

A motor function measure scale for neuromuscular diseases. Construction and validation study

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Received 19 November 2004; received in revised form 7 March 2005; accepted 15 March 2005

Abstract

A new scale for motor function measurement has been developed for neuromuscular diseases. The validation study included 303 patients, aged 6–62 years. Seventy-two patients had Duchenne muscular dystrophy, 32 Becker muscular dystrophy, 30 limb-girdle muscular dystrophy, 39 facio-scapulo-humeral dystrophy, 29 myotonic dystrophy, 21 congenital myopathy, 10 congenital muscular dystrophy, 35 spinal muscular atrophy and 35 hereditary neuropathy. The scale comprised 32 items, in three dimensions: standing position and transfers, axial and proximal motor function, distal motor function. Agreement coefficients for inter-rater reliability were excellent ($\alpha=0.81-0.94$) for nine items, good ($\alpha=0.61-0.80$) for 20 items and moderate ($\alpha=0.51-0.60$) for three items. High correlations were found between the total score and other scores: Vignos ($r=0.91$) and Brooke ($r=0.85$) grades, Functional Independence Measure ($r=0.91$), the global severity of disability evaluated with visual analog scales by physicians ($r=0.88$) and physiotherapists ($r=0.91$). This scale is reliable, does not require any special equipment and is well-accepted by patients. Its sensitivity to change is being assessed to permit its use in clinical trials of neuromuscular diseases.

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Keywords: Neuromuscular disease; Motor function; Methodology; Scale; Validation; Clinical trials

1. Introduction

In neuromuscular diseases, identification of new genotypes and hope for gene therapy have obliged scientists and clinicians to collaborate in order to classify phenotypes more precisely and to link them to specific genetic defects. Evaluation of motor deficit, and in particular measurement of muscle force by muscle testing or instrumental measures, is the most frequently used evaluation [1,2]. However, this muscle testing does not reflect the subject's functional abilities. These depend on the heterogeneity of the muscle defect, the muscular compensations and the limitations of the joints.

Several tests for the measurement of motor function have been proposed: the Functional Motor Scale for spinal

muscular atrophy (SMA) [3]; the ALS score [4], the Tufts Quantitative Neuromuscular Exam [5] and the Amyotrophic Lateral Sclerosis Functional Rating Scale [6] for amyotrophic lateral sclerosis; the Hughes Functional Score [7] for Guillain-Barré syndrome and the Hammersmith Motor Ability Score [8] for Duchenne muscular dystrophy (DMD). Some tests focus on the function of one part of the body: the Zupan Functional Test [9] or the Brooke Upper Extremity Scale [11] for the upper limbs and the Vignos Lower Extremity Scale for the lower limbs [10]; other tests specifically address a single medical question such as the Diagnostic Motor Performance Test [11] for establishing the differential diagnosis between myopathy and neuropathy. Some have not been validated: Timed tasks [1] and others are non-specific such as the Jobben Hand Function Test [12], or have not been adapted or validated for neuromuscular diseases, like the Gross Motor Function Measure which has been validated for cerebral palsy [13]. At the moment, there is no well validated test which is easy to administer and which has been adapted for the objective

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