Brazilian Journal of Physical Therapy 2017;xxx(xx):xxx–xxx

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Associação Brasileira de Pesquisa e Pós-Graduação em Fisioterapia

Brazilian Journal of Physical Therapy

https://www.journals.elsevier.com/brazilian-journal-of-physical-therapy

ORIGINAL RESEARCH

Reliability, validity and description of timed performance of the Jebsen–Taylor Test in patients with muscular dystrophies

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Received 15 February 2017; accepted 18 September 2017

KEYWORDS
Muscular dystrophies;
Upper extremity;
Physical therapy;
Disability evaluation

Abstract
Background: The Jebsen–Taylor Test evaluates upper limb function by measuring timed performance on everyday activities. The test is used to assess and monitor the progression of patients with Parkinson disease, cerebral palsy, stroke and brain injury.
Objectives: To analyze the reliability, internal consistency and validity of the Jebsen–Taylor Test in people with Muscular Dystrophy and to describe and classify upper limb timed performance of people with Muscular Dystrophy.
Methods: Fifty patients with Muscular Dystrophy were assessed. Non-dominant and dominant upper limb performances on the Jebsen–Taylor Test were filmed. Two raters evaluated timed performance for inter-rater reliability analysis. Test–retest reliability was investigated by using intraclass correlation coefficients. Internal consistency was assessed using the Cronbach alpha. Construct validity was conducted by comparing the Jebsen–Taylor Test with the Performance of Upper Limb.
Results: The internal consistency of Jebsen–Taylor Test was good (Cronbach's $\alpha = 0.98$). A very high inter-rater reliability (0.903–0.999), except for writing with an ICC of 0.772–1.000. Strong correlations between the Jebsen–Taylor Test and the Performance of Upper Limb Module were found (rho = −0.712).

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https://doi.org/10.1016/j.bjpt.2017.09.010
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Please cite this article in press as: Artilheiro MC, et al. Reliability, validity and description of timed performance of the Jebsen–Taylor Test in patients with muscular dystrophies. *Braz J Phys Ther.* 2017, https://doi.org/10.1016/j.bjpt.2017.09.010

Conclusion: The Jebsen–Taylor Test is a reliable and valid measure of timed performance for people with Muscular Dystrophy.
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Introduction

New pharmacological and therapeutic interventions during the past three decades contributed to a longer survival of people with Muscular Dystrophy (MD).[1,2] Therefore, the number of non-ambulatory people with upper limb dysfunction has increased, as has the demand for more accurate assessment protocols.[2] The lack of instruments to quantify upper limb functional impairments is a challenge faced by health professionals who work with people with MD.[3]

Some tests evaluate upper limb motor function in MD or specifically in Duchenne Muscular Dystrophy (DMD), but none evaluate timed performance. The Brooke Scale classifies upper limb active movements in DMD and Becker muscular dystrophy (BMD) with a six-point scale.[4] However, Brooke Scale did not quantify functional performance. Dimension 3 of the Motor Function Measure (MFM) has six items referring to upper limb function.[5] However, in people with less severe MD, the Motor Function Measure might not detect early stage disabilities and might show scoring ceiling effects. ABILHAND questionnaire points to the subject's perception of difficulty performing activities of daily living involving upper limb functions.[6] ABILHAND classifies the tasks as fully or partially performed, or not performed at all. Upper limb performance is inferred according to the subject's report and not specifically tested. The Performance of Upper Limb Test assesses shoulder, elbow and hand functions in DMD. Four items of this scale measure timed performance only as additional qualitative information, with no impact on the total score.[7]

Timed performance is an accurate functional measure in people with DMD.[8,9] This evaluation strategy has been used in DMD for functional performance of the lower limbs, for example, the six-minute walk test,[10] in the North Star Ambulatory Assessment[11] and in the Functional Evaluation Scale for Duchenne Muscular Dystrophy.[12] The Jebsen–Taylor Test evaluates upper limbs timed performance in seven subtests that represent everyday activities, such as writing, turning cards, picking up objects or beans with a spoon, stacking checkers, and picking up light or heavy cans. The subtests assess the distal and proximal upper limb performance. Materials are standardized and have low-cost. Assessment requires about 35 min.[13]

The Jebsen–Taylor Test was translated and cross-culturally adapted into Brazilian Portuguese and showed excellent intra and inter-rater reliability in people with stroke, cerebral palsy and Parkinson disease.[14–17] Scores are determined by timed performance on functional activities, which differentiates this test from others. The test has normative data for healthy people[18] and was previously applied in boys with DMD and considered as a sensitive method to assess DMD progression. However, measurement properties were not tested and people with other types of MD were not evaluated.[19]

We hypothesized that Jebsen–Taylor Test would generate accurate measures[20] of upper limb motor function in people with MD. First, we aimed to analyze the reliability, internal consistency and validity of Jebsen–Taylor Test in people with Muscular Dystrophy. Second, we aimed to describe and classify upper limb timed performance in people with MD.

Methods

Experimental design

This was an observational study using a cross-sectional design approved by the Universidade Federal de São Paulo (UNIFESP) Ethics Committee (process 132–193), São Paulo, SP, Brazil.

Participants

All participants who submitted to clinical and therapeutic treatment by the Brazilian Association of Muscular Dystrophies (ABDIM) were invited to participate (80 people). They had their diagnosis of DMD, BMD, fascioscapulohumeral dystrophy (FSH), limb-girdle muscular dystrophy (LGMD) or Myotonic Dystrophy type 1 (MD1) confirmed by DNA analysis. Parents/legal guardians signed the consent form.

Two participants were excluded due to having associated neurological diseases, three were excluded due to participation refusal by participants/parents/legal guardians, three were excluded due to unavailability, eight were excluded due to severe cognitive impairment (i.e. scoring lower than 11 on the Mini-Mental State Examination).[21–23] In a previous pilot study,[22] we observed that a cut-point of 10 points (instead of eighteen) could be considered for DMD people. Fourteen participants were excluded due to the absence of upper limb function (i.e. severe cases, bed restricted). The minimum upper limb function required to participate in this study was the ability to grasp objects and not just the presence of an active muscle contraction in the hands and fingers without function. Therefore, participants who were not able to grasp objects were excluded.

The 50 participants included in this study were diagnosed with DMD (72%), LGMD (16%), BMD (6%), MD1 (4%) and FSH (2%). In the total sample, 18 (36%) were ambulatory and 32 (64%) were non-ambulatory. The sample size was calculated to achieve 80% power with alpha error of 5% and expected

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