One year changes in disability in multiple sclerosis: neurological examination compared with patient self report

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Objective: To characterise prospectively the relation between one year changes in neurologist rating of neurological exam abnormalities as measured by the Expanded Disability Status Scale (EDSS) and changes in patient perceived disability as measured by the Guy's Neurological Disability Scale (GNDS) in patients with multiple sclerosis.

Methods: Two hundred and fifty patients with MS were recruited at an outpatient clinic. Disability at baseline and one year follow-up was assessed using the EDSS and GNDS. Correlations between change in EDSS, GNDS-sum score, Functional Systems and GNDS subcategories were studied as well as the significance of changes in EDSS associated with changes in perceived disability.

Results: The correlation between one year changes in EDSS versus GNDS was substantially lower (0.19) than cross-sectional correlations between EDSS and GNDS either at baseline (0.62) or at follow-up (0.77). Notably, changes in functional system scores that are based on neurological examination are poorly or not at all correlated with changes in disability as perceived by the patient. Analysing the impact of a significant worsening in EDSS-score, a commonly applied outcome criterion in clinical trials, we found that this was associated with significant worsening, insignificant change, and significant improvement in the patients' perceived disability in 45%, 39% and 15% of patients, respectively.

Conclusion: Patients' perception of change in disability differs not only quantitatively but also qualitatively from that of an examining physician. This seems to be due both to the fact that there are true differences in change as perceived by the patient and that measured by the physician and to the fact that changes in many dimensions of disability that are relevant to the patient have no measurable impact on the EDSS.