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Journal of Hand Therapy

journal homepage: www.jhandtherapy.org



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Scientific/Clinical Article

Reliability and validity of the Manual Ability Measure-36 in persons with Charcot-Marie-Tooth disease



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ARTICLE INFO

Article history:

Received 15 July 2014

Received in revised form

18 March 2015

Accepted 23 April 2015

Available online 30 April 2015

Keywords:

Manual ability

Charcot-Marie-Tooth disease

Manual ability measure

Outcome measure

ABSTRACT

Study design: Descriptive, clinical measurement.

Introduction: Charcot-Marie-Tooth disease (CMT) is a genetic disorder that results in demyelination or axonal degeneration in peripheral nerves. Characteristic symptoms include decreased muscle strength and sensation, particularly in the hands and feet.

Purpose: Examine the reliability and validity of the Manual Ability Measure (MAM-36), a 36-item self-report questionnaire specific to hand function, in persons with CMT.

Methods: Fourteen participants with CMT completed the MAM-36 at two points one week apart. Participants were also administered performance-based tests for grip and pinch strength, dexterity, and sensation.

Results: The test-retest intraclass correlation coefficient (ICC) for the MAM-36 was 0.96. Pearson correlation coefficients showed fair to good relationships ($r = 0.41$ – 0.64) between the MAM-36 scores and most of the performance tests.

Conclusion: The MAM-36 is a reliable and valid assessment tool for measuring hand function during everyday tasks in persons with CMT.

Level of evidence: IIb.

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Charcot-Marie Tooth disease (CMT) is a genetic disorder that results in demyelination or axonal degeneration in peripheral nerves.^{1–3} CMT affects approximately 1 in 2500 people in the United States.⁴ Inheritance follows a dominant pattern, meaning that a parent with CMT has a 50/50 chance of passing along the disorder to each child.⁵ CMT is primarily categorized into different types based on age of onset, inheritance pattern, location of gene mutation and whether the defect is in the axon or myelin^{3,4}; the most common are CMT Type 1 and 2. CMT Type 1 is caused by demyelination and Type 2 is caused by axonopathy but both present with similar symptoms which are described below.^{3,4}

Many individuals with CMT first exhibit gradual muscle weakness and wasting and decreased sensation in the lower extremities. With disease progression, muscles in the hand and forearm become

weak and atrophied which affects hand function.^{3,6–8} Proximal upper extremity muscles are rarely affected.⁴ Weakness in the intrinsic muscles of the hand, particularly the thenar muscles, impairs tip and lateral pinch strength.^{9–11} People with CMT typically have 50–67% of the grip strength of healthy adults^{9,12}; however, weakened intrinsic muscles of the hand do not appear to predict impaired grip strength, presumably due to the compensatory recruitment of extrinsic hand muscles during grip.¹¹ Overall manual dexterity is also diminished, as people with CMT manipulate one-inch wooden cubes (Box and Block Test) much slower than controls and require 50% more time, on average, to place and remove one-quarter-inch diameter wooden dowels in a peg board (Nine-Hole Peg Test).¹² Diminished sensation, including pain, temperature, vibration, and proprioception, is also a typical symptom of CMT.^{6,13}

The few studies that have examined the impact of impairments in the hand on functional activities in people with CMT reported that dexterity, hand strength, and sensation are associated with difficulty with functional activities.^{12,14} While these studies used psychometrically sound measures of hand function such as the

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Disability of the Arm, Shoulder and Hand questionnaire (DASH) and the Michigan Hand Questionnaire (MHQ), these questionnaires have not been specifically validated for persons with CMT. Furthermore, several categories of items on these questionnaires are not relevant for persons with CMT. For example, people with CMT do not generally have pain in their hands and adaptations to perform work or other activities occur over longer periods of time than measured by the DASH and MHQ due to the slow progressive nature of the disease. A recently developed patient reported outcome that may have the potential to assess hand function in people with CMT is the Manual Ability Measure (MAM-36).^{15,16} The MAM-36 is a 36 item self-report that measures a person's perceived ability to complete a wide range of common hand activities such as writing, opening containers, using a knife and fork, handling money, and managing fasteners on clothes and shoes.¹⁶ The ability to perform each item is rated on a 4 point scale. Validity of the MAM-36 was established in people with a wide variety of orthopedic and neurological conditions.¹⁷ However, the neurological diagnoses of the sample included multiple sclerosis, spinal cord injury and traumatic brain injury. These conditions of the central nervous system are different from CMT as they involve the central nervous system and often affect the proximal musculature of the upper extremities while CMT involves the peripheral nervous system without proximal musculature involvement. Furthermore, to use the MAM-36 as an outcome measure in clinical or research studies with people with CMT, the psychometric properties of the MAM-36 need to be established specifically with this population. Since no self-report questionnaires on hand function have been validated with CMT, we validated the MAM-36 by correlating the scores on the MAM-36 with scores on performance based tests that have been validated with persons with CMT.

Purpose

The purpose of this study was therefore to examine the reliability and validity of the MAM-36. Validity was evaluated by examining the relationship between MAM-36 and hand strength, dexterity, and sensation in persons with CMT.

Methods

Participants

A convenience sample of participants was recruited from a CMT support group. Inclusion criteria were between eighteen and seventy-five years of age and having a diagnosis of CMT and no other neurological conditions that may interfere with hand function, such as stroke, brain injury, Parkinson's disease, or multiple sclerosis.

Measures

Demographic information was collected from participants regarding age, gender, handedness, disease duration, and subtype of CMT, if known.

MAM-36

The MAM-36 is a 36 item self-report that measures a person's perceived capability in performing common tasks using the hands.^{15–19} Items are rated on a scale from 1 (cannot do it) to 4 (easy). There is also a zero option, indicating that task is almost never performed, with or without hand impairment. The scoring of the MAM-36 highlights a person's level of ability rather than limitation, with higher scores indicating better hand function. Raw scores for each item were summed and then converted to a MAM conversion score according to the table in Chen and Bode.¹⁷

Hand strength

Grip strength was measured with a Jamar dynamometer, with the mean of three trials recorded as the score. Tip and lateral pinch strength were measured using a pinch meter, and the mean of three trials was again recorded as the score. The procedures followed the guidelines established by the American Society of Hand Therapists.²⁰

Dexterity

The procedures used to administer the dexterity tests followed guidelines in the literature^{21,22} and the Arthritis Hand Function Test manual.²³ For all the dexterity tests, participants were given 1 practice trial and then 2 trials (the best time was the score). The Dexterity measures included the Button Test and Coin Pick-Up Test from the Arthritis Hand Function Test²³ and the Nine-hole Peg Test,²¹ and the Box and Blocks Test.²² The Button Test is the time needed to button and unbutton five buttons on a button board.²³ The timed Coin Pick-Up Test involves picking up, transferring, and then inserting four coins of different sizes into a slot on a box.²³ The Nine-hole Peg Test is the time needed to place and remove 9 pegs from a pegboard.^{21,23} The Box and Block Test (BBT), assessed gross manual dexterity.²² The BBT is a 1-min timed test in which an individual is scored according to how many blocks are picked up from one compartment of a box and placed in another compartment while clearing a central dividing partition.²²

Sensation

Two-point discrimination, a test of sensation, was assessed with the Disk-criminator. One or two points, with a 5 mm separation of points, were applied to each fingertip. Each fingertip received a score of intact if 4 or more out of 7 touches were correctly identified. The number of fingers identified as intact was summed to obtain total scores.

Hand grasp

Hand grasp was scored using a functional classification developed by Vinci et al.¹⁰ Participants were asked to pinch the pulp of the thumb against the pulp of the index and third fingers. A score from 1 (typical, pulp to pulp pinch with thumb opposition and abduction) to 4 (thumb is not included in pinch) was then assigned based on position and contact surface of the thumb.

Procedure

The study was approved by the University Institutional Review Board. After informed written consent was obtained, participants completed the MAM-36 at the initial evaluation and were given a second copy of the questionnaire and a stamped, self-addressed return mailer to complete and return a week later. At the initial evaluation, participants also completed measures of grip and pinch strength, dexterity, two-point discrimination, and hand grasp. The performance tests were interspersed with the questionnaires to allow participants a rest period. Thus the order of testing was the MAM-36, grip and pinch strength, demographic questionnaire, nine-hole peg test, sensory test, coin test, and button test.

Data analysis

Intraclass correlation coefficients (ICC) were calculated between Time 1 and Time 2 for the MAM-36 to determine test-retest reliability. Pearson's correlation coefficients were used to establish validity between MAM-36 scores and grip and pinch strength, Nine-hole Peg Test, Box and Blocks Test, Button Test, Coin Pick-Up Test, two-point discrimination, and hand grasp.

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