Abstract:

OBJECTIVE: To develop a short instrument to examine quality of life (QoL) which specifically addresses patients with movement disorders treated by deep brain stimulation (DBS). DESIGN: The instrument was developed within an existing concept of a modular questionnaire (questions on life satisfaction: "general life satisfaction" QLS(M)-A, and "satisfaction with health" QLS(M)-G), in which each item is weighted according to its relative importance to the individual. METHODS: Items were generated by interviews with 20 DBS patients, followed by item reduction and scale generation, factor analysis to determine relevant and final questionnaire items, estimation of reliability, and validation based on the medical outcome study 36 item short form health survey (SF-36) and the EuroQol (EQ-5D) (data from 152 patients with Parkinson's disease, essential tremor, or idiopathic torsion dystonia, including 75 patients with DBS). RESULTS: Initial questionnaires were reduced to 12 items for a "movement disorder module" (QLS(M)-MD), and five items for a "deep brain stimulation module" (QLS(M)-DBS). Psychometric analysis revealed Cronbach's alpha values of 0.87 and 0.73, and satisfactory correlation coefficients for convergent validity with SF-36 and EQ-5D.

CONCLUSIONS: QLS(M)-MD and QLS(M)-DBS can evaluate quality of life aspects of DBS in movement disorders. Psychometric evaluation
showed the questionnaires to be reliable, valid, and well accepted by the patients.