Assessing the health status of people with arthritis: example of osteoarthritis of the knee

Do outcome measures help the clinician?

Over the past few decades many articles about outcome measures have been published. A variety of self-assessment instruments are now available to help assess the health status of people with almost any disease [1]. The drive to develop more and better outcome instruments has been part of evidence-based medicine, which has been led by the need to find reliable and valid ways of assessing the response to interventions in clinical trials. The use of such instruments certainly helps the researchers who develop them, but do they help the clinician? Here we argue that they do not, and using the example of OA of the knee, we suggest that simpler approaches are needed for routine clinical practice.

In the case of OA of the knee, research organizations such as the Outcome Measures in Rheumatoid Arthritis Clinical Trials (OMERACT)/Osteoarthritis Research Society International (OARSI) [2] and Group for the Respect of Ethics and Excellence in Science (GREES) [3] recommend that pain severity, disability and quality of life should be assessed using validated, standardized self-assessment measures such as the Western Ontario and McMaster Universities Arthritis Index (WOMAC) and EuroQoL-5D (EQ-5D). But the clinician may need to take a different approach.

Pain is the dominant symptom for most people with OA. Usually researchers just assess severity, using many different self-assessment approaches, although many new and more complicated ways to assess pain, such as quantitative sensory testing [4], are now available and recommended for use in research.

Qualitative work on people with OA of the knee shows that they have two types of pain: their constant, usual pain and more distressing, intermittent attacks of pain [5]. In addition, they are often as distressed by fatigue as they are by pain. So clinicians need simple ways to assess constant pain, intermittent pain and fatigue—perhaps with the use of face charts. If clinicians do ask about these issues, it shows the patient that they understand the symptoms the patient is experiencing.

Rheumatologists have used a restricted approach to assess disability, generally using self-assessment of standard activities of daily life such as walking or dressing. The International Classification of Functioning, Health and Disability (ICF) framework [6] reveals the weakness of such measures, as they ignore the key issue of participation in society. People with OA of the knee often say that what they want most is to be able to play with their grandchildren or to go out to a social club; thus we need to assess such functions along with the limitations to important activities such as the ability to walk. However, it is becoming apparent that self-assessment of activities and participation may not always be very reliable. More objective means of assessment, such as timed walking tests or sophisticated accelerometry, may be better [7]. But such clever, time-consuming and difficult tests do not help clinicians; they need a simple test that can be done in the clinic. Observing the ability of a patient to squat or to climb a step might work, but we need more research on the value of these simple tests.

Quality of life measures, such as EQ-5D, are preferred by researchers, as they can be used to assess cost-effectiveness. Moreover, measures such as the Short Form 36 (SF-36) are used because everyone uses them, and because we (the academics) prefer using some global, holistic-sounding assessment of quality of life of our patients, even if we have very little idea of what that means. The clinician, in contrast, needs to understand the needs and values of the individual patient in order to understand what matters most to that patient and to be able to tailor the disease management. Perhaps use of the Measure Yourself Medical Outcome Profile (MYMOP) [8], which allows patients to state what problems are most important to them and rate them, would be of more clinical value than the SF-36?

Researchers tend to study homogeneous groups of patients who only have a single problem. However, life is not so simple. Most people with OA of the knee who are seen by clinicians have a range of other medical and social problems. As OA is age related, comorbidities are usually present, and may be more important to function and quality of life than the OA itself. For example, Ayis et al. [9] have shown that OA alone has little effect on the ability to walk, but if combined with a sensory problem such as reduced eyesight or a psychological problem such as depression, the impact can be immense. So the clinician needs to assess the patient as a whole and not just the disease alone.

Finally, we agree with Paterson et al. [10], who argue that the idea behind outcome measures in health care is inappropriate for chronic illnesses, as there is no clearly defined point of outcome. Instead, it is a constantly changing journey and a narrative of the patient’s altering health status in the context of adaption to a changing environment.
Our clinical work is now dominated by guidelines. And guidelines, such as those produced by the National Institute for Health and Clinical Excellence (NICE) to help manage OA [11], are based on research that uses measures favoured by the academics rather than those that matter to clinicians and their patients. In conclusion, if research on measures of health status in conditions such as OA of the knee is to help the clinician, and thus their patients in turn, it needs to focus more on what is of value to patients and clinicians in the real world, rather than research settings alone.

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References