New developments in the Ankylosing Spondylitis Quality of Life (ASQoL) scale

McKenna SP, Wilburn J, Crawford SR, Twiss J, Aryamanesh M.
Galen Research Ltd, Manchester, UK

Background

Quality of life (QoL) is often poorly defined and most QoL measures are not based on a clear theoretical model. In contrast, the needs-based QoL model (see below) used as the basis for the ASQoL has been applied successfully in the development of numerous disease-specific patient-reported outcome measures.

Patient reported outcome measures (PROMs) are becoming increasingly widely used, especially in clinical trials. Patients now require evidence of patient benefit in addition to the efficacy of interventions.

PROMs used in clinical studies are required to have extremely good psychometric properties including reproducibility, construct validity and responsiveness to changes in health status. It is also now widely accepted that PROMs should also be unidimensional.

The needs-based QoL model is the most operationalised in QoL assessment and research. It considers that the most important aspect of a disease or illness is the impact that impairments and functioning have on patients’ ability to meet their needs. For example, a person who is restricted in their ability to walk may become deprived of a number of needs such as their sense of identity, gaining access to exercise and pleasure, participating in work, spending time with friends and family or purchasing essential food.


The ASQoL was first published in 2003 and has been regularly used in clinical studies since that time.


Content for the ASQoL was derived from qualitative interviews conducted with AS patients. Several stages of testing followed the development of a draft version of the measure. These ensured that it was well accepted by patients and that it had good face and content validity, reproducibility and construct validity.

The ASQoL is easy to administer and score and it has been shown to provide a valuable tool for assessing the impact of interventions for AS and for evaluating models of service delivery. The ASQoL takes about four minutes to complete and has excellent scaling and psychometric properties.

Aim

This poster reports on further developments of the ASQoL.

In order to make the measure more available the ASQoL was successfully translated into eight languages. Psychometric properties were excellent for US English, Canadian English, and German and extremely promising for the other languages.


Authors have shown that disease-specific assessment of patient-reported outcomes in AS is more effective than using generic measures. This is because carefully developed disease-specific measures assess all relevant issues and omit others that are not specific to the disease.


Others have used the ASQoL to investigate specific AS-related issues:


Table 1: ASQoL language versions available

Table 2: ASQoL Test-retest reliability and internal consistency

Conclusions

There are now 37 language versions of the ASQoL available for use. The ASQoL is currently being used by five major pharmaceutical companies to evaluate new biological therapies for AS. Each of these international clinical trials involves up to 17 different language versions of the measure.

Anyone interested in further validating existing versions of the ASQoL or developing new language versions should contact the authors at the address shown below.

Contact details

Professor S P McKenna; Director of Research and CEO, Galen Research Ltd, Enterprise House, Manchester Science Park, Lloyd Street North, Manchester, M15 6BE, UK.
Tel: +44 (0)161 226 4445
Email: smckenna@galen-research.com