Keywords: Patient reported outcome; Questionnaire; Muscular dystrophies; Adults; Validity; Scale; Neuromuscular diseases; Item response theory

Introduction. -- Several neuromuscular reference centers collaborate work (Reims, Créteil, Lille, Angers, Nantes, Nancy, Paris, Garches, Nice) allowed to develop a new tool for specific measures reported by neuromuscular disease persons.

Patients and methods. -- A first qualitative stage has building a bank of items with five focuses groups among various functional patient stages of the disease (n = 41) then a study of acceptance and feasibility of items (n = 56). The second phase (n = 127) built the structure and calibrate the metrics of the questionnaire Qol-NMDv1.0 (factorial analysis and Item Response Theory).

Results. -- The factorial analysis and data application in a item response theory (n = 127) construct a questionnaire v1.0 with three dimensions.

Discussion. -- Qol-NMD have to measure specific reported outcome from NMD patient. Qol-NMD V1.0 is now structured and allows the calculation of a research score (IRT method) or a clinical one (factorial analysis). Qol-NMD scale consists of 26 items grouped in three domains: physical symptom impacts (nine items), self perception (eight items), activities and participation (nine items). An optional domain for the ventilated persons requires additional inclusions before a consolidation of its structure and its metrics.

Conclusion. -- This new tool Qol-NMDV1.0 will be compared with French InoQol version and pursues its final psychometric validation with a new NMD persons sample: phase III of the project.

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Balance and gait parameters in sensory ataxia; effects of a balance training program
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Keywords: Balance; Gait; Ataxia; Neuropathy; Training

Aims. -- When rehabilitation is proposed for a long time to improve balance in patients with mixed motor and sensory neuropathy, no study was performed to characterize balance and gait in sensory neuropathy and their changes following a specific training program.

Patients and method. -- A rehabilitation program including foot sensory stimulation, balance and gait training with limited vision was followed by 30 patients with ataxic neuropathy in order to stimulate multi-sensory compensation in a no-controlled and no-blinded study. Ataxic neuropathy was graded by a pallesthetic score. The evaluation of patients and healthy subjects was performed with clinical tests (Berg Balance Scale, Functional Reach Test and Timed up and Go test) and instrumental tests for balance (force platform) and gait (Locomet).

Results. -- All patients exhibited impairments in balance and gait parameters compared to control group values. A high pallesthetic score correlated with increased sway area when standing with the eyes open on a firm surface. At the end of the training program, significant changes were observed in balance control assessed using the three clinical tests (Wilcoxon test, P < 0.001). A tendency towards a reduction of the Romberg sign was noticed and limited changes were observed after training in instrumental tests for balance and for gait parameters. Age induced some limitations in balance and gait parameters but had no effect on training results.

Discussion. -- These results show that ataxic patients are impaired in balance and gait but can improve clinical balance parameters following training with a multisensory approach. We observed only limited correlations between the pallesthetic score and some balance parameters, suggesting that various levels of compensation occur in these patients. It confirms that balance and gait training have to be recommended in the non-pharmacologic approach of ataxic neuropathy with a positive short-term effect on dynamic balance parameters without limitation due to age or degree of sensory impairment. The effectiveness of this training program has to be evaluated in the future in a controlled study to ascertain the contribution of the placebo effect in these data.

Further reading

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Gait and balance parameters in patients with fascioscapulohumeral muscular dystrophy: A short term evaluation of a rehabilitation program