



## Communicative participation restrictions in multiple sclerosis: Associated variables and correlation with social functioning



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### ABSTRACT

Individuals with multiple sclerosis (MS) are at risk for communication problems that may restrict their ability to take participation in important life roles such as maintenance of relationships, work, or household management. The aim of this project is to examine selected demographic and symptom-related variables that may contribute to participation restrictions. This examination is intended to aid clinicians in predicting who might be at risk for such restrictions and what variables may be targeted in interventions. Community-dwelling adults with MS ( $n = 216$ ) completed a survey either online or using paper forms. The survey included the 46-item version of the Communicative Participation Item Bank, demographics (age, sex, living situation, employment status, education, and time since onset of diagnosis of MS), and self-reported symptom-related variables (physical activity, emotional problems, fatigue, pain, speech severity, and cognitive/communication skills). In order to identify predictors of restrictions in communicative participation, these variables were entered into a backwards stepwise multiple linear regression analysis. Five variables (cognitive/communication skills, speech severity, speech usage, physical activity, and education) were statistically significant predictors of communication participation. In order to examine the relationship of communicative participation and social role variables, bivariate Spearman correlations were conducted. Results suggest only a fair to moderate relationship between communicative participation and measures of social roles. Communicative participation is a complex construct associated with a number of self-reported variables. Clinicians should be alert to risk factors for reduced communicative participation including reduced cognitive and speech skills, lower levels of speech usage, limitations in physical activities and higher levels of education.

**Learning outcomes:** The reader will be able to: (a) describe the factors that may restrict participation in individuals with multiple sclerosis; (b) list measures of social functioning that may be pertinent in adults with multiple sclerosis; (c) discuss factors that can be used to predict communicative participation in multiple sclerosis.

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## 1. Introduction

Multiple sclerosis (MS) is an adult onset neurologic condition in which scattered lesions in the central nervous system produce varying combinations of motor, sensory, and cognitive impairments (Joy & Johnston, 2001). Speakers with MS may experience a number of communication problems. The most common of these is dysarthria, occurring in approximately half of the population depending on sampling techniques and measures reported (Darley, Brown, & Goldstein, 1972; Hartelius, Runmarker, & Andersen, 2000; Hartelius & Svensson, 1994; Yorkston et al., 2003). Others include language changes such as word finding difficulties and impaired word fluency that may be associated with underlying cognitive impairments (Murdoch & Lethlean, 2000a, 2000b). Communication problems place those with MS at risk for restrictions in the many social roles common in adult life, including work, home management, and leisure activities. Applying terminology from the International Classification of Functioning, Disability, and Health (World Health Organization, 2001) to communication problems, speakers with MS may be restricted in participating in life situations where knowledge, information, ideas and feelings are exchanged (Eadie et al., 2006). The restrictions in communicative participation they experience would seem to be an important target for intervention. As part of the process of developing interventions that target communicative participation, it is critical to understand the many factors that may contribute to such restrictions. Two important research methods, qualitative analysis and development of psychometrically rigorous patient-reported outcome measures, have been applied to broaden our understanding of participation restrictions in disabling conditions. Each of these methods is reviewed briefly along with research applications related to MS.

Qualitative methods are well suited to gathering an in-depth understanding of complex issues that cannot be separated from the context in which they occur. Methods including focus groups and semi-structured interviews have been used in the field of MS rehabilitation to investigate multifaceted issues such as employment (Johnson, Yorkston, Klasner, Kuehn, & Amtmann, 2004; O'Day, 1998) and aging with disability (DalMonte, Finlayson, & Helfrich, 2003; Dilorenzo, Becker-Feigeles, Halper, & Picone, 2008; Fong, Finlayson, & Peacock, 2006; Ploughman et al., 2012). Qualitative methods have also been applied in the study of communication disorders associated with MS (Baylor, Burns, Eadie, Britton, & Yorkston, 2011; Yorkston, Klasner, & Swanson, 2001). Analyses of interviews suggest that changes in cognition, susceptibility to fatigue, and reduced vision and mobility may all affect communicative participation. Thus, in order to plan intervention, speech-language pathologists must understand a broad constellation of factors.

Although qualitative methods provide insights into factors that shape communicative participation, they do not provide speech-language pathologists with readily available tools to measure the severity of these restrictions or to document the outcomes of participation-focused intervention. Development of psychometrically-sound, patient-reported outcome measures may fill this gap. Patient-reported outcomes directly reflect the effects of a condition such as a communication problem from the perspective of the person experiencing the problem. These measures are appropriate when symptoms, functioning in everyday life, and well-being are important outcomes (Frost, Reeve, Liepa, Stauffer, & Hays, 2007). They are commonly used to measure “latent traits” that cannot be directly observed such as fatigue, pain, or self-efficacy. In 2004, the National Institutes of Health funded a roadmap initiative called Patient-Reported Outcomes Measurement Information System (PROMIS) to develop self-report outcome measures that can be used across healthcare disciplines (<http://www.nihpromis.org>). The PROMIS group used rigorous procedures for item generation, item reduction, and psychometric evaluation to develop sets of item banks to measure a number of important subjective constructs (Cella et al., 2007, 2010). Using rigorous modern psychometric methods for instrument development including Item Response Theory (IRT) (Embretson & Reise, 2000), measures of anxiety, depression, fatigue, positive affect, stigma, and others have been developed. A tutorial introduction of IRT in the field of communication disorders is available (Baylor, Hula, et al., 2011).

Guided by principles outlined by the PROMIS group (Reeve et al., 2007), a program of research was undertaken to develop a measure of communicative participation for community-dwelling adults with speech or voice problems. Development started with an investigation of existing self-report psychosocial outcomes instruments for adults with communication disorders (Eadie et al., 2006). This review found that while the concept of communicative participation is reflected in several instruments, the construct is mingled with other constructs including physical symptoms, emotional coping, and discreet task performance. Instruments often bundle these multiple constructs together in measures of ‘quality of life.’ These instruments confound the measurement of participation and limit the ability to study how variables such as physical symptoms, personal coping, or environmental conditions operate separately to influence participation. Thus, the field lacked the needed participation-focused, self-report instruments.

Extensive cognitive interviews were then conducted to receive specific feedback on candidate items for a new instrument, the Communicative Participation Item Bank (CPIB). Although initial phenomenological studies focused on spasmodic dysphonia (SD) (Baylor, Yorkston, & Eadie, 2005; Baylor, Yorkston, Eadie, & Maronian, 2007) and MS (Yorkston et al., 2007), 44 individuals across seven diagnoses (SD, MS, laryngectomy, stuttering, stroke, Parkinson's disease, and amyotrophic lateral sclerosis) participated in cognitive interviews (Baylor et al., 2011; Yorkston et al., 2008). Development continued with an item calibration study using IRT (Baylor et al., 2013) based on data collected from 701 individuals across four populations – MS, Parkinson's disease, head and neck cancer, and amyotrophic lateral sclerosis.

The availability of the CPIB opens up new opportunities to explore how individuals with MS view their communication in their daily lives. On the surface, communication is critical to achieving most daily activities; but the extent to which individuals with MS feel that their communication is restricted, what variables associated with MS contribute to those restrictions, and how those restrictions impact broader life and social roles can now be explored in further detail. While the

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