Archives of Physical Medicine and Rehabilitation

journal homepage: www.archives-pmr.org

Archives of Physical Medicine and Rehabilitation 2016;97:386-94

ORIGINAL RESEARCH

Cross-Sectional Examination of the Associations Between Symptoms, Community Integration, and Mental Health in Multiple Sclerosis

Anna L. Kratz, PhD,[a] Dawn M. Ehde, PhD,[b] Marisol A. Hanley, PhD,[c] Mark P. Jensen, PhD,[b] Travis L. Osborne, PhD,[d] George H. Kraft, MD[b]

From the [a]Department of Physical Medicine and Rehabilitation Medicine, University of Michigan, Ann Arbor, MI; [b]Department of Rehabilitation Medicine, University of Washington, Seattle, WA; [c]Seattle Psychology, Seattle, WA; and [d]Evidence Based Treatment Centers of Seattle, Seattle, WA.

Abstract

Objective: To determine the frequency and severity of 8 symptoms in persons with multiple sclerosis (MS) and to examine the association between these symptoms and community integration and mental health.

Design: Cross-sectional survey that assessed 8 symptoms (pain, fatigue, imbalance, numbness, weakness, shortness of breath, vision loss, and memory loss), disease progression (self-report version of the Expanded Disability Status Scale), community integration, and mental health.

Setting: Community.

Participants: Adults with self-reported MS who responded to a mailed survey ($N=180$).

Interventions: Not applicable.

Main Outcome Measures: The presence and intensity of symptoms were measured with a symptoms checklist. Community integration was assessed with the Community Integration Questionnaire, and mental health was measured by the Mental Health Index of the Medical Outcomes Study 36-Item Short-Form Health Survey.

Results: The average number of symptoms reported was 5.07 ± 2.18. The most common symptoms (fatigue, weakness, and imbalance) were also rated as the most severe. Not all symptoms were associated with level of disease progression or with MS subtype. Symptoms related to mobility were more likely to be associated with these variables. The 8 symptoms as a whole accounted for significant amounts of variance (range, 13%—21%) in measures of community integration and mental health, with specific symptoms making differential independent contributions to these measures.

Conclusions: This study demonstrates that most individuals with MS report a number of bothersome symptoms. Type of MS or level of progression does not tell the whole story regarding the impact of symptoms.

Archives of Physical Medicine and Rehabilitation 2016;97:386-94

Multiple sclerosis (MS) is a chronic neurologic disease associated with a constellation of symptoms, including impaired ambulation, cognitive dysfunction, depressed mood, weakness, pain, and fatigue. The impact of some of these symptoms on mental health, physical functioning, participation, and quality of life in general has been well documented. For example, fatigue is recognized as a highly disabling symptom of MS, limiting physical exertion and the ability to participate in work, leisure activities, and social roles.[1-6] Similarly, it has been shown that many persons with MS experience chronic pain,[7-9] and that for approximately 25%, pain is severe and negatively impacts daily activities and functioning over and above the effects of MS itself.[8-10] The burden of cognitive dysfunction,[11-13] depression[12,14,15] and impaired mobility[16-18] on functional ability (eg, activities of daily living)

Supported in part by the National Institute on Disability and Rehabilitation Research (grant no.H133B031129); Management of Chronic Pain in Rehabilitation, from the National Institutes of Health, National Institute of Child Health and Human Development (National Center for Medical Rehabilitation Research) (grant no. P01 HD/NS33988); the National Institute of Neurological Disorders and Stroke; and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (grant no. 1K01AR064275).

Disclosures: none.

0003-9993/15/$36 - see front matter © 2016 by the American Congress of Rehabilitation Medicine

http://dx.doi.org/10.1016/j.apmr.2015.10.093

and quality of life has also been described extensively in the literature.[19-22]

To date, most studies of MS symptoms have focused on the impact of a single symptom or small collection of symptoms (eg, pain, fatigue, depression). Consequently, the severity and impact of any given symptom relative to others is not well understood. Only a few studies have examined the relative prevalence and severity of a broad range of MS symptoms.[22] One study of an MS sample with severe disability found that the most common symptoms were problems using arms and legs, fatigue, spasms, pain, and sleepiness and that only some of these symptoms were significantly correlated with measures of disability; however, the association of symptoms with community integration or mental health was not assessed in this study.[23] An early study in a community sample of 656 individuals with MS found that fatigue, balance problems, weakness or paralysis, and numbness or other sensory disturbance were the most common symptoms and that fatigue, balance problems, and weakness were related to difficulty in activities of daily living, but the type of difficulty was not reported, and again, the association of symptoms to community integration and mental health was not examined.[24]

Knowledge about the frequency and severity of a broader range of symptoms and their impact on community integration and mental health is needed to inform symptom management, including self-management. Such information may guide decisions about the specific symptoms targeted, skills taught, and/or goals set within a self-management intervention. It may also inform the degree to which self-management interventions should focus on teaching skills to manage a specific symptom, as is most commonly done,[25] or multiple co-occurring symptoms.[26] Given that rehabilitation interventions often target symptom management, community integration, and mental health, knowing how different symptoms relate to these outcomes may help patients and rehabilitation providers prioritize symptoms and care.[1,3,7,9,10]

This study aims to address gaps in our knowledge regarding the relative frequency and intensity of a broad range of symptoms in MS and examine the association of symptoms with community integration and mental health. Community integration can be defined as integration into multiple domains of community life, including social, self-care/independence, and productive activity/occupational participation.[27,28] Mental health can be assessed as the absence of mental distress (eg, depressive symptoms) or psychopathology (eg, depression, anxiety). The specific aims were (1) to determine the relative frequency and severity of 8 symptoms in persons with MS; (2) to determine the extent to which MS subtype and disease progression relate to the frequency and severity of symptoms; and (3) to estimate the associations between symptom severity and both community integration and mental health, above and beyond the effects of relevant demographic and clinical variables.

List of abbreviations:

CIQ	**Community Integration Questionnaire**
EDSS	**Expanded Disability Status Scale**
MS	**multiple sclerosis**
RR	**relapsing remitting**
SF-36	**Medical Outcomes Study 36-Item Short-Form Health Survey**

Methods

Participants and procedures

Participants came from a postal survey of quality of life in persons with MS; see our primary article for more details on study methodology.[10] Questionnaires and a consent forms were mailed to 287 individuals randomly selected from a larger pool of research participants that were drawn from the membership list of the Multiple Sclerosis Association of King County, WA. Inclusion criteria were self-report of MS diagnosis and age ≥18 years. Participants were told the purpose of the study was to examine quality of life in MS. Respondents were compensated $25 for returning completed consent forms and surveys. The University of Washington Human Subjects Review Committee approved all procedures; study participants provided informed consent.

Measures

Demographics

Participants reported age, sex, race/ethnicity, employment status, education level, and marital status.

MS-related measures

To identify MS subtype, relapsing remitting (RR), secondary progressive, primary progressive, or progressive relapsing, respondents were asked to select the pictorial graph accompanied by a written description of the clinical course that most closely corresponded to their disease course.[29] This measure has been shown to correspond well with physician diagnosis of MS disease subtype ($\kappa = .62$) and provides a reasonable estimate of MS subtype for research.[30]

Respondents completed the self-report version[31] of the Expanded Disability Status Scale (EDSS),[32] the standard measure of disease progression and neurologic impairment used in MS care and research. The self-report version of the EDSS is highly correlated ($r = .89$) with the physician-administered EDSS.[31] In our analyses the EDSS scores were categorized as mild (0−4), moderate (4.5−6), or severe (6.5−9.5) to reflect milestones in progressive loss of functioning. The survey also assessed the date of MS diagnosis to estimate disease duration.

Symptoms

Respondents were asked to rate the presence and severity of 8 symptoms: pain, weakness, fatigue, numbness, imbalance, memory loss, vision loss, and shortness of breath. For each symptom, participants were asked to rate its current severity on an 11-point scale from 0 (none) through 10 (very severe). This symptom list was originally designed to be used with a broad range of disability populations for the purpose of making comparisons across conditions,[33] with the expectation that some symptoms would be fairly common across conditions (eg, fatigue), and others would be more common in specific groups (eg, shortness of breath).

Mental health and community integration

The 5-item Mental Health Index of the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36)[34] was used to assess mental health. This widely used measure has demonstrated high internal consistency reliability, (.81−.95), test-retest stability coefficients (.75−.80), and convergent validity.[34] The Mental Health Index total score has a possible range of 0 to 100, with higher scores indicating better mental health.