

# Measuring Function in Chronic Progressive Disorders

## MeSH TERMS

- chronic disease
- outcome assessment (health care)
- treatment outcome

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To support the continued role of occupational therapy in the changing landscape of health care policy, the challenge for practitioners is to develop assessment tools that are valid, reliable, and sensitive to change in performance; to develop and test functional interventions that demonstrate improvements at the impairment, activity, and participation levels; and to develop methods to improve adherence to therapeutic interventions. The focus of this editorial is on choosing assessment tools and measuring function in chronic progressive disorders.

## Challenge of Chronic Progressive Disorders

The U.S. population is aging. According to the U.S. Census Bureau (2012), life expectancy was 78.0 yr in 2008 and is projected to reach 79.5 yr by 2020. As the population ages, the prevalence of chronic diseases and disability will increase (Crimmins & Saito, 2000). Even in middle age, the proportion of people who require assistance with activities of daily living increased from 1997 to 2007 as a result of chronic diseases (Martin, Freedman, Schoeni, & Andreski, 2010). Chronic progressive disorders are particularly challenging because the underlying pathology and body functions worsen with time, resulting in greater activity limitations and disability (Murphy, 2010).

Occupational therapy practitioners routinely work with people who have chronic neurological disorders, including Parkinson's disease (Rao, 2010), Huntington's disease (Bilney, Morris, & Perry, 2003), multiple sclerosis (Steultjens, Dekker, Bouter, Leemrijse, & van den Ende, 2005), amyotrophic lateral sclerosis (Lewis & Rushanan,

2007), essential tremor, and Alzheimer's disease (Letts et al., 2011). For example, in Parkinson's disease, the primary pathology is a depletion of dopamine in the substantia nigra, a nucleus in the basal ganglia. Dopamine depletion leads to motor and nonmotor impairments that give rise to activity limitations and participation restrictions. As the disease progresses, impairments and resulting activity limitations worsen (Evans et al., 2011).

Figure 1 presents a simplified hypothetical scenario in which functional decline takes place over time. Decline in functional ability beyond a critical point results in disability. Occupational therapy services aim to modify the slope of functional decline so that the onset of disability is either delayed or prevented. It is therefore important to choose assessment tools that are responsive to change in performance.

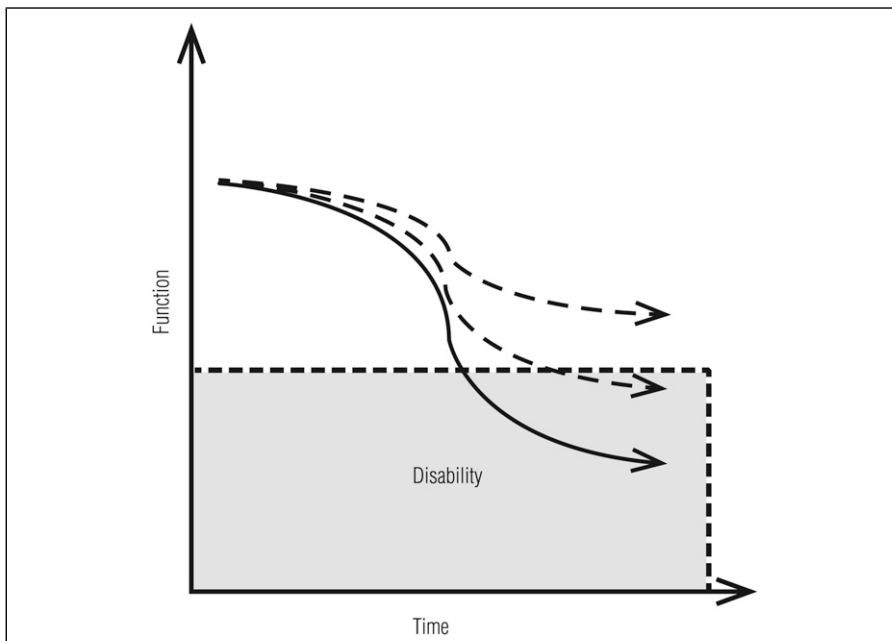
## Choosing Assessment Tools to Measure Changes in Function

Occupational therapists are skilled at measuring body function, activity limitations, and participation restrictions (World Health Organization [WHO], 2001). Doucet and Gutman (2013) recommended the use of multiple assessment tools that provide information on body function, activity limitations, and participation. The following sections briefly discuss considerations in the selection of assessment tools on the basis of the framework proposed by Law and MacDermid (2008).

### *Focus of Measurement*

The *International Classification of Functioning, Disability and Health (ICF; WHO, 2001)* provides a framework for evaluating whether assessment tools measure body

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**Figure 1. Simplified hypothetical scenario depicting functional decline (solid line) over time.** Decline in functional ability beyond a critical point results in disability (gray line). Occupational therapy services aim to modify the slope of functional decline so that the onset of disability is either delayed (lower dashed line) or prevented (upper dashed line).

function, activity limitation, or participation restrictions. For instance, balance and mobility can be measured using assessments of body function (e.g., Berg Balance Scale [BBS]; Berg, Wood-Dauphinee, Williams, & Maki, 1992) or activity limitation (e.g., Timed Up and Go [TUG] test; Podsiadlo & Richardson, 1991).

Measurements can be used to describe current function (descriptive), predict function at a later time (predictive), or document change over time (evaluative; Law & MacDermid, 2008). In clinical practice, evaluative assessments are perhaps most commonly used because they allow practitioners to measure change following intervention. For example, to measure balance in Parkinson's disease, assessment tools may include the BBS, Functional Reach Test, and TUG test (Steffen & Seney, 2008). These scales were developed specifically to measure change in function.

### Clinical Utility

The clinical utility of an assessment tool is enhanced if the instructions for test administration are clear and if the test can be administered in a reasonable period of time. In addition, the tool must be freely available to practitioners across practice settings.

### Scale Construction

Practitioners need to determine whether the assessment tool includes all relevant items

pertaining to the function being tested. For instance, in assessing balance, it is important to use an assessment tool that tests both prospective and reactive balance within a functional context. It is also important to consider the level of measurement used in the assessment tool, which may be nominal (descriptive categories; e.g., male and female), ordinal (ordered categories; e.g., minimal, moderate, and maximal assistance), or ratio scale (interval scale with a true zero point; e.g., time spent in one leg stance). Assessment tools that use a ratio scale are best suited for measuring functional change over time.

### Standardization

Practitioners should choose assessment tools with specific criteria for administration, scoring, and interpretation. Standardized assessments enable comparison of assessment scores within a person at different times and across individuals. Clear standards for test administration hold every client and tester to the same criteria, consistency that is important in interpretation of test results.

### Characteristics of an Assessment Tool

**Validity.** *Validity* indicates whether an assessment tool measures what it claims to measure. Validity is typically established by comparing the assessment tool with a gold standard tool (Law & MacDermid, 2008).

When choosing an assessment tool, practitioners should examine whether it has been validated for the population in question.

**Responsiveness.** *Responsiveness* is the ability of an assessment tool to measure change in function over time. Responsiveness can be evaluated in terms of minimal detectable change, minimal clinically important change, and item response theory.

**Minimal detectable change (MDC)** indicates whether change in function reflects actual change that is greater than random variation in measurement (Haley & Fragala-Pinkham, 2006). MDC is calculated from the standard error of measurement, a confidence factor of change in measurement, and test-retest reliability. In documenting change in function, it is important to ensure that the observed change is greater than random variation. For example, for the BBS, the MDC for Parkinson's disease is 5 points (Steffen & Seney, 2008). Any change in score less than 5 points may not be considered a true change in function.

**Minimal clinically important change (MCID)** refers to the minimal change in score that is clinically meaningful to individual clients. Because MCID is change that is important to clients, assessment may involve asking clients to evaluate whether the change in function is meaningful in their daily life.

Scores on assessment tools developed using *item response theory* (IRT) methodology take into account the relative difficulty of individual items in the tool. For example, the Manual Ability Measure is a client-centered functional questionnaire that assesses hand function (Chen, Granger, Peimer, Moy, & Wald, 2005). The advantage of using such an instrument is that a score is anchored to the client's actual ability; when the client's ability improves, the test score changes accordingly. Assessment tools designed with this methodology thus provide information on clinically important change.

**Reliability.** *Reliability* refers to the consistency between repeated measurements made by an assessment tool when there has been no change in function. Three forms of reliability are test-retest, interrater, and internal consistency.

**Test-retest reliability** refers to consistency in test results when the assessment tool is administered on more than one occasion. For instance, test-retest reliability for the BBS in Parkinson's disease has been reported to be

.94, indicating a 94% probability that repeated administrations of the test would yield the same result (Steffen & Seney, 2008).

*Interrater reliability* refers to the consistency in test results when different testers administer the assessment tool. For instance, the interrater reliability for the BBS for clients with multiple sclerosis was reported to be .96 (Cattaneo, Jonsdottir, & Repetti, 2007).

*Internal consistency* refers to the degree to which different items within an assessment tool measure the underlying construct. Values for internal consistency range from 0 to 1, with higher values indicating that items within an assessment measure the same construct. For example, the internal consistency of the BBS for clients with Parkinson's disease was found to be .86, indicating that this assessment is good for measuring balance (Steffen & Seney, 2008).

## Potential Changes in Medicare Reimbursement Policy

The Centers for Medicare and Medicaid Services (CMS) recently announced a potential change in reimbursement policy (Center for Medicare Advocacy, 2012; see [www.medicareadvocacy.org/hidden/highlight-improvement-standard/](http://www.medicareadvocacy.org/hidden/highlight-improvement-standard/)). At present, reimbursement for occupational therapy services is based on the *improvement standard*: Practitioners must demonstrate improvement in clients to be reimbursed for services provided. The improvement standard has meant that people with progressive disorders are often denied therapy services if they did not improve over the course of therapy (typically 6–8 wk).

The potential change in Medicare policy comes on the heels of a nationwide class-action settlement, approved in January 2013, for provision of skilled health services (“A Humane Medicare Rule Change,” 2012). Under the settlement, reimbursement for therapeutic services will be based on a *need standard*; Medicare will cover services if they are needed to maintain the client's condition or to prevent or slow the decline in function. According to CMS, the new settlement applies to Medicare Parts A and B and specifically covers occupational, physical, and speech therapy in outpatient, home health, and skilled nursing facilities. The change in policy is significant for occupational therapy practice because it may provide reimbursement for a large number of clients who are currently

denied coverage. In light of these policy changes, occupational therapy practitioners must select appropriate assessment tools to accurately document the need for services to maintain and improve function in clients with chronic progressive disorders. ▲

## References

- Berg, K. O., Wood-Dauphinee, S. L., Williams, J. I., & Maki, B. (1992). Measuring balance in the elderly: Validation of an instrument. *Canadian Journal of Public Health, 83*(Suppl. 2), S7–S11.
- Bilney, B., Morris, M. E., & Perry, A. (2003). Effectiveness of physiotherapy, occupational therapy, and speech pathology for people with Huntington's disease: A systematic review. *Neurorehabilitation and Neural Repair, 17*, 12–24. <http://dx.doi.org/10.1177/0888439002250448>
- Cattaneo, D., Jonsdottir, J., & Repetti, S. (2007). Reliability of four scales on balance disorders in persons with multiple sclerosis. *Disability and Rehabilitation, 29*, 1920–1925. <http://dx.doi.org/10.1080/09638280701191859>
- Center for Medicare Advocacy. (2012). *Updated improvement standard and Jimmo news from CMS*. Retrieved May 3, 2013, from [www.medicareadvocacy.org/hidden/highlight-improvement-standard/](http://www.medicareadvocacy.org/hidden/highlight-improvement-standard/)
- Chen, C. C., Granger, C. V., Peimer, C. A., Moy, O. J., & Wald, S. (2005). Manual Ability Measure (MAM-16): A preliminary report on a new patient-centred and task-oriented outcome measure of hand function. *Journal of Hand Surgery, 30*, 207–216. <http://dx.doi.org/10.1016/J.JHSB.2004.12.005>
- Crimmins, E. M., & Saito, Y. (2000). Change in the prevalence of diseases among older Americans: 1984–1994. *Demographic Research, 3*, Article 9. <http://dx.doi.org/10.4054/DemRes.2000.3.9>
- Doucet, B. M., & Gutman, S. A. (2013). Quantifying function: The rest of the measurement story [Editorial]. *American Journal of Occupational Therapy, 67*, 7–9. <http://dx.doi.org/10.5014/ajot.2013.007096>
- Evans, J. R., Mason, S. L., Williams-Gray, C. H., Foltyniec, T., Brayne, C., Robbins, T. W., & Barker, R. A. (2011). The natural history of treated Parkinson's disease in an incident, community based cohort. *Journal of Neurology, Neurosurgery, and Psychiatry, 82*, 1112–1118. <http://dx.doi.org/10.1136/jnnp.2011.240366>
- Haley, S. M., & Fragala-Pinkham, M. A. (2006). Interpreting change scores of tests and measures used in physical therapy. *Physical Therapy, 86*, 735–743.
- A humane Medicare rule change [Editorial]. (2012, October 23). *New York Times*. Retrieved from [www.nytimes.com/2012/10/24/opinion/a-humane-medicare-rule-change.html?partner=rssnyt&emc=rss&\\_r=1&](http://www.nytimes.com/2012/10/24/opinion/a-humane-medicare-rule-change.html?partner=rssnyt&emc=rss&_r=1&)
- Law, M., & MacDermid, J. (Eds.). (2008). *Evidence-based rehabilitation: A guide to practice* (2nd ed.). Thorofare, NJ: Slack.
- Letts, L., Minezes, J., Edwards, M., Berenyi, J., Moros, K., O'Neill, C., & O'Toole, C. (2011). Effectiveness of interventions designed to modify and maintain perceptual abilities in people with Alzheimer's disease and related dementias. *American Journal of Occupational Therapy, 65*, 505–513. <http://dx.doi.org/10.5014/ajot.2011.002592>
- Lewis, M., & Rushanan, S. (2007). The role of physical therapy and occupational therapy in the treatment of amyotrophic lateral sclerosis. *NeuroRehabilitation, 22*, 451–461.
- Martin, L. G., Freedman, V. A., Schoeni, R. F., & Andreski, P. M. (2010). Trends in disability and related chronic conditions among people ages fifty to sixty-four. *Health Affairs, 29*, 725–731. <http://dx.doi.org/10.1377/hlthaff.2008.0746>
- Murphy, S. L. (2010). *Centennial Vision—Geriatric research*. *American Journal of Occupational Therapy, 64*, 172–181. <http://dx.doi.org/10.5014/ajot.64.1.172>
- Podsiadlo, D., & Richardson, S. (1991). The Timed “Up & Go”: A test of basic functional mobility for frail elderly persons. *Journal of the American Geriatrics Society, 39*, 142–148.
- Rao, A. K. (2010). Enabling functional independence in Parkinson's disease: Update on occupational therapy intervention. *Movement Disorders, 25*(Suppl. 1), S146–S151. <http://dx.doi.org/10.1002/mds.22784>
- Steffen, T., & Seney, M. (2008). Test–retest reliability and minimal detectable change on balance and ambulation tests, the 36-item Short-Form Health Survey, and the unified Parkinson disease rating scale in people with parkinsonism. *Physical Therapy, 88*, 733–746. <http://dx.doi.org/10.2522/ptj.20070214>
- Steultjens, E. M., Dekker, J., Bouter, L. M., Leemrijse, C. J., & van den Ende, C. H. (2005). Evidence of the efficacy of occupational therapy in different conditions: An overview of systematic reviews. *Clinical Rehabilitation, 19*, 247–254. <http://dx.doi.org/10.1191/0269215505cr870oa>
- U.S. Census Bureau. (2012). *Table 104: Expectation of life at birth, 1970 to 2008, and projections, 2010 to 2020*. Washington, DC: Author.
- World Health Organization. (2001). *International classification of functioning, disability and health*. Geneva: Author.