

Research Paper

Importance of an individual's evaluation of functional status for health-related quality of life in patients with multiple sclerosis

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Abstract

Background: Quantifying the clinical impact of multiple sclerosis (MS) is one of the most important determinants for optimizing individual patient care. Useful clinical measures for MS can be evaluated from different perspectives.

Objective/Hypothesis: This cross-sectional study compared physical disability and functional status as assessed by a neurologist and by a patient and explored how they are associated with the health-related quality of life (HRQoL).

Methods: We collected data from 223 patients. One neurologist scored functional disability using the Kurtzke's Expanded Disability Status Scale (EDSS) and patients evaluated their functional status using the Incapacity Status Scale (ISS). HRQoL was assessed using the Physical and Mental Component Summary (PCS, MCS) of the Short Form-36 Health Survey (SF-36). Multiple linear regressions were applied to analyze the data.

Results: Total EDSS and ISS scores correlated significantly ($r = .67$; $p \leq .001$). Regression analyses showed that EDSS was significantly related to PCS, but not to MCS. After adding ISS into the analysis the association between EDSS and PCS became non-significant. ISS contributed significantly to the explained variance in both models. The final model explained 49% of the total variance for PCS and 15% for MCS.

Conclusions: Functional disability as measured by a neurologist (EDSS) is associated with PCS, but not with MCS, whereas functional disability as measured by patients (ISS) is significantly associated with both HRQoL dimensions. Neurologists should target their attention more on patients' evaluations of their functional status in order to detect the most bothersome problems that are affecting a patient's quality of life. © 2015 Elsevier Inc. All rights reserved.

Keywords: Multiple sclerosis; Incapacity Status Scale; Expanded Disability Status Scale; Health-related quality of life; Neurological impairment

Multiple sclerosis (MS) is the most common chronic neurological disease of the central nervous system (CNS) in young adults in European countries, with approximately 1 in 10,000 people affected.^{1–5} The disease may lead to a

wide spectrum of physical and non-physical disabilities among young and middle-aged adults. Symptoms of the disease begin mostly between ages 20 and 50 years, with a peak at age 33 years.^{1–5} MS symptoms may be mild, such as numbness in the limbs, or severe, such as paralysis or loss of vision. The progress, severity and specific symptoms of MS are unpredictable and vary from death within a few weeks after clinical onset to asymptomatic cases accidentally discovered at autopsy in old age.

Quantifying the clinical impact of multiple sclerosis (MS) is one of the most important determinants for optimizing individual patient care. In addition to measures of disease severity, measures of functional status may provide useful

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information to aid in prognostic stratification and help guide treatment decisions. Functional status refers to the ability to perform daily activities to meet basic self-care needs and to maintain health and well-being. It reflects functional capacity — what an individual is capable of doing — and functional performance — what an individual actually does in daily life. Functional status may be affected by impairments in physical, sensory, cognitive or social function.⁶ Useful clinical measures of functional status for MS can be evaluated from different perspectives. In the first approach information is based on neurological examination by a physician. Examples in this category include the Expanded Disability Status Scale (EDSS) and related instruments.^{7–9} Neurologists evaluate a patient's physical impairment and functional status using the EDSS,¹⁰ which is the most widely used method of clinical and research assessment in MS. The rating system was recommended by Kurtzke and combines the assessment of impairment. Other multi-item measures for neurologists have been developed, but none has been as widely as the EDSS.^{10–13} The second approach focuses on information provided by the patient or a family member. Measures of disability and handicap, such as disease-specific instruments like the Incapacity Status Scale (ISS) and the Environmental Status Scale (ESS), can be categorized in this approach.^{14,15} Scales measuring both disability and handicap, as reported by the patients, are an additional useful measure of disablement in MS.¹¹ The Incapacity Status Scale (ISS) was developed to describe disability and assess functional status from the patient's perspective.^{14,15} This scale quantifies the individual's physical and mental dysfunction, closely reflecting the activities of daily living, and has been found to be relevant for evaluating the clinical impact of MS.^{11,16,17}

Previous research shows that clinicians' and patients' perceptions of health status and disability did not lead to consensus.^{18–20} Clinicians most frequently focus on physical impairment as a relevant indicator of a patient's self-rated health or well-being. In clinical practice, strategies aimed at improving patients suffering from MS are most frequently focused on patients with more severe disability.²⁰ In many cases health professionals perceive physical impairment as a relevant indicator of patients' poorer HRQoL, but in doing so, these professionals might overlook aspects of patients' own perception of their health status. That is, MS patients themselves may perceive physical functioning differently.¹⁹ Midgard et al compared the EDSS and ISS among 124 MS patients with mean disease duration of 7.8 years.²¹ Their results showed a consistently strong relationship between the EDSS score (i.e. the clinician's measure of disability) and the single items of the ISS (i.e. a self-report measure). However, the items from the cognitive and psychosocial dimensions of the ISS, namely Speech and hearing, Mood and thought, Mentation, and Medical problems, did not correlate significantly or showed a weak correlation with the physical impairment as expressed in the EDSS. A similar observation was made in a recent pilot study on the Functional Limitations Profile

as a measure of disability in MS, indicating that the psychosocial factors reported in MS are not associated with physical functioning.²²

Health-related quality of life (HRQoL) is an important consideration in the treatment of patients with MS and seems to be more sensitive to changes during a disease than conventional disability measurements such as EDSS.^{12–17} Thus, HRQoL has started to be widely applied as an outcome measure.^{9,22–30} HRQoL is a concept that most people intuitively understand, but one that is difficult to define precisely. Most definitions of HRQoL are centered on the notion of health put forth by the WHO. Accordingly, HRQoL is often defined as optimum levels of physical, emotional, mental, role (e.g. work, parent, career) and social functioning, including relationships, and perception of health, fitness life satisfaction and well-being.⁶ Several previous studies^{18,20,31–33} investigated the relationships between disability and HRQoL in MS patients. Studies examining HRQoL in patients with MS showed that patients suffering from MS have lower HRQoL compared with the healthy population and especially have worse self-rated physical and mental health status.^{18–20,26,34–39} In addition, the results of studies comparing MS patients with patients affected by other chronic diseases show that MS patients have the least favorable ratings of general health, vitality, physical functions and limitations in social roles.⁴⁰ This is because the effect of physical disability on activities of daily living is supposed to be greater in MS than in other chronic diseases.^{33,34,41–43}

Previous studies in this field have concentrated mainly on the differences between a patient's and a physician's evaluation of functional status and have shown that they indeed differ. These studies have focussed less on their associations with HRQoL, however. Therefore, the aim of this study was to compare the physical disability and functional status as assessed by a neurologist and by a patient and to explore their relationships with patient's health-related quality of life (HRQoL).

Methods

Study design

This was an observational cross-sectional study.

Participants and procedure

The study sample consisted of MS patients from hospitals, outpatient clinic and MS clubs and in the eastern part of Slovakia. Exclusion criteria were cognitive impairment (determined by a Mini-Mental State Examination (MMSE) score of <24), a history of psychiatric or medical conditions affecting the outcomes of the study, pregnancy, under 18 years of age or not speaking Slovak. Patients were enrolled in the study between 2003 and 2006.

Data collection consisted of a medical examination carried out by a neurologist and an interview conducted with

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