COMMENTARY

Measuring quality of life in osteoporosis

Osteoporosis is the most prevalent metabolic bone disease in older people. It causes much morbidity, mortality and cost in terms of health and social services expenditure. Fractures, typically of the hip, wrist and vertebrae, are the important consequences of osteoporosis and can adversely affect quality of life by causing pain, reducing physical functioning and mobility, and affecting the activities of daily living. Low mood, depression and social isolation can often result.

As in other important chronic conditions, assessing health-related quality of life and using this as an outcome measure is becoming increasingly important in health services research and in clinical trials. Broadly speaking, two different types of instruments—generic and disease-targeted—can be used in measuring health-related quality of life in osteoporotic subjects, although hybrids incorporating elements of both approaches are emerging.

Generic instruments

Generic instruments have the advantage that the consequences of osteoporosis can be compared with those of other diseases, as these tools are not specific for any particular condition. The results can also be compared with normative scores. The following are the most widely used of the generic measures. (The review is not intended to be exhaustive.)

The commonly used Medical Outcomes Study Short Form 36-item questionnaire (SF-36) [1] was originally developed in the US and has been further validated in a British population [2, 3]. It consists of 36 questions, 35 pertaining to health over the previous 4 weeks and one which asks about changes in health compared with 12 months previously. The SF-36 measures the eight health domains of physical functioning, role limitation due to physical health, social functioning, vitality or energy, bodily pain, mental health, role limitation due to emotional problems and general health. Each dimension has a score ranging from 0 (worst possible health) to 100 (best possible health).

Early criticism of its suitability in older populations and use of non-anglicized phraseology have been answered by interview administration and modification of questions [4, 5]. The SF-36 is proving useful as a means of assessing the outcome of interventions in that it is sensitive to longitudinal changes in population health [6]. Furthermore, normative data from a community-based older population (aged 65 years and over) in Sheffield have recently become available [7].

The Sickness Impact Profile employs a broad series of 136 statements relating to 12 categories of activities to measure perceived changes in daily functioning, feelings and attitudes due to sickness. The Sickness Impact Profile is lengthy and its emphasis on behaviours limits its sensitivity to change in health status. It is, however, a truly generic health rating scale which is applicable across all age groups and in a wide variety of conditions.

The other widely used generic tool is the Nottingham Health Profile [8]. Although the design and content was based upon the Sickness Impact Profile, the Nottingham Health Profile asks directly about feelings and emotions rather than indirectly referring to these important factors through questions about change in behaviours. Normative data for local communities are available for comparison [9, 10]. However, the Nottingham Health Profile may not be sensitive enough to detect lower levels of morbidity (floor effect), which may nevertheless be important [2].

Other generic tools used in osteoporosis research include the EQ-5D (formerly the EuroQol), which is increasingly being used in the assessment of technological developments and resource allocation through cost-utility analyses [11, 12].

Disease-targeted instruments

The second approach is to use disease-targeted tools, a title preferable to ‘disease-specific’ as no such measure has domains specific to osteoporosis [13]. These are designed to give increased coverage to domains of relevance to particular conditions. In osteoporosis-targeted scales, fear of falling, mood, independence, self-image, pain and self-efficacy have been highlighted. Additionally, those factors most sensitive to changes, for example as a result of interventions, are given prominence.

Several osteoporosis-targeted quality of life instruments have been developed in recent years using subjects with established osteoporosis, and most have been used for vertebral osteoporosis subjects. All have been designed to assist in the evaluation of interventions but cannot be applied to studies of prevention in early post-menopausal women, as they do not contain domains covering menopausal symptoms. Measures that include coverage of menopausal symptoms—such
as the Women’s Health Questionnaire [14]—have been advocated in this situation [13].

The Osteoporosis Assessment Questionnaire, a 71-item self-report questionnaire based on version 2 of the Arthritis Impact Measurement Scale [15], and its revised form (OPAQ2) have also been used for subjects with non-vertebral fractures [16–18].

The Osteoporosis Functional Disability Questionnaire has been used to demonstrate improvements in daily activity in women with vertebral fractures engaged in an active exercise programme, when compared with sedentary controls [19]. This self-administered 59-item scale also shows reliable correlations with objective measures of spinal damage caused by osteoporosis but has not been widely used.

The 30-item (interview administered) Osteoporosis Quality of Life Questionnaire can detect improvement or deterioration in patients [20, 21]. Its shortened 10-item version, the mini-OQLQ, is useful in a selected group of patients with back pain caused by vertebral fractures [22]. Unlike the Osteoporosis Assessment and Osteoporosis Functional Disability Questionnaires, the Osteoporosis Quality of Life Questionnaire shows only weak correlation with clinical severity [13].

The Osteoporosis-Targeted Quality of Life survey instrument is particularly useful for epidemiological studies. It is reliable and has been validated as a cross-sectional survey tool for assessing health-related quality of life in community-dwelling women [23, 24]. It has been translated into several languages and adapted to facilitate cross-cultural studies.

Finally, the European Foundation for Osteoporosis has recently developed the QUALEFFO (Quality of Life Questionnaire of the European Foundation for Osteoporosis), a specific tool for vertebral fracture subjects, which includes questions on pain, physical function, social function, general health perception and mental function [25]. It has been shown to be repeatable, and coherent. It discriminates well between patients with vertebral fractures and controls in comparison to the SF-36, particularly in the domains of pain, physical function and social function, which are seriously affected in patients with vertebral osteoporosis. Further work is required on the sensitivity of QUALEFFO to change in order to assess its ability in measuring improvement in health-related quality of life following treatment.

The use of these instruments in daily clinical practice is not feasible because of the time taken to administer them. For this reason, an easy-to-administer 16-item questionnaire (ECOS-16) has been developed from modifications of the Osteoporosis Quality of Life Questionnaire, QUALEFFO and SF-36. This distillate, resulting from the combination of the generic and disease-specific approach, seems promising, but requires further validation before it can be advocated for use in clinical practice [26].

Conclusion

Measuring health-related quality of life has become an important issue in health service research and in clinical trials involving osteoporosis. Ideally, an osteoporosis-targeted tool should be combined with a generic tool. The choice of instrument will depend on the type of research and the particular research question asked, as each instrument may have particular advantages over others.

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