

Reliability and validity analyses of the North Star Ambulatory Assessment in Brazilian Portuguese

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Received 20 January 2017; received in revised form 8 May 2017; accepted 22 May 2017

Abstract

The North Star Ambulatory Assessment measures motor performance in ambulatory boys with Duchenne muscular dystrophy, a hereditary and degenerative muscle disorder. To use the North Star Ambulatory Assessment in Brazilian boys, we performed the cross-cultural adaptation to the Portuguese language spoken in Brazil and evaluated the reliability and validity of the instrument. Cross-cultural adaptation included: independent translations, synthesis, committee review, pre-testing in 12 boys, back-translation and comparison with the original instrument. Thirty-five boys with Duchenne muscular dystrophy and 38 healthy age-matched controls were recruited for further analyses. Reliability was assessed by internal consistency and reproducibility. Validity studies included face, content, construct and known-groups analyses. Cross-cultural adaptation resulted in an adequate instrument. Reliability studies demonstrated high internal consistency (Cronbach's $\alpha = 0.935$) and adequate intra and inter-rater reproducibility (intraclass correlation coefficient = 0.988 and 0.962). Validation analyses indicated satisfactory content, face and convergent construct validities, with positive correlations with the Motor Function Measure total score ($r = 0.863$) and the 6-minute walk test ($r = 0.433$). The known group validity was demonstrated by higher scores in younger boys with Duchenne muscular dystrophy ($p = 0.005$). North Star Ambulatory Assessment in Brazilian Portuguese is a reliable and valid instrument to measure functional capacity in boys with Duchenne muscular dystrophy. © 2017 Elsevier B.V. All rights reserved.

Keywords: Duchenne muscular dystrophy; Functional capacity; North Star Ambulatory Assessment; Cross-cultural adaptation; Reliability; Validity

1. Introduction

Duchenne muscular dystrophy (DMD) is a hereditary, X-linked recessive and degenerative disease, caused by mutation in the dystrophin gene, with consequent lack of this protein in skeletal muscle and other tissues [1]. It is the most common myopathy in childhood and affects 1:5000 male live births [2].

Functional assessment in boys with DMD allows quantification of the physical disability, which is important for the characterization of the clinical picture, as well as for analyzing the response to treatment and disease progression. There are different instruments developed for quantification of motor performance, including timed tests and functional rating scales [3–6].

The North Star Ambulatory Assessment (NSAA) is a functional scale specifically designed for ambulant boys with DMD, developed in the United Kingdom by the North Star Clinical Network for Paediatric Neuromuscular Disease Management [6]. The instrument contains clear and detailed instructions, with item scores varying according to a simple three point criteria, which should allow accurate reproduction by different groups. The scale has also the advantage to be quick to perform and to be suitable for application in young children [7]. The NSAA also includes two timed items, run/walk for 10 meters and rise from the floor. While those times do not influence the score, they can be used to monitor changes over time [6,8]. Although it was developed to assess ambulatory patients, the NSAA has been widely accepted and used to evaluate ambulatory motor performance in children and young adults with DMD, as well as in patients with other neuromuscular diseases [9–12]. As the NSAA was not available in Brazilian Portuguese, the purposes of this study were to perform a cross-cultural adaptation for the Portuguese language spoken

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in Brazil and to evaluate the reliability and validity of the adapted instrument.

2. Methods

2.1. Participants

Eighty-five boys were enrolled in the study: 12 participated in the cross-cultural adaptation process, for pre-testing; 35 patients with DMD were included in the reliability analyses, of which 31 participated in the validation process because four DMD boys lost ambulation during the study; 38 healthy controls were included for comparison.

Inclusion criteria for patients were:

- 1 Boys with diagnosis of DMD, based on the absence of dystrophin in muscle biopsy and/or a pathogenic mutation in the dystrophin gene;
- 2 Older than four years;
- 3 Follow-up at the Neuromuscular Disease Outpatient Clinic of the Clinical Hospital of Ribeirao Preto Medical School, University of Sao Paulo;
- 4 Able to walk at least ten meters independently and to understand simple instructions;
- 5 Agreed to participate in the study.

Inclusion criteria for controls were:

- 1 Healthy boys with no additional comorbidities;
- 2 Aged from 4 to 15 years;
- 3 Ability to understand simple instructions;
- 4 Agreed to participate in the study.

Exclusion criteria for patients and controls were the presence of an acute disease in the last month or other contraindication to exercise.

The Ethics Committee of our institution previously approved the study. All parents or legal representative gave written informed consent, as did the children aged 10 years or older.

2.2. Design

This single center, observational, cross-sectional study was designed to perform the cross-cultural adaptation of the NSAA to the Portuguese language spoken in Brazil and to analyze the reliability and validity of the adapted instrument.

2.3. Cross-cultural adaptation of the NSAA

The permission to use and translate the NSAA was requested and granted by the North Star Clinical Network.

The original English version of the NSAA was adapted to Portuguese spoken in Brazil following recommended guidelines, described in Fig. 1 [13,14]. During pre-testing, the examiner instructed the boys to ask about any doubts they had with the commands during the assessment. If a question had more than 85 percent of non-understanding, it should be reviewed.

2.4. Outcome measures

The NSAA is organized in 17 items to assess motor performance in ambulatory boys with DMD [6]. The activities

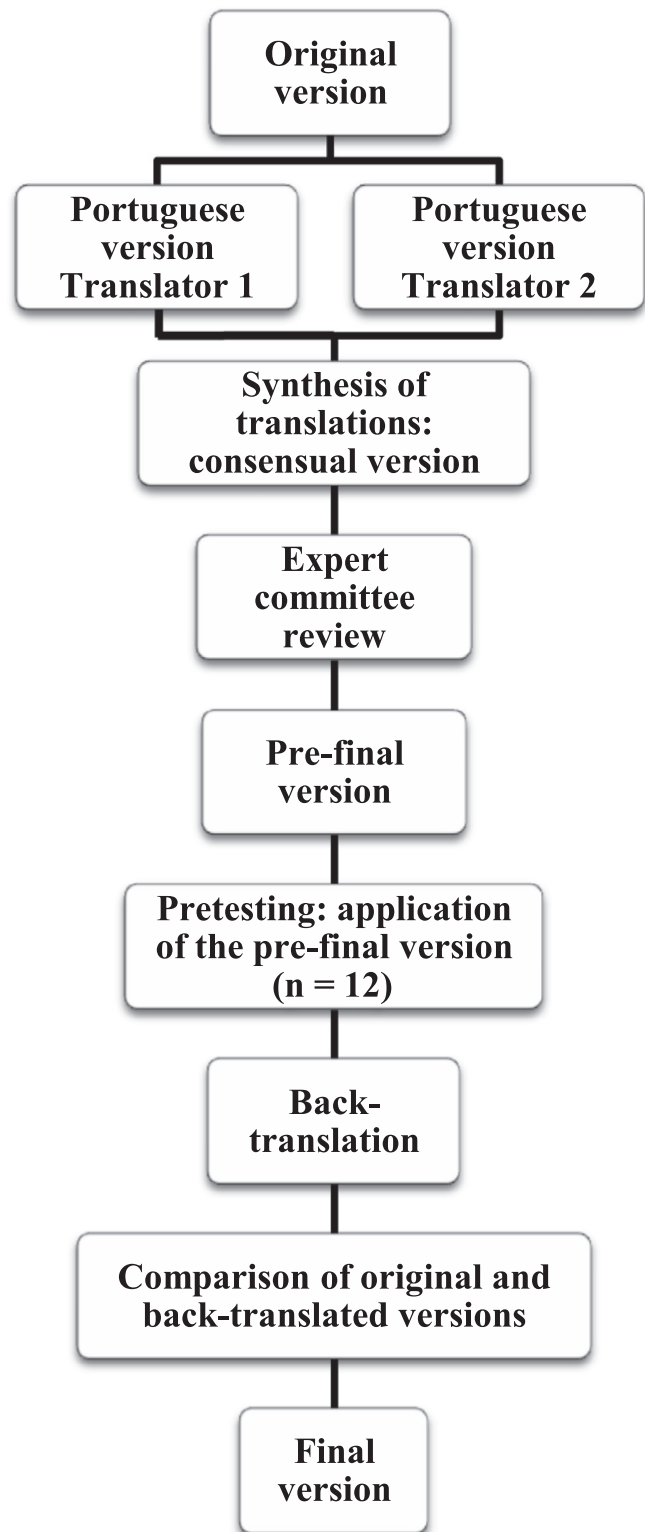


Fig. 1. Process of cross-cultural adaptation of the North Star Ambulatory Assessment (NSAA). Two independent translations were performed by two native Brazilian health science professionals, proficient in English. The expert committee was composed of two translators and three physiotherapists. The pre-final version was applied to 12 boys, who had physical disability due to a muscular disease. The back-translation was performed by an English translator, fluent in Brazilian Portuguese, who had not seen the original version. The expert committee compared the original and back-translated versions and generated the NSAA in Brazilian Portuguese.

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