International Journal of Physical Medicine & Rehabilitation

Rabadi, Int J Phys Med Rehabil 2015, 3:4
DOI: 10.4172/2329-9096.1000285

Short communication open access

Comparison of the Kurtkze Expanded Disability Status Scale and the Functional Independence Measure: Measures of Multiple Sclerosis Related Disability

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Received date: May 22, 2015; **Accepted date:** June 07, 2015; **Published date:** June 10, 2015

Abstract

This is a summary of an observational study we published in Disability and Rehabilitation in 2003[1], where we compared the Kurtkze expanded disability status scale (EDSS) and the Total functional independence measure (FIM) scale as measures of MS-related disability. On retrospective electronic charts review of 76 veterans with MS regularly followed in our VA MS clinic, we found the EDSS score to accurately measure MS-related impairment at initial evaluation and on follow-up. However, the EDSS score did not change over time, compared to the FIM suggesting reduced sensitivity of the EDSS for detecting change in MS-related disability over time.

Multiple sclerosis (MS) is a neurodegenerative condition that leads to cognitive and physical impairments resulting in disability with shortened life expectancy. It is the most common neurological cause of debilitation in young people and it is more common in women and in whites. According to the National Institute of Neurological Disorders and Stroke, about 250,000-350,000 people in the United States have been diagnosed with multiple sclerosis [2,3].

MS is a disease with a variable clinical presentation and a variable clinical course. Therefore, accuracy of clinical rating scales to measure disability at initial clinical presentation and during follow-up visits is essential to accurately capture the variability inherent in this disease. This is particularly vital when attempting to identify the efficacy of interventions.

At present expanded disability status scale (EDSS) is the most commonly used scale to record the neurological status of patients with MS, assesses disease progression, and monitor response to treatment. It is considered the "gold standard" in measuring MS-related disability in clinical research trials [4]. In 1955 Kurtkze JF first described a new scale to assess MS related-disability called the disability status scale (DSS) [5]. This scale was expanded in 1983 with the addition of 8 functional systems (FS), into what is now called the expanded disability status scale (EDSS) [4]. The EDSS score is based on a detailed neurological examination that combines impairment and disability in a 10-step ordinal scale, ranging from 0 (normal) to 10 (death). Thus, higher scores indicate increased levels of disability. The EDSS is scored in increments of 0.5 points, and includes the scores of eight FS items: pyramidal, cerebellar, brain-stem, sensory, bowel and bladder, visual, mental and other functions (Appendix 1A and 1B). The EDSS has a bi-modal distribution in valid cross-sectional studies [6], and has a fair to substantial inter-rater reliability (κ=0.32 to 0.76) [7,8], with a 2 point change considered a reliable indicator of the patient's response to treatment [9]. Though EDSS is an impairment scale it has been commonly used as an outcome measure of MS-related disability [10,11]. However, it has a number of limitations these include: i) lack of precision in defining FS grades due to its use of subjective terms (e.g., mild, moderate and severe); ii) inadequate assessment of cognitive and visual components; iii) failure to measure common MS symptoms (e.g., fatigue and pain); iv) cumbersome to administer; v) poor correlation with activities of daily living (ADL) [12]; and vi) strong emphasis on ambulation status.

Recently attempts have been made to use a new scale called the multiple sclerosis functional composite scale (MSFCS) in MS clinical trials to overcome limitations perceived in the use of EDSS. The total MSFCS score is derived from the combination of results from three performance tests: the timed 8-meter Walk (t-8m) to assess lower limb function (ambulation), the Nine-Hole Peg Test (9HPT) to assess upper limb function, and the 3-second version of the Paced auditory serial addition test (PASAT) to assess cognition. Tests results are converted to z-score [13]. Its advantages include it being reliable (intra-rater intra-class correlation (ICC)=0.98, inter-rater ICC=0.96) [8,14,15], efficient, and reproducible [16]. However, it is a cumbersome scale to use in everyday clinical practice for the following reasons: i) complains such as dysarthria affects PASAT performance; ii) visual disturbance affects 9HPT; iii) there is no measure for involved vision; iv) calculation and clinical interpretation of Z-scores are difficult; and v) there is a practice effect with tests repetition especially for the PASAT.

Given the limitations of both the EDSS and MSFCS scales, another scale, the Total Functional Independence Measure (FIM) was studied as an alternative to both these scales for assessing MS related-disability. 1 The FIM is a reliable (0.86 to 0.97) [17] and valid [18] functional assessment instrument that is widely used in many rehabilitation settings [19] to measure degree of disability [20]. The FIM has 18 items; each item is scored on an ordinal scale ranging from 1 ("total assist": patient performs<25% of task) to 7 ("complete independence"). The resulting FIM score indicates the level of assistance needed to achieve independence and ranges from 18 (totally dependent) to 126 (independent). Thus, more disability is shown by a lower score. The FIM includes both cognitive (5 items) and motor (13 items) subscales. This structure allows clinicians to calculate a cognitive FIM sub-score (range, 5-35) that is independent from the motor FIM sub-score (range, 13-91) (Appendix 2). The cognitive FIM sub-score is based on observations of the patient's behaviours and is less affected by language disorders as is the Mini-Mental State Examination.

Rabadi MH and Vincent A [1] in their study of 76 veterans with MS who were regularly followed in VA MS clinic, found the initial EDSS and FIM scores were significantly negatively correlated (p<0.001) due to the scale characteristics. Less disability in ADLs was associated with

lower EDSS and higher FIM scores, while a higher degree of disability was found at a higher EDSS and lower FIM scores. When the responsiveness to change in EDSS and FIM scores over time was assessed by the standard response mean (SRM, an assessment for clinically meaningful change over time for the diagnostic test) found EDSS was less sensitive (0.15) than FIM (0.53) in measuring MS-related disability. The EDSS score accurately measured MS related-impairment at initial evaluation and follow-up relative to an Impairment Index, however; the EDSS score did not change over time to reflect the change in the veteran's level of MS-related disability, compared to the FIM. This suggested FIM scale was a more sensitive measure of MS-related disability than EDSS scale as it provides information on a wider range of essential functions that help define MS-related disability and is preferable to use in future MS clinical trials.

Summary

Our study suggests FIM scale is a more sensitive measure of MS-related disability than EDSS for use in future MS clinical trials.

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