



Disability and Health Journal 9 (2016) 472-478

Research Paper

Disability and Health Journal

www.disabilityandhealthjnl.com

Selected health behaviors moderate the progression of functional limitations in persons with multiple sclerosis: Eleven years of annual follow-up

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Abstract

Background: Multiple sclerosis (MS), a chronic neurological disease typically diagnosed in young adulthood, presents with a wide variety of symptoms, impairments and functional limitations. Given the chronic, unpredictable and long-term nature of this disease, preserving function is essential.

Objective: The purpose of this study was to identify psychosocial and behavioral factors that might influence the trajectory of functional limitation through eleven years of longitudinal follow-up of a sample of persons with MS.

Methods: Participants (N = 606) completed measures of health behaviors, related constructs and functional limitations annually over eleven years. Longitudinal measures of functional limitations were analyzed using random-effects regression that allows for study of individual differences in the trajectories of a measure. Using the best fitting quadratic growth model, we tested the within and betweenperson effects of Nutrition, Interpersonal Relationships, Exercise, Stress Management, Health Responsibilities, Spiritual Growth, Self-rated Health and Barriers, controlling for Age, Year since Diagnosis and Year of Dropout, on Functional Limitations in the 11th year.

Results: After adjusting for covariates, higher mean scores for Exercise and Self-rated Health were related to lower levels of Functional Limitations in Year 11. Higher mean scores for Stress Management, Health Responsibilities and Barriers were related to higher levels of Functional Limitations in Year 11. Higher mean Exercise scores and lower mean Health Responsibilities scores were related to slower rates of progression of functional limitations in Year 11.

Conclusion: Findings suggest that the highly variable trajectory of functional limitations in MS may be extended and shaped through health behavior strategies. © 2016 Elsevier Inc. All rights reserved.

Keywords: Multiple sclerosis; Functional limitations; Health behaviors

According to current estimates, approximately 400,000 persons in the United States and 2.5 million worldwide live with multiple sclerosis (MS)¹ (http://ghr.nlm.nih.gov/ condition/multiple-sclerosis, 2013). This immune-mediated disease is characterized by the destruction of the myelin insulating the axons thus interfering with electrical conduction within the nervous system where axon

damage and death may also occur.² MS is typically diagnosed in young adulthood; over time varying patterns of demyelinating lesions produce virtually infinite symptom combinations, impairment, and functional limitation. Although there may be long periods of time with few or no symptoms, it is now recognized that the disease is neurologically active in most persons with MS most of the time.

The last twenty years have brought major advances in understanding of the pathological changes of MS alongside an array of new disease-modifying medications. However, limited information about how individual behaviors and choices may serve as potential *moderators* of the course of the disease-related limitations^{3,4} results in a key question for those with MS as well as clinicians and researchers interested in developing interventions to preserve function,⁵ prevent disability and promote quality of life: What factors (other than the biological disease) influence the

This work was supported by the National Institutes of Health, National Institute of Nursing Research 5R01NR003195. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Nursing Research or the National Institutes of Health.

The author(s) declare(s) that there is no conflict of interests regarding the publication of this article.

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^{1936-6574/\$ -} see front matter © 2016 Elsevier Inc. All rights reserved. http://dx.doi.org/10.1016/j.dhjo.2016.01.006

development of functional limitations? The primary purpose of this study was to identify psychosocial and behavioral factors that might influence the trajectory of functional limitation through eleven years of continual longitudinal follow-up of a sample (N = 606) of persons with MS.

Ideal studies assessing the potential moderating effects of health promoting behaviors on functional limitations would follow large samples of persons newly diagnosed with MS, consider type of MS and use of diseasemodifying medications, and assess the influence of multiple health behaviors on functional limitations over an extended period of time. While studies sharing all of these characteristics do not presently exist, there is a growing body of literature providing indirect support for the moderating effects of health behaviors. Experimental studies (typically with small samples and brief follow-up) provide limited evidence that specific health behaviors may moderate the trajectory of limitations. One systematic review of 27 studies concluded that evidence supports possible diseasemodifying effects of exercise or physical activity⁵ and a second review of 54 studies found that while there was moderate evidence that exercise improved aerobic capacity and muscular strength, there was not consistent evidence that exercise-training programs improved mobility, fatigue or health-related quality of life for persons with MS.⁶ Similarly, two recent Cochrane reviews found little data to support specific dietary strategies as disease-modifying therapies in MS.^{7,8}

Prospective natural history studies of persons with MS tend to have larger samples and longer follow-ups, but most have addressed only biological (e.g. age, gender) or clinical (duration of MS) variables that provide only limited explanatory power for the progression of functional limitations.^{9–13} In a widely cited study conducted before the advent of disease-modifying medications, Weinshenker and colleagues found that 50% of persons with MS require the use of an assistive device for walking 15 years after diagnosis and 10% require a wheelchair to support mobility.¹⁴ Recently published studies with assessments over five to eleven years have explicated more nuanced changes in functional limitations, disability and quality of life.^{3,15,16} In one study, those with the lowest disease severity at the initiation of the study experienced the greatest increases in disability and decreases in quality of life over time.¹⁵ Other investigators^{3,16} reported measures of walking, manual dexterity, activities of daily living and cognition reflecting deterioration over time while indicators of mood, social functioning and emotional well being remained stable or improved.

To date, only a few cross-sectional studies have considered health-promoting behaviors, continuing behavioral, cognitive, and emotional efforts to sustain and improve health and well being,¹⁷ as potential moderators of the progression of functional limitations.^{18,19} For example, D'hooghe and colleagues found that participants (N = 1372) with relapsing onset MS who reported more frequent health promoting behaviors (physical activity,

nutrition and spiritual growth) had a reduced risk of reaching an Expanded Disability Status score of 6 (requiring a cane for mobility) compared to a reference group.¹⁹

The few prospective longitudinal studies to date assessing health behaviors and functional limitations in MS have had relatively small samples, limited length of follow-up (6 months–5 years) and have assessed the impact of a single health behavior over time. In a 6-month longitudinal study with 276 persons with MS, Motl and McAuley found that change in physical activity was associated with changes in function, quality of life and selected symptoms.^{20,21} Stuifbergen and colleagues followed a large sample of persons with MS (N = 606) for five years and reported that rates of change in functional limitation correlated negatively with rates of exercise behavior and quality of life ratings.⁴

The study reported here extends the follow-up of the sample from that earlier study⁴ to an 11-year time period and explores the impact of multiple health behaviors (physical activity, healthy eating, stress management, supportive interpersonal relationships, health responsibility and spiritual growth) as moderators of the progression of functional limitation. Specifically, this study aims to test the within-person and between-person effects of health behaviors on functional limitations over an 11-year period. Two hypotheses were proposed:

1. Healthy behaviors are related to lower functional limitations levels within any given year; and

2. Healthy behaviors, averaged across time, are related to lower functional limitations levels and to a slower rate of progression in functional limitations at the end of the 11-year time period.

Methods

This longitudinal study followed a large sample of community residing persons with physician-diagnosed MS over an eleven year period. Participants completed self-report measures of health behaviors, related constructs and functional limitations annually through a mailed survey. The study design was consistent with the IOM recommendations for longitudinal studies with persons with MS, as it did not rely on a small sample from specific subpopulations (e.g. clinic or support group), did not focus on a single issue, and included groups of persons with MS who may have markedly different limitations.²²

Data collection procedures

Study information and consents for this longitudinal study were mailed to 749 persons with MS who had participated in an earlier cross-sectional study.²³ Those who returned questionnaires (N = 621; 84%) were enrolled in the longitudinal study and received study surveys over each of the following eleven years. Participants received two

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