J Commun Disord. Author manuscript; available in PMC 2016 January 19.

Published in final edited form as:

J Commun Disord. 2014 ; 52: 196–206. doi:10.1016/j.jcomdis.2014.05.005.

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.

Keywords

Multiple sclerosis; Speech; Participation

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Financial and Non-financial Disclosures: The authors have no nonfinancial relationships to disclose.

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, 200b). 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 outcomes 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 CPIB was still under development, a preliminary item set was used to examine communicative participation in a large sample of community-dwelling adults with MS, not selected for the presence of communication disorders. An initial regression analysis found the following variables to be statistically significantly associated with communicative participation: fatigue, self-reported symptoms of “slurred speech," depression, self-reported symptoms of "problems thinking," employment status, and social support (Baylor, Yorkston, Bamer, Britton, & Amtmann, 2010). The study was then extended with repeated measures of communicative participation over two years (Baylor, Amtmann, & Yorkston, 2012). A growth-mixture modeling analysis found relatively stable communicative participation over time. Three latent classes were evident in the data, suggesting different levels of communicative participation restrictions. The class with the least restrictions in communicative participation was characterized by fewer symptoms of slurred speech, depression, and fatigue. The class with moderate restrictions in communicative participation was characterized by low social support. The class with the greatest restrictions in communicative participation was characterized by low social support and more self-reported cognitive symptoms. While these two preliminary studies suggest multiple variables that may be associated with communicative participation, one key limitation of the studies is that a large portion of the sample did not report having notable communication disorder symptoms. This raises the question as to whether different results might be found when focusing exclusively on individuals with MS who do report symptoms of communication disorders.

The primary purpose of this study was to examine the extent to which variables typically available in the clinical setting are predictive of communicative participation in a new sample of participants with MS who all report communication problems. In other words, can variables such as MS symptoms and severity, as well as demographic variables, give an indication of who might be at risk for restrictions in communicative participation? The results of this analysis might facilitate early identification of individuals at risk for communication restrictions. The results of this analysis may also point to variables that can be targets of intervention to help minimize participation restrictions. Speech-language pathologists are likely targeting communication and cognitive symptoms in therapy with the assumption that managing these will minimize participation restrictions, but there may be other variables, if understood and identified, that could also be intervention targets with resulting gains for communicative participation. A secondary purpose of this study was to explore in a preliminary manner the relationships of communicative participation with recently developed measures that include self-reported abilities to fulfill social roles and satisfaction with social roles (such as employment, caring for family members, household management, and community involvement). The results of these analyses may reveal the extent to which communication contributes to fulfillment of and satisfaction with life roles.

2. Methods

This analysis utilized data collected for calibration of the CPIB. A more detailed explanation of data collection methods is presented elsewhere (Baylor et al., 2013).

2.1. Participants and data collection

Participants included community-dwelling adults over 18 years of age who had been diagnosed with MS for at least 3 months. Proficiency in written or spoken English was required. Participants also reported that communication was affected by MS. Exclusionary criteria included use of augmentative communication systems as a primary means of communication, although use as a supplemental communication method was allowed.

Participants were also excluded if cognitive or language problems were so severe that they prevented provision of answers to the questionnaires even with assistance. Residents of skilled nursing facilities were excluded because they are not likely engaged in the same communication situations as community-dwelling adults. Participants were recruited from across the United States via listservs directed to speech-language pathologists, consumer-oriented newsletters, and websites. They were paid $20 upon completion of the questionnaires.

Participants were asked to complete a battery of self-reported questionnaires. They were offered the option of completing the questionnaires online or using paper forms. Online data collection was done via the Assessment Center website (www.assessmentcenter.net) developed by NIH PROMIS (www.nihpromis.org). Participants who chose to complete the questionnaires on paper forms were provided with a stamped envelope for their use in returning the questionnaires.

2.2. Questionnaire battery

2.2.1. Communicative Participation Item Bank—The development of the CPIB used in this study is described elsewhere (Baylor et al., 2013). The scores for this analysis are based on the final 46 items from the calibration study (Baylor et al., 2013). Most items start with the stem, “Does your condition interfere with…” followed by a specific communication situation such as, “making a telephone call to get information.” The participant selects one of following choices: Not at all; A little; Quite a bit; or Very much.

2.2.2. Demographics—The demographic questionnaire included age, sex, living situation, employment status, education, and time since onset of diagnosis of MS. In addition, the Levels of Speech Usage rating scale was administered (Baylor, Yorkston, Eadie, Miller, & Amtmann, 2008; Gray, Baylor, Eadie, Kendall, & Yorkston, 2012). This is a single-item scale that asks participants to choose a category which best represents the level of speech demands they experience in their daily activities: Undemanding; Intermittent; Routine; Extensive; or Extraordinary. Definitions of each category were provided to participants.

2.2.3. Symptoms of MS

2.2.3.1. Physical activity: Physical activity was measured using a single item that asks participants to rate their ability to carry out everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair: Not at all, A little Moderately; Mostly; or Completely (Hays, Bjorner, Revicki, Spritzer, & Cella, 2009).

Emotional problems were measured using a single item that asks how often participants have been bothered by emotional problems such as feeling anxious, depressed or irritable: Always; Often; Sometimes: Rarely; or Never (Hays et al., 2009).

Fatigue was measured using a single item that asks participants to rate their fatigue on average: Very severe; Severe; Moderate: Mild; or None (Hays et al., 2009).

Pain was measured using a single item that asks participants to rate their pain on average using a 10 point scale. The item is re-scored with high scores being preferable (no pain) (Hays et al., 2009).

Speech severity was measured using a single item that asks participants to select one of the following categories describing their speech: Normal; Sounds different but people understand me; Sometimes I have to repeat words to be understood; I use gestures, writing or drawing to help people understand my speech; and Not understandable, I do not use speech for communication (Cedarbaum et al., 1999).

Cognitive/communication skill was measured using a subset of items from the Neuro-QOL item banks (www.neuroqol.org) that addresses reading and writing tasks in daily activities as well as tasks related to memory and problem solving. The items for this study were used with permission before finalization of the NeuroQOL item banks. Six of the eight items used in this study are in the current NeuroQOL Applied Cognition–Executive Function item bank. Of the two remaining items, one has been re-worded and the newer version is in that same item bank. The final item used in this study, asking about composing a brief note or email to someone, does not appear to be in the final NeuroQOL item set but is similar to an item about writing in the NeuroQOL Communication item bank. For this study, possible scores range from 8 to 40 with high scores being better.

2.2.4. Social roles—Two items from the PROMIS Global Health questionnaire (Version 1.0) (Hays et al., 2009) provide self-report of social roles using ordinal rating scales. One item, *Social Roles Ability,* asks participants to rate how well they carry out usual social activities and roles including activities at home, work, and in the community. The second item, *Social Roles Satisfaction,* asks how satisfied the participant is with social roles and relationships. For both social role items, responses included the following categories: Poor, Fair, Good, Very good, and Excellent.

2.2.5. Data analysis—Data from the Assessment Center website were downloaded in an Excel format. Data from the paper questionnaires were entered into Excel using a double entry system for reliability whereby two researchers entered the data independently and any discrepancies between the two entries were identified and resolved. Data analyses were completed using SPSS version 17 (SPSS, 2008).

3. Results

3.1. Demographics and MS symptoms as predictors of communicative participation

A total of 216 individuals who reported communication problems associated with MS completed the questionnaire. Thirteen demographic and symptom-related variables were selected to test as possible predictors of communicative participation (measured by the CPIB). These variables were chosen because they are typically available on referral for speech pathology services or they are symptoms common to MS. Descriptive statistics for the CPIB and all of the tested predictor variables are included in Tables 1 and 2. A review of the demographics (Table 1) suggests a pattern typical of MS, i.e. mostly middle-age, female, highly educated with over 80% reporting some college level education. Only the minority had current paid employment. Most rated their speech usage in the intermittent or routine category. A review of the prevalence of symptoms (Table 2) suggests many symptoms are common. For example, many participants report at least moderate difficulty with fatigue (87%) or physical activity (67%). Over 80% report emotional problems at least sometimes and 46% report that their speech is not normal.

Before conducting the regression analyses, the correlations among all the variables (the thirteen predictor variables and the CPIB) were examined using Pearson and Spearman correlations (according to variable type) to examine the potential for multicollinearity (Table 3). Variables with correlations greater than 0.7 would be considered for removal from the analysis. No pairs of variables had correlations greater than 0.7. The highest correlation was between the CPIB and the cognitive-communication score at 0.6. All variables were therefore retained in the regression analysis.

A backwards stepwise multiple linear regression analysis was conducted with SPSS version 17.0. Variables that were not significant predictors of the CPIB were removed in the following order: time since MS diagnosis, age, pain, fatigue, employment, emotional problems, sex, and living situation (alone, with family, etc.). The remaining five variables were significant predictors of CPIB scores and remained in the model (Table 4). Using this model, restricted communicative participation is associated with more problems with cognitive–communication function, more severe speech symptoms, lower levels of speech usage, lower levels of physical activity, and higher levels of education. This final model was significant ($p = .000$) with an adjusted $R^2 = .507$.

The quality of the regression model was evaluated by examining a plot of the residuals to check the assumption of normality of the error. The plot approximated a normal curve. The plot of Cook's distance vs. center leverage values was examined for potential outlier participants. Only one data point appeared to be an extreme outlier. This participant was removed and the analysis was repeated with no change to the final set of variables in the model, so the model reported here contains that participant's data.

3.2. Relationship of communicative participation with social role variables

Two items from the PROMIS Global Health questionnaire (Hays et al., 2009) provide self-report of social roles. Descriptive data for these variables are included in Table 5. A review of this table suggests that 46% of participants reported fair or poor ability to carry out social roles and half reported fair or poor satisfaction with social activities. In order to examine the relationship between communication participation and variables related to social roles, bivariate Spearman correlations were conducted across the following variables: CPIB scores, Social Roles Ability, Social Roles Satisfaction, and self-rated speech severity. Correlation between CPIB scores and Social Roles Abilities was .48 and between CPIB scores and Social Roles Satisfaction was .38. These results suggest only a fair to moderate relationship between communicative participation and social roles variables. The correlations between the CPIB scores and social role variables were higher than they were between self-rated speech severity and Social Roles Ability (.209), or speech severity and Social Roles Satisfaction (.153).

4. Discussion

The results of this study add to prior evidence that communicative participation is likely a complex construct with several influences. Similar to other studies (Yorkston et al., 2003), speech changes take place within a content of other problems including cognition and limitations in physical function. The following is a discussion of the pattern of variables that might predict level of communicative participation, how it might be related to changes in social functioning, and the clinical implications of these patterns of symptoms. Limitations and future directions of this research will also be discussed.

4.1. Variable associated with restricted communicative participation

The primary purpose of this research was to examine the demographic and symptom-related variables that might be predictive of restricted participation in participants with MS who report changes in communication. Results indicate that restricted communicative participation is associated with some demographic variables, specifically lower level of speech usage and higher levels of education. It is also important to note that many of the demographic variables (age, time since diagnosis, sex, living situation and employment) were not represented in the final model. The finding that some demographic variables may not be helpful in predicting communicative participation is consistent with previous work (Baylor et al., 2010, 2012). Participants who reported less demanding speech usage reported more restricted communicative participation. This is a somewhat surprising result because logic might lead one to assume that people who have more speech demands would feel more restricted as a result of a communication disorder. Because this regression evaluates association but not causation, it is impossible to know if participants with MS reduce their speech usage because of problems communicating and therefore feel restricted; or if participants who are in less demanding communication situations at baseline feel more restricted. Further research would be needed to clarify the direction of this relationship, but it suggests that participants who are in environments where they are speaking less, whether due to MS or because that was their premorbid situation, report more restrictions in their communicative participation.

In terms of symptom-related variables, communicative participation was also found to be associated with more problems in cognitive–communication function, more severe speech symptoms, and lower levels of physical abilities. Cognitive function showed a stronger relationship to communicative participation than did speech. One of the reasons that speech severity was a weaker predictor than cognitive function might be related to the nature of the sample. Over half of the participants reported that they felt their speech sounded normal. Descriptive data related to cognitive communication skills, however, suggested that the presence of cognitive impairments for the group as a whole in this group. It may be that this sample is characterized more by cognitive than speech changes, and this might impact the relative strengths of the associations of these variables with communicative participation. It is important to note that even participants who reported normal speech can also report restricted communicative participation. Although over half of the participants in this sample reported that they felt their speech sounded “normal,” the CPIB scores in this subset of participants ranged from –1.82 (very restricted participation) to +2.61 (very good participation) with an even distribution across this range. Participants with self-rated normal speech were not clustered at the end of high CPIB scores with good communicative participation. Regardless, both cognitive and speech symptoms contribute to restricted communicative participation as might be expected.

More restricted communicative participation was associated with greater difficulties with physical activities such as walking. This may simply indicate that communicative participation is more restricted because individuals are not able to take part in the many everyday activities that require high levels of communication. Results of the current study remind clinicians to take a broader view in considering the many ways that different aspects of the experience of living with MS could impact communicative participation. The final significant variable in the model was education. Individuals with higher levels of education reported more severe communicative participation restrictions, perhaps because they have higher expectations about preferred levels of participation. It is also possible that education may be highly correlated with variables not tested in this study such as type of occupation.

Other variables such as fatigue were not represented in the final model despite the high prevalence of self-reported fatigue in our sample. This is inconsistent with other regression models where fatigue was among the groups of variables that predicted communicative participation (Baylor et al., 2010). These differences are difficult to interpret because they may have resulted from a number of factors. For example, the previous study sampled all individuals with MS, not just those reporting changes in communicative function; different constructs were tested (e.g. depression and social support were included in the previous model); and different instruments were used for measurement of fatigue.

4.2. Relationship of communicative participation with measures of social functioning

In order to further understand the role that the construct of communicative participation may play in clinical decision-making, a preliminary analysis was undertaken to explore its relationship to broad measures of social functioning. CPIB scores were more strongly correlated with satisfaction with social roles than were speech severity symptoms. Thus, the CPIB may better reflect changes in social roles than symptom-related measures such as speech. Measures of symptom severity are important, but they may not reveal the entire picture of an individual's experiences. These results provide quantitative evidence to support qualitative reports from research participants that even if their speech sounds good and they appear able to carry on a conversation, they are often working hard and struggling with communication in a way that impacts their daily activities (Baylor et al., 2011a). In addition, the fair to moderate correlations suggest the constructs of general social functioning and communicative participation are not the same. Thus, social functioning does not capture all of the factors that might influence communicative participation. If participation in situations requiring communication is a goal of treatment, communicative participation should be measured directly rather than through a surrogate such as a general measure of social participation.

4.3. Clinical implications

From a clinical perspective, results of this study suggest to speech-language pathologists (and others on the MS healthcare team) that there is a cluster of characteristics that healthcare providers should be alert in order to address potential problems with communicative participation. Risk factors include reduced cognitive and speech skills, lower levels of speech usage, limitations in physical activities, and higher levels of education. While all individuals with MS should be asked how they are doing with their everyday communication, particular attention should be paid to individuals with this constellation of characteristics.

Many of our prior qualitative research participants have described hidden communication problems that are not always obvious to others in causal encounters. Individuals with these problems are frequently not referred to a speech-language pathologist or do not receive any support for managing their communication from their healthcare teams. An instrument such as the CPIB that asks individuals to rate their experiences with communication may provide a window into how well they are doing and bring to light challenges and barriers that individuals are facing with communication that are not highly obvious to a healthcare provider or other communication partners.

4.4. Limitations and future directions

A number of study limitations point to future research directions related to communication and MS. First, all of the measures in the current project are self-reports. While self-report is the best way to assess constructs such as fatigue or pain, the relationship between self-reports and performance measures for variables such as speech or cognitive skill is less clear cut. Prevalence of speech changes tends to be higher when clinicians rate speech as opposed to self-reports (Yorkston et al., 2003) and cognitive changes are often difficult to reliably measure without objective performance measures (Benedict et al., 2003). Thus, research is needed to explore the relationship of self-report and performance-based tests of speech and cognition, and how these may relate to communicative participation.

The restricted list of variables examined is another limitation of the study. Constrained by the sample size, a small list of variables was included in the regression model. This list was certainly not comprehensive and many constructs were measured by one item. Longer and more reliable instruments would be useful to better measure the symptoms (e.g. depression, fatigue) and quality of life indicators (e.g. social function). Other variables such as depression and social support have been associated with communicative participation in other studies (Baylor et al., 2010). In addition, measures such as level of self-confidence and self-efficacy would seem to be important variables for understanding how people cope with MS but were not available for this study. Because the current study is cross sectional, it does not allow for the examination of how restrictions in communicative participation develop over time, how they relate to the development of other MS symptoms, or how they may be reduced by intervention. In the future, it will be important for speech-language pathologists and other healthcare providers to anticipate and identify when people with MS may experience problems with communication. Understanding how communication restrictions might impact their broadly-defined life roles may lead to intervention and management recommendations.

Acknowledgments

The authors wish to thank the participants for their time and efforts in this study. This research was supported by grants from the National Institute of Health (National Institute of Deafness and Other Communication Disorders) (R03DC010044) and the National Institute on Disability and Rehabilitation Research, Department of Education (Grants H133B031129). The authors would like to thank Christa Gray and Brittney Skrupky for their help with data collection and data entry.

Appendix A. Continuing education

Continuing Education Questions

1. Communication problems in multiple sclerosis are:
    - **a.** Very rare
    - **b.** A constellation of changes in speech and cognitive skills
    - **c.** Restricted to speech changes
    - **d.** Restricted to changes in cognition
2. Qualitative research methods:
    - **a.** Includes both focus group and semi-structured interviews
    - **b.** Have never been used to study multiple sclerosis
    - **c.** Are appropriate for examination of complex experiences
    - **d.** Both a and c
3. The PROMIS Initiative:
    - **a.** Is funded by the NIH
    - **b.** Provides a protocol for developing measures of latent traits
    - **c.** Is helpful in providing measures of constructs that cannot be directly observed
    - **d.** All of the above
4. Communicative participation:
    - **a.** Can only be measured using individual qualitative interviews
    - **b.** Is consistent with terminology used by the World Health Organization in the Classification of Functioning, Disability and Health
    - **c.** Can be predicted solely on the basis of the severity of speech symptoms
    - **d.** Can be predicted solely on the basis of self-reported measures of social functioning.
5. Risk for restriction in communicative participation in multiple sclerosis:

a. Can be predicted by a constellation of speech and demographic factors

b. Can be predicted by age and time since diagnosis

c. Can by predicted by living situation and employment status

d. Cannot be predicted

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Table 1

Summary data for CPIB scores and demographic variables.

Construct	Instrument	Responses	Results, *n* = 216
Communicative participation	Communicative Participation Item Bank (Baylor et al., 2013)	Mean	0.11
		(SD)	(0.94)
		Range	−2.31 to +2.61
		Scores in logits typically range from −3.0 to +3.	
		High scores are better	
Age (in years)		Mean	50.0
		(SD)	(9.6)
		Range	24–78
Sex		Male	39 (18.1%)
		Female	176 (81.5%)
Who do you live with?		Alone	32 (14.8%)
		Family	176 (81.5%)
		Friends/Roommate	4 (1.9%)
		Assisted living	1 (0.5%)
Time since MS diagnosis (in years)		Mean	12.2
		(SD)	(10.1)
		Range	1–60
Education		No high school	1 (0.5%)
		Some high school	1 (0.5%)
		High school graduate	22 (10.2%)
		Vocational/technical training	14 (6.5%)
		Some college	59 (27.3%)
		College graduate	75 (34.7%)
		Post–graduate (masters; PhD)	44 (20.4%)
Employment		Currently in paid employment	63 (29.2%)
Speech usage	Levels of speech usage (Baylor et al. (2008)	Undemanding	41 (19.0%)
		Intermittent	67 (31.0%)
		Routine	79 (36.6%)
		Extensive	25 (11.6%)
		Extraordinary	3 (1.4%)

Note: Where totals do not add to 100%, the remainder are missing data not included to save space.

Table 2

Summary data for symptoms variables.

Construct	**Instrument**	**Responses**	**Results, *n* = 216**
Physical activity	PROMIS Global Health – physical function item (Hays et al., 2009)	Completely	29 (13.4%)
		Mostly	52 (24.1%)
	Item: to what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?	Moderately	63 (29.2)
		A little	50 (23.1%)
		Not at all	20 (9.3%)
Emotional problems	PROMIS Global Health – emotional problems item (Hays et al., 2009)	Never	6 (2.8%)
		Rarely	33 (15.3%)
	Item: in the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?	Sometimes	81 (37.5%)
		Often	74 (34.3%)
		Always	21 (9.7%)
Fatigue	PROMIS global health (Hays et al., 2009)	None	2 (0.9%)
		Mild	27 (12.5%)
	Item: in the past 7 days, how would you rate your fatigue on average?	Moderate	92 (42.6%)
		Severe	68 (31.5%)
		Very severe	27 (12.5%)
Pain	PROMIS Global Health (Hays et al., 2009).	Mean	6.12
	Item: in the past 7 days, how would you rate your pain on average?	(SD)	(2.65)
	(0–10 scale reversed scored so 0 = worst pain)	Range	0–10
Cognitive–communication skill	8 items selected from the Neuro-QOL item bank. All items ask how much difficulty the subject has with tasks related to memory, reading, writing, and problem solving[a]	Mean	26.8
		(SD)	(6.63)
		Range	8–40
		Possible range	8–40
		High scores are better	
Speech severity	Cedarbaum et al. (1999)	Normal	117 (54.2%)
		Sounds different but people understand me	37 (17.1%)
		Sometimes have to repeat words to be understood	59 (27.3%)
		Use gestures, writing or drawing to help people understand my speech	2 (0.9%)
		Not understandable	0

Note: Where totals do not add to 100%, the remainder are missing data not included to save space.

[a] The Neuro-QOL items were chosen and used with permission prior to publication of the final Neuro-QOL item banks. The specific items used are available from the authors.

Table 3

Bivariate correlations for demographic and symptom variables.

	CPIB	Age	Sex	Who live with	Time since diagnosis	Education	Employment	Speech usage	Physical activity	Emotional problems	Fatigue	Pain	Cognitive–communication	Speech severity
CPIB	1.0													
Age	**.090**	1.0												
Sex	.095	.127	1.0											
Who live with	−.003	.093	.053	1.0										
Time since diagnosis	**−.022**	**.289**	.174	.117	1.0									
Education	−.021	.079	−079	.015	.049	1.0								
Employment	.225	−.134	−.113	−.027	−.214	.182	1.0							
Speech usage	.313	−.261	.000	.135	−.135	.085	.286	1.0						
Physical activities	.304	−.091	−.107	−.134	−.132	.048	.385	.163	1.0					
Emotional problems	.183	.109	.166	.152	.149	.067	.032	.103	.045	1.0				
Fatigue	.286	.101	.015	.046	.014	.120	.136	.055	.299	.356	1.0			
Pain	**.204**	**.000**	.159	−.026	**.109**	.077	.267	.052	.274	.287	.052	1.0		
Cognitive−communication	**.647**	**−.022**	.144	..039	**.048**	.094	.180	.222	.182	.340	.222	.327	1.0	
Speech severity	.349	−.038	−.038	.103	−.140	.023	.110	.068	.271	.064	.165	.119	188	1.0

Bold indicates Pearson correlation for continuous variables; all other are Spearman correlations.

Table 4

Regression coefficients and results of significance tests for the final regression model. This model was significant ($p = .000$) with an adjusted $R^2 = .507$.

Variable	**Significance level (*p*-value)**	**Unstandardized regression coefficient**	**Standardized regression coefficient**
Cognitive communication skills	.000	.078	.559
Speech severity	.000	.201	.194
Speech usage	.002	.145	.154
Physical activities	.014	.099	.127
Education	.028	−.080	−.108

Table 5

Summary data for social roles variables.

Construct	**Instrument**	**Responses**	**Results, *n* = 216**
Ability to carry out social roles	PROMIS Global Health - social roles item (Hays et al., 2009)	Excellent	5 (2.3%)
	Item: in general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work, and in your community; and responsibilities as a parent, child, spouse, employee, friend, etc.)	Very good	32 (14.8%)
		Good	79 (36.6%)
		Fair	70 (32.4%)
		Poor	29 (13.4)
Satisfaction with social activities and relationships	PROMIS Global Health–social roles item (Hays et al., 2009)	Excellent	6 (2.8%)
	Item: in general, how would you rate your satisfaction with your social activities and relationships?	Very good	28 (13.0%)
		Good	71 (32.9%)
		Fair	65 (30.1%)
		Poor	45 (20.8%)

Note: Where totals do not add to 100%, the remainder are missing data not included to save space.