REVIEW

Performance Measures for Upper Extremity Functions in Persons with Multiple Sclerosis

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ABSTRACT

Recent studies suggest that upper extremity dysfunction is a quite common symptom in multiple sclerosis (MS), and affects adversely the activities of daily living even in the early stages of the disease. It is an undeniable fact that assessment is a crucial component for a disease management. The performance is defined as “what an individual does in his or her current environment” according to the International Classification of Functioning, Disability and Health (ICF). Performance measures for upper extremity have been used relatively recent in persons with MS. ABILHAND, Manual Ability Measurement (MAM), Disabilities

of the Arm Shoulder and Hand Outcome Measure, and Motor Activity Log are commonly used perceived performance measures for upper extremity functions in persons with MS. Because of their modern psychometric properties, ABILHAND and MAM stands out from other measures. Only available actual performance measures for upper extremity functions in persons with MS are accelerometers. In addition to their advantages, they have some disadvantages waiting to be solved.

Keywords: Task performance and analysis; measure; upper extremity; function; multiple sclerosis

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INTRODUCTION

Multiple sclerosis (MS), which has a predominantly young age of onset is one of the leading causes of disability in young-middle aged adults (1). MS has highly variable and often unpredictable clinical presentations ranging from mild infrequent relapses causing mild functional impairments to rapidly accumulating severe disability including loss of independent walking or severe cognitive impairment (2). It is well known that walking impairment is one of the most visible and important symptoms that may be present even in early stages of the disease and in patients with lower Expanded Disability Status Scale (EDSS) scores (3–5). More priority has been given to the walking impairment, therefore, upper extremity dysfunction has been under-recognized until very recently.

Recent studies suggest that upper extremity dysfunction is a quite common symptom in MS and affects adversely the activities of daily living, even in the early stages of the disease. Holper et al. reported that 56% of the persons with MS have impairment in structure of have upper extremity and 71% of those have limitations in activities and participation related with hand and arm use (6). Additionally, upper extremity dysfunction increases with disease progression (i.e. progressive forms have more common upper extremity dysfunction compared to relapsing-remitting form) (6). Another study conducted by Johansson et al. on persons with MS with wide range of EDSS scores (from 0 to 9.5) reported that 79% of the patients have manual dexterity impairment in their dominant hand assessed by Nine-Hole Peg Test

(9HPT) (7). This proportion increases up to 97% in persons with MS with high EDSS scores (6.0–9.5) (7). The upper extremity dysfunction inevitably affects many activities of daily living, health-related quality of life and participation in persons with MS (8, 9).

It is an undeniable fact that assessment is a crucial component for a disease management. The EDSS is the most commonly used measure in the current clinical practice and trials in the past 35 years to assess the progression of the disease and effects of interventions (4, 10). Although in the low range (≤ 3.5), the EDSS is based on the change in one or more of the functional systems, the middle range is mainly based on the walking ability. The EDSS cannot assess upper extremity and cognitive dysfunctions which are common symptoms as much as walking impairment in MS. In 1999, the National Multiple Sclerosis Society's Advisory Committee on Clinical Trials of New Agents in Multiple Sclerosis introduced a new outcome measure called the Multiple Sclerosis Functional Composite (MSFC) to overcome the shortcomings of the EDSS (11). This new method evaluates not only lower extremity function but also upper extremity and cognitive functions and was found that more sensitive to change than the EDSS (11). The MSFC includes the 9HPT to assess upper extremity function regarding manual dexterity. After the introduction of the MSFC, the 9HPT has been the most commonly used outcome measure to assess upper extremity dysfunction in clinical practice and trials in MS (12).

The 9HPT created an important awareness about the upper extremity dysfunction in persons with MS. Over the years, the 9HPT was investigated about its psychometric properties and found that has excellent psychometric properties regarding reliability, discriminant, concurrent, and ecological validity (13). Therefore, the 9HPT is recommended as a gold standard for measuring manual dexterity in persons with MS (13). The 9HPT only assesses fine manual dexterity, however, in everyday life, many other important upper extremity functions are required such as manipulation of larger objects, proximal upper extremity movements (e.g. reaching, lifting) or complex coordinated bimanual tasks (e.g. eating with knife and fork) (12). Besides this, the 9HPT is a measure of capacity, and cannot assess performance which is another component of activity level in the International Classification of Functioning, Disability and Health (ICF).

Difference between performance and capacity

The ICF, a classification system, was officially endorsed by World Health Organization in 2001 as the international standard to describe and measure health and disability (14). The ICF is widely use to classify the outcome measures according to levels including body functions and structures, activity and participation (Figure 1).

According to the ICF definitions, “body functions are the physiological functions of body systems including psychological functions, and body structures are anatomical parts of the body such as organs, limbs and their components” (14). When there is a problem in a body function or structure as a significant deviation or loss, it is called as an impairment. On the other hand, activity is defined as “the execution of a task or action by an individual” and participation is defined as “involvement in a life situation” (14). In a routine clinical practice, most of the clinicians examine the persons with MS according to the body functions and structures, maybe because the frequent use of EDSS. All the eight functional systems of EDSS (including pyramidal-weakness or difficulty moving limbs, cerebellar-ataxia, loss of coordination or tremor, brainstem-problems with speech, swallowing and nystagmus, sensory-numbness or loss of sensations, bowel and bladder function, visual function, cerebral or mental functions, other) are related with body functions and structures.

Activity level can be divided into two qualifiers: performance and capacity. The performance is defined as “what an individual does in his or her current environment” (14). Since the current environment has a social context, performance can also be understood as “involvement in a life situation” or “the lived experience” of persons in the actual context in which they live. Performance is further divided into two categories: actual (objective) and perceived (subjective) performance.

The capacity is defined as “an individual's ability to execute a task or an action” (14). In other words, the highest probable level of functioning that a person may reach in a given domain at a given moment. To assess the capacity, a standardized environment is needed to neutralize the varying impact of different environments on the ability of the individual (14). Because of the similar use, performance and performance-based measurement methods are confused. Actually, most of the performance-based methods assess capacity such as 9HPT. Clinicians should be aware of the “standardized” environment of the tests to distinguish which measure assess capacity or performance. For example, as a capacity measure, the 9HPT requires a quiet room, a standard tool, and it is tested at a certain time (15). On the other hand, a patient-reported outcome measure asks about the usage of upper extremity tasks in everyday life (i.e. involvement in a life situation or the lived experience). Compared to capacity measures, performance measures for upper extremity have been used relatively recent in persons with MS.

Shortcomings of traditional patient-reported outcome measures

While designing a patient-reported outcome measure, almost all

Figure 1. International Classification of Functioning, Disability and Health (ICF) levels. Adapted from Lamers and Feys (12).

attention is paid on the items, but less attention is paid on response options (16). Most of the patient-reported outcome measures have Likert-type response options. In 1932, an American social psychologist Rensis Likert introduced this scale, after him, called Likert-type scale (17). This scale was revolutionary in its age that allows persons to respond to questions, in order to measure their attitudes. The format of a typical five-level Likert item could be 1) strongly disagree, 2) disagree, 3) neither agree nor disagree, 4) agree, and 5) strongly agree. The total score is calculated as the sum of responses on several Likert items. In a real world, however, it is not so easy (16, 18).

It is assumed that the intervals between the response options to be equal in a Likert-type scale. In the real world, the intervals between the response options are not always equal. Take the Disabilities of the Arm, Shoulder and Hand (DASH) Outcome Measure, for example. It asks the persons to rate their ability to do some activities in the last week with the appropriate response options including 1) no difficulty, 2) mild difficulty, 3) moderate difficulty, 4) severe difficulty, and 5) unable. Actually, the levels of difficulty of transition between categories are different. A patient can think that there is a little difference between “2” mild difficulty and “3” moderate difficulty, however, the same patient can think that the interval between “4” severe difficulty and “5” unable are much larger.

The other problem is that all items are assumed to have equal difficulty level. For example, one of the items of DASH asks about turning a key and another one asks about preparing a meal. Turning a key is a very common daily life activity, however, a young single man who almost always orders his meals from outside can find preparing a meal very difficult due to not only his upper extremity dysfunction but also his cooking incompetence.

Missing items are one of the challenging problems of the patient-reported outcome measures. Take Figure 2 as an example. When the raw data is calculated, it seems that the two patients have same dysfunction level (Figure 2a). However, when the same missing items of the Patient 2 removed (Figure 2b), it seems that Patient 2 has actually less dysfunction level.

Unexpected answers given to the items cannot be detected from the sum scores. Figure 3 presents an example. In this example, Patient 1 seems having less dysfunction level, however, the patient reported one item as “unable”. Similarly, Patient 2 seems having very much dysfunction level, however, this patient also reported one item as “no difficulty”. The total scores cannot display possible wrong answers.

(a)

Item	1	2	3	4	5	6	7	8	Raw score
Patient 1	1	3	---	---	---	5	2	1	12
Patient 2	1	1	2	2	3	1	1	1	12

(b)

Item	1	2	3	4	5	6	7	8	Raw score
Patient 1	1	3	---	---	---	5	2	1	12
Patient 2	1	1	.	.	.	1	1	1	5

Figure 2. (a). Raw data calculation example of missing items in a patient-reported outcome measure. Adapted from Elhan and Atakurt (18). (b). Missing data calculation example of missing items in a patient-reported outcome measure. Adapted from Elhan and Atakurt (18).

A solution for all the problems is to use modern psychometric methods, more specifically, Rasch Measurement Theory or a derivative, Item Response Theory (16). It tries to place the item difficulty values along with a person's ability along a common axis. The probability that a person at a given level of ability will be able to do what he or she wants to accomplish is predicted (18). Although traditional psychometric analysis shows that a patient-reported outcome measure is valid and reliable, a total score derived from this patient-reported outcome measure that has not been tested against the Rasch model (or modeled using Item Response Theory) should be interpreted with caution (16).

Perceived performance measures for upper extremity functions in persons with MS

ABILHAND

ABILHAND as a patient-reported outcome measure is used to assess manual ability performance defined as the capacity to manage activities of daily living that require the use of the upper extremities. It is applied as a semi-structured interview. It was originally developed in French for persons with rheumatoid arthritis using the Rasch model (19). Later, it was validated in various populations including persons with stroke, cerebral palsy, and systemic sclerosis, unilateral upper limb amputation, neuromuscular disorders, and multiple sclerosis (20–25). Various versions with different item numbers are available for ABILHAND, but the 23-item ABILHAND, originally validated in persons with stroke, is used in persons with MS (20, 25).

The ABILHAND has 23 items related with perceived ease or difficulty while performing bilateral activities of daily living tasks with three response categories including 0) impossible, 1) difficult, and 2) easy. Item responses are summed to create a total score which higher scores indicate greater manual ability. Then the raw score can be converted into a linear measure of manual ability (Rasch-derived score) using an online tool (<http://www.rehab-scales.org/abilhand-rasch-analysis-chronic-stroke.html>).

The ABILHAND has adequate psychometric properties tested with both traditional and Rasch-model methods in persons with MS (25). Although

Item	1	2	3	4	5	6	7	8
Patient 1	1	3	2	2	2	5	2	1
Patient 2	4	4	3	1	5	4	4	5

Figure 3. An example of unexpected answers given to the items in a patient-reported outcome measure. Adapted from Elhan and Atakurt (18).

MS validation study did not assess test-retest reliability of the 23-item ABILHAND, its high test-retest reliability which was shown in persons with chronic stroke suggests that it may be similar in persons with MS (25, 26).

The ABILHAND is one of the most suggested patient-reported outcome measures in persons with MS due to its easy and fast administration and Rasch-model obtained validation (12, 25). The other advantage of the ABILHAND is to be available in different languages. Although the Turkish validation of the ABILHAND-Kids in children with neuromuscular diseases is provided, the Turkish version is not available for the 23-item ABILHAND which is highly required to use it Turkish-speaking persons with MS (27). Additionally, the ABILHAND is criticized because it questions only about complex bilateral activities of daily living tasks (12).

Manual Ability Measurement

Manual Ability Measurement (MAM) was originally developed in patients from outpatient hand clinics using Rasch-model analyses (28). It is applied as a semi-structured interview and had 16 items ask about perceived ease or difficulty while performing unilateral and bilateral activities of daily living tasks that cover a wide range of difficulty. A 4-point rating system is used to score the items: 1) I cannot do it, 2) very difficult, 3) a little difficult, and 4) easy; representing that higher scores indicate greater manual ability. Subsequently, the original version of the 16-item MAM was expanded as the 36-item MAM (MAM-36) to increase the utility of the MAM to a general rehabilitation patient population and its validation was obtained in patients with neurologic and musculoskeletal disorders including persons with MS (29). The Rasch-derived conversion table for MAM-36 is available in both the original article (29) and freely in the website of Rehabilitation in MS (RIMS) (<https://www.eurims.org/E-education/manual-ability-measurement.html>). Its broad range of items related with both unilateral and bilateral activities of daily living and Rasch-model provided validity make the MAM-36 a good outcome measure to assess upper extremity performance in persons with MS. However, because its Turkish validation is not available similarly as ABILHAND, it should be used cautiously and Turkish validation is highly warranted.

Disabilities of the Arm Shoulder and Hand Outcome Measure

The DASH Outcome Measure is a patient-reported outcome measure originally developed by collaboration with a number of organizations to assess the symptoms of upper extremity dysfunction during unilateral and bilateral activities of daily living (30). It has 30 items with five response options including 1) no difficulty, 2) mild difficulty, 3) moderate difficulty, 4) severe difficulty, and 5) unable. Higher scores indicate a greater level of disability and severity of upper extremities.

Although the traditional psychometric analysis showed that the DASH was a reliable and valid outcome measure to assess upper extremity function in persons with MS, the Rasch analysis results suggest that the validity of the DASH is questionable (31). Additionally, Barrett et al. conducted a study to determine if ABILHAND's measurement performance in MS can be improved by adding relevant items from the DASH and the results showed that adding 16 DASH items to the ABILHAND did not improve its measurement performance (32). Although its advantages such as very common usage in different populations and available Turkish version, the DASH seems that not a proper measure for upper extremity performance in persons with MS because of its low modern psychometric properties (12, 33, 34). Additionally, the DASH is criticized to have some tasks require good balance and walking ability which may be interfered in persons with MS (12).

Motor Activity Log

Motor Activity Log (MAL) is a semi-structured interview to assess upper extremity functions originally introduced to use in persons with stroke (35). In the MAL, persons are asked to rate quality of movement and

amount of movement (quantity) during unilateral and bilateral activities of daily living tasks. The items scored on a 6-point ordinal scale, which the higher scores indicate grater quality and amount of upper extremity movement.

There are several forms of MAL with different item numbers including 30, 28, 26, 20, and 14 (36, 37). However, the MAL-26 was the first whose psychometric properties were investigated (37). Subsequently, the psychometric properties of the MAL-14 (original version) were investigated and found as reliable and valid in persons with stroke (38). The MAL-28 was translated into Turkish and also found as valid and reliable (36). Although the MAL has been used in various MS studies as an outcome measure, there is a lack of information about its psychometric properties in persons with MS (12, 39–42). Since the MAL provides extensive information about the quality and amount of upper extremity movements, knowing its psychometric properties is highly required.

Actual performance measures for upper extremity functions in persons with MS

Accelerometers

Accelerometers have been used to assess physical activity levels in many populations including persons with MS for many years (43, 44). They are very useful tools to reduce biases of patient-reported outcome measures (43, 44). Smartphones can function as an accelerometer that leads to collect enormous data such as a recent study has reported physical activity levels of 717,527 persons from 111 countries (45). There are several type of accelerometers and a recent review reported that uni-axial accelerometers (69%), pedometers (14%), and tri-axial accelerometers (8%) are most commonly used in persons with MS (43).

Despite the common use of accelerometers to measure physical activity levels, their use to assess upper extremity movements is very recent, especially in persons with MS. A systematic review of clinical studies about accelerometer measurement of upper extremity movement after stroke reported that significant correlations were found between clinical assessments and accelerometer data (46). Additionally, the efficacy of a rehabilitation intervention assessed using accelerometers has conflicting results (46). Lamers et al. also showed that significant correlations between accelerometer data and clinical tests to measure upper extremity performance in persons with MS (42). Kos et al. evaluated the superiority and specificity of accelerometer placement (wrist vs. ankle) in persons with MS and explored the relationship between patient-reported and accelerometer-derived activity patterns (47). They also found that wrist placement of the accelerometer was better tolerated than ankle placement and wrist accelerometer data corresponded to a higher degree with self-reported activities of the upper extremities (47).

Besides the lack of information about psychometric properties of accelerometers used for upper extremities in persons with MS, the accelerometers also have some technical problems (12, 42, 46). For example, accelerating wheelchair is a confusing factor, hand dominance affects the results, and they cannot measure finger movements. Additionally, they cannot differentiate voluntary (purposeful) and involuntary (tremor etc.) upper extremity movements. Because of that a patient with an intentional tremor may show more activity data, but probably he or she actually cannot perform purposeful and smooth movement. Lastly, most of the accelerometers are expensive, therefore, cheap and easily accessible accelerometers are required.

Take Home Messages

Compared to capacity measures, performance measures for upper extremity have been used relatively recent in persons with MS. If a clinician or researcher wants to obtain information about how easy or difficult the upper extremity movements are, he or she can use

ABILHAND or MAM-36. But he or she wants to obtain information on how frequently upper extremities are used in daily life, he or she can use MAL or accelerometer. However, the readers should keep in mind that there is currently no available Turkish versions of ABILHAND or MAM-36, and the psychometric properties of MAL and accelerometer are questionable in persons with MS.

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