

Editorial

Quality of life as the mental aspect of health in the measurement-based care of neurological patients

The family of concepts normally surnamed 'health-related quality of life' or (HRQoL) is measured by the impact of a disease on the patient's ability to function in daily life. In their literature review on HRQoL scales in neurological diseases, Corallo et al. (1) correctly subdivide these scales into (a) the measurement of general disease-anonymous scales or (b) disease-specific scales. Among the specific neurological HRQoL scales Corallo et al. (1) have included the Alzheimer's Disease Questionnaire, the Parkinson's Disease Questionnaire (PDQ-39), the Amyotrophic Lateral Sclerosis Questionnaire, and the Multiple Sclerosis Questionnaire. Of these scales, the Multiple Sclerosis Questionnaire is the most comprehensive, containing 54 items in total (MRSQoL-54). However, in contrast to the other neurological HRQoL disease-specific scales, the MRSQoL-54 actually includes the 36 items from the Medical Outcome Studies Short Form (MOS SF-36), which is a generic or disease-anonymous HRQoL scale (2). In their conclusion, Corallo et al. (1) correctly say that both types of HRQoL scales should be considered. They also correctly point out in their main conclusion that these multi-dimensional HRQoL scales are often aggregated into a total score and/or a limited number of composite indices, which may be the major reason why their ability to discriminate between different interventions in randomised clinical trials of neurological diseases is only modest.

Two decades ago, when reviewing HRQoL scales in neurological diseases, Wilson et al. (3) concluded that in the assessment of Parkinson's disease, the HRQoL instruments would most likely be able to document the impact of fewer side effects with the levodopa-cardiodopa combination. As stated by Corallo et al. (1) the PDQ-39 (4) has now become the most widely used disease specific HRQoL scale in Parkinson's disease. However, according to item response theory models (e.g. the Rasch analysis), the PDQ-39 is not a unidimensional scale (5), that is, the

total score is not a sufficient statistic, and thus we need subscale profiles for side effects induced by the intervention for disease-specific symptoms and for psychological general well-being (6).

Unfortunately, the items of the short-form PDQ-8 have been selected on psychometric terms as the eight items were identified because of high item-to-total correlations (7). The clinical validity of a scale has to be established before the Rasch analysis (6). In the case of PDQ-39, subscales have to be selected on clinical elements taking into account to which dimensions the items must belong, for example, specific disease-related functioning of health, side effects of treatment, and psychological well-being.

When examining the universe of items in widely used generic HRQoL scales by means of an expert panel, Hall et al. (8) focused on the core element of general well-being by disregarding items reflecting symptoms of diseases and items reflecting common medication-induced side effects. They concluded (8) that ~70% of the items in the MOS SF-36 validly covered a generic HRQoL scale, whereas the five items in the WHO-5 (6) had 100% coverage of the dimension for a generic HRQoL scale.

As a generic HRQoL scale Schneider et al. (9) recommended the WHO-5 as the first screening test before the use of the PDQ-39 in Parkinson's disease. The WHO-5 has recently been evaluated by a Rasch analysis in an elderly population when used as the first screening test for depression or apathy (10) and its unidimensionality was confirmed. The WHO-5 was also found valid in an adolescent psychiatric population as the first screening test for depression (11).

Apathy, or depression, is probably the mental syndrome captured by generic HRQoL scales in neurological disorders (10). The specific neurological HRQoL scales described so clearly by Corallo et al. (1) are all very important in capturing the functionally related problems for the individual disorders. The time has come with its electronic data collection to also implement these scales in clinical practice. Quality of

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