ALSFRS and appel ALS scores: discordance with disease progression

ID 1196430
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Year 2008
Title ALSFRS and appel ALS scores: discordance with disease progression
Journal Muscle & nerve
Volume 37
Number 5
Pages / **Article-Number** 668-72
Keywords ALSFRS, ALS, ALS clinical trials, ALS natural history, amyotrophic lateral sclerosis, appel ALS score

Progression of disease and effectiveness of therapy in patients with amyotrophic lateral sclerosis (ALS) are determined by both questionnaire- and examination-based measures. To determine whether both types of measurement tools are equally predictive at all stages of disease, we compared questionnaire-based ALS Functional Rating Scale (ALSFRS) scores to the examination-based Appel ALS (AALS) scores at different stages of disease. Same-day scores were obtained during 174 visits in 62 patients with definite or probable ALS. Using normalized scores, correlation between the scales and predictability were best in mildly affected patients. Predictions of ALSFRS based on AALS scores were less than half as precise in the later stages of disease. Both scales showed significant change with disease progression, but ALSFRS consistently underestimated disease severity defined by AALS ($P < 0.001$). Questionnaire-based measurements should be compared against objective scales at all stages of disease severity before they are accepted as primary endpoint measures.

Publisher John Wiley
ISSN/ISBN 0148-639X
edoc-URL http://edoc.unibas.ch/dok/A6006601
Full Text on edoc No;
Digital Object Identifier DOI 10.1002/mus.20977
PubMed ID http://www.ncbi.nlm.nih.gov/pubmed/18288708
ISI-Number WOS:000255355600017
Document type (ISI) Journal Article