation, using markers such as plasma viscosity, or destruction, measured by bony erosions) to the assessment of patient-centered outcomes such as function or physical and mental well being. Prompted by the publication of some seminal patient-centered measures^{2,3}, substantial research into the development and validation of these patient-centered scales has produced an array of scales constituting an impressive, well respected body of science⁴. Thus in arthritis, perhaps more than in many other diseases, we have moved away from concentrating solely on impairment at tissue level toward a more inclusive approach of assessing symptoms and activity and participation limitations⁵.

The majority of patient-centered measures are collected by self-report and currently concentrate largely on activity limitation (physical function), symptoms (pain, stiffness), and participation limitation (social consequences, quality of life). It might be assumed therefore that because the measures being assessed are generally important to patients^{6,7} and are assessed by patients themselves, we have an adequate picture by which to judge the level of arthritis and its consequences for the patient. However, while patients make their self-reports using these measures, it is

the clinicians who make judgments upon their reports, and it is the clinicians' judgments that are used to guide therapeutic discussions with the patient⁸. It is important, therefore, to ascertain whether patient and professional judgments converge or diverge.

Patient and Professional Views — Convergent or Divergent?

There is an increasing body of evidence that patients' opinions do not coincide with those of the professionals caring for them. In rheumatoid arthritis (RA) it has been shown that patient and professional assessments of the patient's physical and mental function differ (in 42% and 47% of cases, respectively), even though patients and professionals completed the same scale⁹. Other RA studies show discrepancy between patients and physicians in the assessment of physical function (35% of occasions), with physicians' ratings varying between more and less disabled than the patients' self-ratings¹⁰. Discrepancies have also been shown between physician and patient ratings of pain, overall health, and willingness to take risks for improving health, with physicians rating their patients' health status as better than patients do, but physicians being less willing than the patients to take risks to achieve good outcomes¹¹. Similar discrepancies are seen in other rheumatological disorders, such as systemic lupus erythematosus (SLE), where there is discordance between physician and patient assessment of disease activity, with physicians varying between lower and higher scores than patients (6% lower, 16% higher)¹². Further discrepancies between patient and physician assessments of health status are reported in fibromyalgia¹³. Some studies, however, report little difference between self-report

From the ARC Senior Lecturer in Rheumatology (Health Professions), Academic Rheumatology, University of Bristol, Bristol Royal Infirmary, Bristol BS2 8HW, UK. E-mail: Sarah.Hewlett@bristol.ac.uk

and observed assessments of health status by patients and physicians in RA and ankylosing spondylitis¹³⁻¹⁵.

Discrepancies between professional and patient judgments on the patients' health status are reported in other diseases. In cancer, physicians' ratings explained only 30% of the variance in their patients' ratings of quality of life, anxiety, and depression, with physicians systematically underestimating quality of life, social and role functioning in breast cancer, and pain in prostate cancer^{16,17}. In primary care, general practitioners (GP) rate their patients' pain significantly lower than patients (20–40% lower on 57% of occasions) and in osteoarthritis, GP underestimate patient reports of disability, depression, and anxiety^{18,19}. In multiple sclerosis, one study reported strong correlation between physician and patient ratings of physical disability ($r = 0.87$)²⁰.

Physicians and patients differ not only in their assessment of symptom severity but also in symptom importance. Physician and patient opinions on the most important domains of health for patients with multiple sclerosis differ significantly, with physicians rating physical function and physical role limitation as important, and patients rating mental health and emotional role limitations as important²⁰. In rheumatology, physician and patient ratings for the importance of the Health Assessment Questionnaire (HAQ) items show only slight to fair agreement ($\kappa < 0.38$), while physicians' ability to identify their patients' most important and least important outcomes for psychological health is poor (48% and 59%, respectively)^{7,21}.

Why Might Patient and Professional Views Differ?

Patient and professional views might differ because the 2 groups focus on different things. In SLE, patients base their assessments of disease activity on its psychological effects, while physicians base their assessment on its physical effects¹². Patients' assessments may be influenced by their needs, priorities, experiences, expectations, and attitudes²², while professional opinions may be more directly related to the patient's physical health status — perhaps patients rate their illness while professionals rate the disease¹³. Patients may take into account the pain and effort it takes to perform a function, while professionals may rate only the ability¹². This concept is supported by evidence that patients' dissatisfaction with disability is only moderately explained by their level of disability²³⁻²⁵. It could be, therefore, that patients evaluate the personal impact of an outcome when they assess health status. The impact of a health outcome could be related to the interaction between its personal importance and level of severity — that is, only difficulty with outcomes of personal importance cause personal impact. Methodology using importance as a weighting to capture personal impact has been explored in a number of scales²⁶⁻²⁹.

It is conceivable that professionals judge certain activi-

ties as being less important than do patients because professional training encourages them to suggest ways around problems (e.g., the patient could take a shower instead of a bath). Patients, however, may continue to desire to perform valued functions they have lost, no matter that there is a substitute. Qualitative research to establish which outcomes are important to patients reveals concepts such as “feeling well in myself,” “being normal again,” fatigue, and emotional consequences to be important outcomes, although these are not within the American College of Rheumatology core set of outcome measures³⁰. Professional judgments may be made in a manner that is systematically different for different levels of health status severity, or for different aspects of health status. Data show that physicians are more likely to overestimate patients' physical disability in patients with high levels of disability, but that they are more likely to underestimate psychological distress in patients with high levels of psychological distress⁹. However, other researchers report that no special patient characteristics predict divergence of views¹¹. Discrepancies have been shown between change in health status (calculated using serial assessments) and patient perception of change using transition questions³¹. Evidence suggests that patients define “being better” in ways other than a simple resolution of symptoms, for example by concepts such as readjustment or redefinition of the problem³².

What Is the Significance of the Discrepancy Between Patient and Professional Views?

These reported differences between patients and professionals over symptom severity and importance matter because professionals use their judgments of patient self-reported disease status to understand the patient and the disease, to judge the efficacy of treatments, and to guide their therapeutic decisions.

There are 3 potential assumptions that may occur with this approach that bear further consideration, particularly in the light of the evidence of divergence of views. First, familiarity with some measures (e.g., frequently used measures of disability or pain) may lead professionals to assume such scores mean the same in practical and emotional terms to everyone; for example, that a pain score of 7.6 out of 10 has a universal value for all patients. Common sense tells us this is an inappropriate assumption, even though we may still make it unconsciously. Second, as experienced professionals we may have a mental picture of what a particular score means, that is, we know what that universal value is. For example, a disability score of 2.75 on the HAQ² may for most clinicians conjure up a rather gloomy patient scenario. However, we all have patients in our practice with high levels of disability who can still produce intricate paintings or needlework. Third, in the absence of any specific patient information we may assume that the score reported is important to the patient. Such an assumption may be

misguided; for example, an inability to climb stairs in a person living in a bungalow may not be personally important, but even a minor difficulty with stairs might be of major importance to a patient in a 3-storey house. In short, by failing to assess the meaning an outcome score has for a patient, we may unconsciously impose our own judgments upon the facts⁷. The challenge before us, therefore, is to explore how we might incorporate the personal meaning of an outcome for patients into the “facts” of outcome, which is what we currently measure. This would allow us to interpret clinical and trial data better, and target therapies more individually.

By including measures of the patient’s view alongside traditional patient and physician assessments, we would be able to recognize the major impact of “minor” health status problems and also the “minor” impact of major health problems for individual patients.

...approaching disease without consideration of its effect on the individual reduces the concerns of physicians about human suffering to manipulatable, measurable portions but misses its human dimensions.¹

REFERENCES

- Liang MH. The historical and conceptual framework for functional assessment in rheumatic disease. *J Rheumatol* 1987;14:2-5.
- Fries JF, Spitz P, Kraines RG, Holman HR. Measurement of patient outcome in arthritis. *Arthritis Rheum* 1980;23:137-45.
- Meenan RF, Gertman PM, Mason JM. Measuring health status in arthritis: the Arthritis Impact Measurement Scale. *Arthritis Rheum* 1980;23:46-153.
- Bellamy N, editor. *Musculoskeletal clinical metrology*. Lancaster: Kluwer Academic; 1993.
- World Health Organization. International classification of functioning, disability and health (ICIDH-2). Available from: www3.who.int/icf/icftemplate.cfm [cited February 20, 2003].
- Carr AJ. A patient-centred approach to evaluation and treatment in rheumatoid arthritis: the development of a clinical tool to measure patient-perceived handicap. *Br J Rheumatol* 1996;35:921-32.
- Hewlett S, Smith AP, Kirwan JR. Values for function in rheumatoid arthritis: patients, professionals and public. *Ann Rheum Dis* 2001;60:928-33.
- Kirwan JR, Chaput de Saintonge DM, Joyce CR. Clinical judgment analysis. *QJM* 1990;76:935-49.
- Kwoh CK, O’Connor GT, Regan-Smith MG, et al. Concordance between clinician and patient assessment of physical and mental health status. *J Rheumatol* 1992;19:1031-7.
- Berkanovic E, Hurwicz ML, Lachenbruch PA. Concordant and discrepant views of patients’ physical functioning. *Arthritis Care Res* 1995;8:94-101.
- Suarez-Almazor ME, Conner-Spady B, Kendall CJ, Russell AS, Skeith K. Lack of congruence in the ratings of patients’ health status by patients and their physicians. *Med Decis Making* 2001;21:113-21.
- Neville C, Clarke AE, Joseph L, Belisle P, Ferland D, Fortin PR. Learning from discordance in patient and physician global assessments of systemic lupus erythematosus disease activity. *J Rheumatol* 2000;27:675-9.
- Hidding A, Van Santen M, De Klerk E, et al. Comparison between self-report measures and clinical observations of functional disability in ankylosing spondylitis, rheumatoid arthritis and fibromyalgia. *J Rheumatol* 1994;21:818-23.
- Jacobs JW, Oosterveld FG, Deurbouts N, et al. Opinions of patients with rheumatoid arthritis about their own functional capacity: how valid is it? *Ann Rheum Dis* 1992;51:765-8.
- McDaniel LK, Anderson KO, Bradley LA, et al. Development of an observation method for assessing pain behavior in rheumatoid arthritis patients. *Pain* 1986;24:165-84.
- Slevin M, Plant H, Lynch D, Drinkwater J, Gregory W. Who should measure quality of life, the doctor or the patient? *Br J Cancer* 1988;57:109-12.
- Wilson KA, Dowling AJ, Abdolell M, Tannock IF. Perception of quality of life by patients, partners and treating physicians. *Qual Life Res* 2000;9:1041-52.
- Mantyselka P, Kumpusalo E, Ahonen R, Takala J. Patients’ versus general practitioners’ assessments of pain intensity in primary care patients with non-cancer pain. *Br J Gen Pract* 2001;51:995-7.
- Memel DS, Kirwan JR, Sharp DJ, Hehir M. General practitioners miss disability and anxiety as well as depression in their patients with osteoarthritis. *Br J Gen Pract* 2000;50:645-8.
- Rothwell PM, McDowell Z, Wong CK, Dorman PJ. Doctors and patients don’t agree: cross-sectional study of patients’ and doctors’ perceptions and assessments of disability in multiple sclerosis. *BMJ* 1997;314:1580-3.
- Kwoh CK, Ibrahim SA. Rheumatology patient and physician concordance with respect to important health and symptom status outcomes. *Arthritis Care Res* 2001;45:372-7.
- Liang MH, Cullen K, Larson M. In search of a more perfect mousetrap (health status or quality of life instruments). *J Rheumatol* 1982;9:775-9.
- Pincus T, Summey JA, Soraci SA, Wallston KA, Hummon NP. Assessment of patient satisfaction in activities of daily living using a modified Stanford Health Assessment Questionnaire. *Arthritis Rheum* 1983;26:1346-53.
- Giorgino KB, Blalock SJ, DeVellis RF, DeVellis BM, Keefe FJ, Jordan JM. Appraisal of and coping with arthritis related problems in household activities, leisure activities and pain management. *Arthritis Care Res* 1994;7:20-8.
- Hewlett S, Young P, Kirwan JR. Dissatisfaction, disability and rheumatoid arthritis. *Arthritis Care Res* 1995;8:4-9.
- Tugwell P, Bombardier C, Buchanan WW, Goldsmith CH, Grace E, Hanna B. The MACTAR patient preference disability questionnaire — an individualized functional priority approach for assessing improvement in physical disability in clinical trials in rheumatoid arthritis. *J Rheumatol* 1987;14:446-51.
- Hewlett S. Values, disability and personal impact in rheumatoid arthritis [PhD thesis]. Bristol: University of Bristol; 2000.
- Ruta DA, Garratt AM, Leng M, Russell IT, MacDonald LM. A new approach to the measurement of quality of life — the Patient Generated Index. *Med Care* 1994;32:1109-26.
- Laman H, Lankhorst GJ. Subjective weighting of disability: an approach to quality of life assessment in rehabilitation. *Disab Rehab* 1994;16:198-204.
- Felson DT, Anderson JJ, Boers M, et al. The American College of Rheumatology preliminary core set of disease activity measures for rheumatoid arthritis clinical trials. *Arthritis Rheum* 1993;36:729-40.
- Hewlett S, Kirwan JR. Discrepancies between actual and perceived change in function in rheumatoid arthritis are not a function of memory [abstract]. *Br J Rheumatol* 1998;37:S177.
- Beaton DE, Tarasuk V, Katz JN, Wright JG, Bombardier C. ‘Are you better?’ A qualitative study of the meaning of recovery. *Arthritis Rheum* 2001;45:270-9.