DISABILITY is an important outcome in rheumatology. In this paper, we discuss two aspects: where disability fits in the continuum of outcome measures that might be used, and the purpose of disability assessment as an outcome measure in clinical settings.

DISABILITY AND THE CONTINUUM OF OUTCOME MEASURES

Disability represents the impact of a disease process or disorder on the ability of the patient to carry out activities in the manner or within the range considered normal [1]. In this context, disability fits into a continuum of potential measures of outcome (Fig. 1) [2, 3]. Outcome can be measured at a number of levels—pathology, impairment, disability and handicap. For example, in the case of arthritis, there is likely to be pain, swelling and/or stiffness in the joints. These can lead to impairments, such as restricted joint movement, deformity or loss of strength. Impairment may then result in disability, which is the restriction in performance of activities. This might be difficulty or inability in activities of daily living, such as walking, climbing stairs, dressing, or any of the other activities that make up the daily life of the person affected. Particularly in the case of RA, the ability to carry out activities may be further compromised by systemic features of the illness, such as fatigue, morning stiffness and general unwellness.

Disability is important because of its theoretical relationship to the underlying disease process and impairment, and also because it can be viewed as a mediating or intermediate stage on the continuum between the underlying disease and the more social outcomes, handicap. Handicap arises as a result of an interaction between the presence of impairment and disability and a range of other factors external to the disease process [2, 3]. Conceptually and theoretically, it is clear that interventions directed to the underlying disease process, such as medications, or to impairments, such as surgery, should have an impact on the level of disability. In theory, at least, it should be easier to attribute changes in disability to changes in the disease or impairment than handicap, when other aspects will contribute to the overall situation.

It should also be noted that, in North America in particular, the word disability has wider connotations, and encompasses the impact of arthritis (or any other condition) on the ability to carry out social role activities, i.e. it is more akin to handicap. Further, what are essentially disability measures are also referred to by a variety of terms which include ‘functional status’, ‘health status’ and ‘health-related quality of life’. Disability is also frequently assessed by means of ‘activities of daily living’ (ADL) measures. These differences of terminology should be borne in mind when reading the literature.

ASSESSMENT OF DISABILITY IN DIFFERENT CONTEXTS

Most of the practical experience of disability assessment in rheumatology comes from clinical trials of drugs or surgery. Here, changes in disability over time are assumed to be indicative of changes associated with the underlying disease process, including the lessening of symptoms which are attributable to therapy.

Much rheumatology is now practised in a team setting where the rheumatologist is one of a team that may also consist of physical and occupational therapists, nurses, clinical metrologists, and so on. There are special requirements when using disability measures to assess outcome in these settings. Disability is a graded phenomenon so that a person is more or less severely disabled. A person may have more or less difficulty carrying out a particular activity, or may need to use an assistive device or personal assistance. All these aspects, in various combinations, are used to assess the severity of disability.

From the standpoint of progression of the underlying disease process and evaluation of therapy, a marker of deterioration may be that a person can no longer do an activity without the use of an assistive device or personal help. However, in the context of the rheumatological team, where the focus is more on the day-to-day functioning of the patient, the emphasis of assessment may need to be different. For example, assistive devices may be recommended, or the patient encouraged to use personal assistance in the interests of joint protection and preservation of energy. Not all current assessments allow this to be taken into account. For example, one of the most frequently used disability measures for arthritis, the Health Assessment Questionnaire (HAQ) [4], adjusts the score towards more severe disability if respondents report using assistive devices or personal help to carry out activities.

As requirements for data to support clinical audit and programme evaluation increase, there is growing...
Disease or disorder
  arthritis

Impairment
  restricted joint movement
deficiency
  loss of strength, endurance

Disability
  difficulty or inability in activities of
daily living
e.g. walking, dressing

Handicap
  disadvantage - consequences for the individual

Interacting factors

Physical environment
  steps, stairs
  architectural barriers
  housing

Resources
  assistive devices
  personal help
  education, personal attributes
  money & possessions

Social setting
  attitudes of others
  cultural background & values
  expectations

Dimensions of handicap
  Orientation
  Physical independence
  Mobility
  Occupation
  Social integration
  Economic self-sufficiency

Fig. 1.—The WHO ICIDH framework.

interest in the assessment of disability in this context. This is a largely unexplored area in rheumatology. The situation is complex as patients may receive a range of interventions from a number of different health professionals. Depending on the context of the audit, there may be a need to attribute change to particular interventions or to the care of particular types of health professionals. As with clinical trials, the intervention may not be primarily directed to disability. Much more work is required to understand the process of disability and how this relates to the underlying disease and impairment, and the mechanism by which it may contribute to handicap.

GENERAL CONSIDERATIONS IN CHOOSING A DISABILITY MEASURE

The desirable measurement properties of disability questionnaires are now well established and familiar [5]. They should be reliable in the sense of yielding the same results on repeated uses under the same conditions, valid in that they measure what they purport to measure and responsive in that they are capable of detecting significant changes over time. Validity, in particular, is difficult to establish when there are no 'gold standards' against which to measure what is by definition a personal and subjective phenomenon. Content validity is examined informally by inspecting whether questionnaire items adequately cover issues of concern. As far as possible, the questionnaires should have been developed from patients' own concerns and priorities, rather than those of professionals or researchers. Construct validity is examined with reference to more formal evidence of relationships of the new instrument to other information such as disease stage and severity. More informal, but equally important requirements are that instruments need to be acceptable to patients, practically feasible (both in terms of completion by patients and subsequent data processing) and relevant to the particular problem or issue at hand. There are a number of papers in the rheumatological literature which review criteria to be used in the choice of outcome measures to assess disability [6, 7].

RANGE OF AVAILABLE MEASURES

Rheumatology is one of the health care specialties relatively well endowed with health status instruments. All of the instruments discussed in this chapter are in questionnaire format and can be completed by patients without assistance. The two most familiar instruments for use in arthritis are the HAQ [4] and the Arthritis Impact Measurement Scales (AIMS) [8]. Other instruments developed for use in RA include the Lee Functional Index [9], the Toronto Activities of Daily Living Questionnaire [10], the McMaster Health Index Questionnaire (MHIQ) [11] and the MACTAR Patient Preference Disability Questionnaire [12]. However, only the HAQ and AIMS from this list have received sufficiently widespread attention that it is possible to assess their potential value.

A number of recent developments in disability measurement have been intended to make questionnaires more personally relevant to individual respondents. Thus O'Boyle and colleagues [13] have developed an interview schedule—the Schedule for the Evaluation of Individual Quality of Life (SEIQOL)—which elicits patients' five personally identified priorities in life and the personal weight or importance attached to identified priorities. A somewhat simpler approach which also attempts to identify individuals' priorities is the MACTAR questionnaire developed by Tugwell and colleagues [12]. Although such methods would appear to be particularly sensitive to patients' priorities and are quite appropriate as measures of outcome, it is not yet clear that they can be used routinely in a clinical
context as they require sensitive interviewing to be properly conducted.

In addition to instruments developed specifically for use in RA (so-called 'disease-specific' measures), there are now several questionnaires that have been designed to be relevant to a wide range of health problems (so-called 'generic' measures). A number of such generic instruments have been used to assess health status in RA, including the Sickness Impact Profile (SIP) [14], the Nottingham Health Profile (NHP) [15], the Quality of Well Being scale (QWH) [16], the Functional Status Questionnaire (FSQ) [17], the Farmer Quality of Life Scale [18] and the SF-36 [19].

USE OF DISABILITY SCORES TO MEASURE CHANGE: SHORT-TERM OUTCOMES

Short-term outcomes (up to 2 yr) are most frequently assessed in the context of clinical trials. Disability, referred to as functional assessment, is one of the internationally recommended outcome measures for clinical trials [20]. Change in disability is usually assessed by change in scores obtained at two or more points in time. Recent reviews provide evidence of satisfactory measurement properties of the HAQ, AIMS, SIP, NHP, MHIQ and FSQ [21,22]. The HAQ, in particular, has proved sensitive to significant clinical changes in RA in a number of trials, including of psycho-educational interventions [23, 24].

Patients' experiences of outcome can be more directly elicited by means of 'transition questions' in which they are invited directly to judge whether any important change (for better or worse) has occurred since a specific previous occasion. The Modified HAQ [25] contains such transition questions in relation to eight areas of disability (e.g. 'Compared with three months ago, how difficult is it now to get in and out of bed'?—'less difficult', 'the same' or 'more difficult'). In a study assessing patients at three monthly intervals, patients were asked to complete a standard HAQ at each visit and, at later visits, also to complete transition questions comparing current with past disability at their previous visit. The retrospective transition questions correlated considerably more strongly with various other standard rheumatological measures of change than did the prospective evidence from change scores obtained from calculating differences between conventional HAQ scores obtained at each visit [26]. It was inferred that patients observe significant degrees of change in disability that may not be detected by the conventional HAQ.

Some caution is required in using such retrospective judgements of outcome by patients. In some research, patients' retrospective judgements of outcome, as expressed in transition questions, have been found to differ significantly from prospective trends indicated by their self-reports recorded before and after treatment, with retrospective judgements of outcome being influenced by their health status at the time of completing the transition question rather than the degree of change from before treatment [27]. In the study of transition judgements for patients with RA seen at three monthly intervals just referred to, it was possible to show that aspects of health status such as psychological mood had very little influence in biasing patients' retrospective judgements elicited by transition questions [28].

LONGER-TERM OUTCOMES

Many rheumatic disorders, such as RA, are chronic diseases and require follow-up over 20 yr or more fully to assess the course of disease and outcomes of treatment. Unfortunately, we know very little about the longer-term performance of disability measures in this context as only studies using the HAQ or variants of HAQ have been reported. Studies of series of patients with RA over 12 and 8 yr, respectively [29,30], have produced clear evidence of progressive deterioration in disability, as measured by HAQ scores.

COMPARATIVE STUDIES OF INSTRUMENTS

The available health status measures of relevance to rheumatology are so numerous that, in recent years, studies have begun directly to compare the performance of different instruments. A number of studies have compared the performance of a variety of disability measures in patients with RA and OA in both surgical and medical contexts [31–36]. Whilst some instruments appear to have scales or dimensions that are more or less sensitive than others, overall instruments perform rather similarly, and there is little evidence of longer instruments or instruments developed specifically for arthritis being more sensitive to change. If this is the case, then instruments may well be selected in terms of criteria such as the length of time required for patients to complete the questionnaire and for investigators to process the information.

FUTURE APPLICATION OF DISABILITY ASSESSMENTS

Substantial progress has been made in the use of disability measures to assess outcomes in clinical and other trials. The HAQ has to date received far more attention than other instruments and in many respects stands up well as a measure of functional status. It also has the merits of being quite short and lending itself to quite simple processing and intuitively accessible results. It is increasingly clear that shorter instruments, as well as being more readily processed, may actually be as sensitive to important aspects of health status and changes in health status as longer and more detailed measures. For the most part, our experience with standardized disability assessments has been in research contexts and there is far less evidence regarding their applicability to other contexts such as quality assurance, evaluation or individual patient care. This, together with greater understanding of the process and meaning of disability, is an area where more attention is urgently required.

REFERENCES