Published in final edited form as:

Am J Speech Lang Pathol. 2010 May ; 19(2): 143–153. doi:10.1044/1058-0360(2009/08-0087).

Variables associated with communicative participation in people with multiple sclerosis: A regression analysis

Carolyn Baylor, Kathryn Yorkston, Alyssa Bamer, Deanna Britton, and Dagmar Amtmann
Department of Rehabilitation Medicine, University of Washington

Abstract

Purpose—The purpose of this study was to explore variables associated with self-reported communicative participation in a sample (n=498) of community-dwelling adults with multiple sclerosis (MS).

Methods—A battery of questionnaires was administered online or on paper per participant preference. Data were analyzed using multiple linear regression with backwards stepwise regression. The dependent variable was an Item Response Theory score of communicative participation measured by a subset of items from the Communicative Participation Item Bank asking respondents to rate how much their health condition interferes with participation in real-life speech communication situations. Thirteen independent variables were included in the model as self-reported symptoms: problems thinking, slurred speech, vision loss, pain, mobility, depression, fatigue, perceived social support, age, education level, employment status, gender, and MS duration.

Results—Fatigue, slurred speech, depression, problems thinking, employment status and social support were significantly associated with communicative participation accounting for 48.7% of the variance.

Conclusions—Communicative participation is significantly associated with multiple variables, only some of which reflect communication disorders. If the goal of intervention is to improve communicative participation, intervention may need to extend beyond traditional speech pathology boundaries to include other health symptoms as well as personal, social and physical environments.

Introduction

Communicative Participation

The World Health Organization's (WHO) *International Classification of Functioning Disability and Health* (ICF) (World Health Organization, 2001) provides a biopsychosocial framework for exploring health conditions. The framework outlines how interactions among impairments, activity performance, participation and environmental factors may shape individual experiences with health conditions. Biopsychosocial frameworks have also been proposed specifically for communication disorders emphasizing the inter-relationships among participation, the severity of the communication disorder, the communication environment and each individual's personal identity and attitudes (Kagan *et al.*, 2008).

Publisher's Disclaimer: This is an author-produced manuscript that has been peer reviewed and accepted for publication in the *American Journal of Speech-Language Pathology* (AJSLP). As the "Papers in Press" version of the manuscript, it has not yet undergone copyediting, proofreading, or other quality controls associated with final published articles. As the publisher and copyright holder, the American Speech-Language-Hearing Association (ASHA) disclaims any liability resulting from use of inaccurate or misleading data or information contained herein. Further, the authors have disclosed that permission has been obtained for use of any copyrighted material and that, if applicable, conflicts of interest have been noted in the manuscript.

The ICF defines participation as involvement in life situations (World Health Organization, 2001). Communicative participation has been more specifically defined as, “taking part in life situations where knowledge, information, ideas or feelings are exchanged,” (Eadie *et al.*, 2006; Yorkston *et al.*, 2008a). Communicative participation encompasses the myriad of communication situations that occur as people engage in their life activities. Communication disorders may interfere with communicative participation resulting in many negative consequences including loss of employment, social isolation and difficulty negotiating community services and activities.

The WHO ICF and other biopsychosocial frameworks may provide mechanisms for helping us understand communicative participation and the many variables that potentially contribute to communicative participation. From a theoretical perspective these biopsychosocial frameworks suggest that while impaired speech, language or cognitive function might influence communicative participation, other variables may also affect communicative participation including health symptoms, features of the physical and social environments and personal characteristics. At present these suppositions are largely theoretical because the construct of communicative participation is still a relatively new area of research for the speech pathology discipline, although a body of literature is emerging.

Cruice, Worrall and Hickson (2005) provided an example of research exploring the relationships between participation and different variables in typically aging adults (ranging in age from 62 – 98 years). Participation was measured by the size of the social network (defined as the number of people in an individual's social network) and the frequency of engaging in a variety of social activities. Independent variables were naming accuracy, hearing status, vision status, demographic variables and the frequency of performing various communication activities. Results indicated that a higher frequency of communication activities was associated with younger age, more education and better distance vision. Participation was most strongly associated with the frequency of communication activities combined with education level and emotional health (depression). Specific communication indicators such as hearing status and naming accuracy were not significantly associated with participation (Cruice *et al.*, 2005).

Cruice and colleagues (2005) provided insight into predictors of communicative participation, but caution is warranted in generalizing results of the study. This is because adults with communication disorders may face different issues related to communicative participation than typically aging adults. Additional research is needed to explore these relationships across populations with different health conditions. The current study explored variables that may contribute to communicative participation in one health condition – multiple sclerosis (MS). MS is a good population for studying communicative participation due to the diverse disorder characteristics (including a range of motor speech and cognitive-communication impairments) and demographic variables represented (i.e. age and involvement in various life domains such as employment and household management).

Multiple Sclerosis and Communicative Participation

MS is a degenerative neurologic disease in which lesions caused by demyelination of axons occur throughout the brain and spinal cord (Joy & Johnston, 2001). MS occurs in a variety of patterns with the four key patterns consisting of relapsing remitting, primary progressive, secondary progressive and progressive relapsing (Lublin & Reingold, 1996). MS usually begins in young adulthood, and most people survive twenty-five years or more after onset (Sliwa & Cohen, 1998). MS is more common in women than in men, and is more prevalent in northern European populations including in the northern U.S. (Kurtzke, 2005) as opposed to more southern regions of the country. Symptoms associated with MS are varied and may include motor weakness and loss of coordination, sensory changes, vision changes, pain, depression and fatigue (Sliwa & Cohen, 1998). Available treatments for MS are usually

categorized as either disease-modifying treatments (usually pharmacologic) targeting the underlying physiologic processes, or symptomatic and supportive therapies designed to help maximize function and coping for people with MS.

Communication disorders associated with MS have a variety of characteristics and may range in severity from mild to profound. Dysarthria may occur in up to 40% of people with MS (Hartelius & Svensson, 1994; Yorkston *et al.*, 2003b). More severe speech symptoms are usually associated with disease progression and correspond with the presentation of other MS symptoms involving mobility, vision changes, fatigue and depression (Yorkston *et al.*, 2003b). Cognitive impairment is also common with MS including problems with memory, attention, speed of information processing and executive functions (Fraser & Stark, 2003; Pierson & Griffith, 2006; Shevil & Finlayson, 2006). One important consideration with communication disorders in MS is not simply the severity of dysarthria or cognitive impairment in isolation, but the interaction of these impairments with other MS symptoms. When describing the life impact of cognitive changes, Shevil and Finlayson (2006) reported that, "Various complicating factors interacted with participants' cognitive changes to create a complex reality and further affect their ability to manage these changes" (p. 782). The impact of a communication disorder may be magnified when combined with the effects of pain, fatigue or depression as well as with personal or environmental conditions.

Communicative participation in people with MS has been explored using qualitative research (Bringfelt, Hartelius, & Runmarker, 2006; Fraser & Stark, 2003; Shevil & Finlayson, 2006; Yorkston *et al.*, 2007; Yorkston *et al.*, 2003a; Yorkston, Klasner, & Swanson, 2001). Yorkston *et al.* (2001) reported that participants attributed changes in communicative participation to a variety of factors including changes in speech, language and cognition as well as fatigue, visual changes and limited mobility. For example, one participant described how it was difficult to maintain social conversations with colleagues when going out for lunch because she could not keep up with the walking pace of the other people. When she fell behind in walking with them she was unable to participate in their conversations. Another participant reported that he was not able to exchange social greetings with people he might encounter when walking outside because his vision problems prevented him from easily recognizing people he knew across distances outdoors.

Participants interviewed by Yorkston *et al.* (2007) described various dimensions that contributed to satisfactory communicative participation. One dimension was their comfort level with communication. They defined comfort as either feeling confident or being in situations where communication was easy for them. A second dimension to satisfaction was the success of communication. As might be expected, one measure of success was, "...getting my point across," (p. 440). In addition, success was defined as making a social connection with others. Finally, satisfaction with communicative participation was shaped by each individual's personal priorities. For example, when participants were asked about making "small talk," one participant felt it was very valuable to engage in small talk because it provided a sense of belonging to a community and connection to other people; while another participant felt that small talk was a waste of valuable and limited time and energy that needed to be spent on more substantive issues (Yorkston *et al.*, 2007). Bringfelt *et al.* (2006) reported that reduced communicative participation was closely related to restricted interpersonal interactions and relationships, and that these were affected by a wide range of "barriers" (p. 133) including communication disorder symptoms, mobility, bowel and bladder function, pain, fatigue, "increased emotionality" (p. 137) and reactions and availability of communication partners.

These qualitative studies suggest that communicative participation for people living with MS may be a complex construct with many potential contributing factors. At this time, quantitative studies exploring variables that contribute to communicative participation in people with MS

are lacking. This lack of research raises concerns about gaps in our understanding of how communication disorders might interact with other MS symptoms to shape important life outcomes such as communicative participation. The purpose of this study was to explore the relationships between self-reported communicative participation and various demographic and self-reported disorder characteristics in a sample of community-dwelling adults with MS. The specific research question was: What self-report variables are most strongly related to communicative participation in a sample of adults with MS? The hypothesis was that multiple variables would be significantly related to communicative participation, and that these variables would extend beyond communication symptoms to include other symptoms of MS. The intent of this study was to provide insight into communicative participation as a biopsychosocial construct and to provide a guide for future research and clinical efforts targeting improved communicative participation for people with MS.

Methods

Participants

All study procedures were approved by the human subjects division of the University of Washington. Data for this study were collected as part of an ongoing longitudinal study exploring the impact of MS on self-reported experiences of individuals living with MS. Research participants were recruited through the Greater Washington chapter of the USA National Multiple Sclerosis Society (NMSS) which serves 23 counties in Washington State. Letters of invitation were sent to 7,806 persons from the NMSS mailing list which primarily included individuals who self-identified with the NMSS as having MS. Of the 1,629 who expressed interest in participating in the study, 1,597 met eligibility criteria and were sent an initial survey for the larger MS project. Eligible individuals were required to report having a definitive diagnosis of MS and to be at least 18 years of age. Participants were given the option of completing the survey on paper (n=1,368) or online (n=229). This first survey was completed by 1,271 individuals (16.3% of the original invitations sent).

Due to budgetary constraints, a subset of participants (n=562) in the cross-sectional study (n=1,271) was randomly selected and invited to continue in the longitudinal series of surveys, with the number of participants selected determined by available funding. Every four months these 562 participants were sent questionnaire packets until six data collection points were completed. The communicative participation questionnaire which was the focus for this particular analysis was included in the second data collection point in that series, so all data included in this analysis were from that second data collection point. During this second data collection point, surveys were returned by 513 participants (394 paper; 119 online), a response rate of 91.3% of the 562 participants enrolled in the longitudinal study. Of these, 498 participants (88.6% of those enrolled) had complete data sets. All 498 participants were included in this study regardless of presence or severity of communication disorder symptoms in order to include a range of communication experiences in the sample.

Questionnaires

Questionnaire battery—In the longitudinal portion of the study, respondents completed a battery of self-report questionnaires covering a wide range of topics including fatigue, pain, sleep, anxiety, depression, social support, mobility status, health-related quality of life, general social participation, ratings of MS symptom severity and demographic information. The specific variables that were included in the analysis reported here were chosen based on: (1) the instruments that were included at the second data collection point and (2) results from prior qualitative research that indicated which variables participants with MS most commonly talked about in association with communicative participation. These variables are described in more detail in the following sections.

Communicative Participation—For this study communicative participation was measured using the Communicative Participation Item Bank which is a set of self-report items designed to measure the impact of communication disorders (or other health conditions) on communicative participation (Baylor, 2007; Baylor, Yorkston, Eadie, Miller, & Amtmann, in press; Yorkston et al., 2008a). It was designed for community-dwelling adults across a range of communication disorders. Participants are asked to rate how much their condition interferes with participation in a variety of real-life speech communication situations using a four-point scale ranging from “not at all” to “very much.” Examples of communication situations included in the items are having a casual conversation, communicating with health care providers and making a phone call to get information. Participants' answers to these items provide an indication of the life-impact of the communication disorder.

The Communicative Participation Item Bank was developed using Item Response Theory (IRT). IRT provides model-based measurement (Embretson & Reise, 2000) in that mathematical models are used to describe the relationships between overt behaviors (responses to items on a questionnaire) and underlying latent traits (the self-perceived impact of a communication disorder). In the context of the Communicative Participation Item Bank, individuals who experience greater levels of interference in communication situations in their lives (latent trait) would be expected to endorse more interference in the situations asked about in the items (rating quite a bit or very much on any individual item). In the development of item banks, candidate items are administered to a large sample of respondents. The data are first analyzed to determine if IRT model assumptions (dimensionality and local independence) are sufficiently met. If these assumptions are met, response patterns predicted by the IRT model are compared to the collected responses and the goodness of fit is expressed as fit statistics. Item fit to the model indicates how closely participants' responses to items follow the response patterns expected based on the model. Items that conform to the properties of the model are retained in an item bank which serves as a repository from which items can be drawn for specific assessment situations. Additional information about the process of developing item banks in general is available elsewhere (Fries, Bruce, & Cella, 2005; Reeve *et al.*, 2007), as is more information about the development of the Communicative Participation Item Bank (Baylor et al., in press; Yorkston et al., 2008a).

IRT provides several advantages for measuring health outcomes including construction of item banks. An item bank is a collection of items that have been calibrated by IRT analyses, that is, each item is assigned a location on the underlying continuum that is being measured. This continuum is measured by an equal interval scale. The units of measurement on the scale are log odds units or logits which represent the odds of a participant responding to the item in a particular manner (Bond & Fox, 2001). Once a core item bank is constructed by identifying items that fit the IRT model and sequencing them on the logit scale, any number or combination of items can be drawn from the item bank to create statistically equivalent item subsets or short forms for any particular assessment situation. This provides “measurement efficiency” (Cook, O'Malley, & Roddey, 2005) in that small item subsets can be targeted to specific measurement needs at hand. This reduces respondent burden because a small number of items can be administered while maintaining the measurement precision of longer traditional questionnaires. The score obtained from administering any subset of items drawn from an item bank can be compared across different item subsets and across individuals. For each individual, IRT analyses provide a logit “score” (usually referred to as theta) for that individual. The logit score is based on item characteristics (such as item difficulty) as well as the individual's response patterns on the items. Zero logits is typically regarded as the mean score.

The selection of items from the item bank for a particular assessment situation can be done in a variety of ways. The most advanced method is computerized adaptive testing (CAT) in which a computer algorithm selects subsequent items for a participant based on the individual's

responses to prior items (Cook et al., 2005; Fries et al., 2005; Ware, Gandek, Sinclair, & Bjorner, 2005). When CAT is not available (as is currently the situation for the Communicative Participation Item Bank), items can be chosen at the discretion of the examiner for a variety of reasons such as relevance of content or item difficulty level for a particular individual or group of people.

Past analyses of the Communicative Participation Item Bank using responses from people with spasmodic dysphonia (SD) have yielded favorable results including sufficient unidimensionality of the items. The items range from “easy” situations in which people rarely report interference in participation (e.g., Telling someone at home what you would like to eat) to “difficult” situations in which people more frequently report interference (e.g., Making a phone call to get information) (Baylor, 2007; Baylor et al., in press). Higher logit scores for participants are more favorable (indicate less interference in participation) than lower scores.

For this study one short form was generated from the item bank. Twenty-five items were selected from the Communicative Participation Item Bank by the authors to represent a range of content (different communication situations such as home management, healthcare, social situations and personal relationships) as well as a range of item difficulty based on the data from the SD sample in the prior study. The items were selected to provide measurement across a diverse participant sample in the MS study. Figure 1 contains a sample of the items used in this study. Factor analyses and IRT analyses were completed on this set of 25 items with data from the MS participants in the current study to examine the psychometric properties of this smaller item set. The results demonstrated acceptable psychometric properties including strong evidence of essential unidimensionality with all items having acceptable fit to a 2-parameter (Graded Response) IRT model (Thissen, Chen, & Bock, 2003).

MS symptoms—Participants were asked to rate the extent to which sixteen common MS symptoms were a problem for them on a five point scale ranging from 0 (not at all) to 4 (very much). Three symptoms were included in the regression analysis for this study. Two of the symptoms, “problems thinking” and “slurred speech” were selected because they provide an indication of self-reported cognitive-communication function. Two other self-report indicators of cognitive function were available in the data set. These were “difficulty learning” and “memory loss.” These variables were not included in the final regression analysis due to concerns about multicollinearity based on the relatively high correlations among these variables and the “problems thinking” variable (ranging from .72 to .77). The variable “problems thinking” was chosen because semantically it appeared to cover the range of cognitive issues more generally than specific references to memory or learning.

The third symptom to be included from the general MS symptom list was, “vision loss.” This was selected based on prior qualitative interviews with people with MS that have suggested that vision symptoms interfere with their communication and interactions with other people (Yorkston et al., 2001). In addition to these overall symptom ratings respondents were also asked to complete more detailed questionnaires to address the specific MS-related issues described below.

Pain—Pain levels were assessed with a single item asking participants to rate their pain on average over the past week using a scale of 0 – 10 with 0 = no pain and 10 = pain as bad as it could be. This item was adapted from the Brief Pain Inventory and has been widely used in MS-related research (Von Korff, Ormel, Keefe, & Dworkin, 1992).

Mobility—The Self-administered Expanded Disability Status Scale (EDSS-S) (Bowen, Gibbons, Gianas, & Kraft, 1999, 2001) is a self-report version of the physician administered Expanded Disability Status Scale (EDSS) (Kurtzke, 1983) - a common measure of physical

function for MS. The EDSS-S contains sections that address mobility, strength, coordination, sensation, bowel and bladder function, speech, swallowing and cognition. Only the mobility subscale of the EDSS was included in this survey. These items ask participants to identify how far they can walk, the level of assistance they need for walking and their use of a wheelchair on an average day. For this study the raw EDSS-S scores were recoded as 1 – 9 with 1 = raw score of 4.0 or lower, 9 = raw score of 8.0 or higher and each number between representing an increase of 0.5 on the EDSS scale. Lower scores indicate better mobility function.

Depression—The short form of the Center for Epidemiological Studies Depression Scale (CESD), a common screening instrument for depressive symptoms was used in this study (Andresen, Malmgren, Carter, & Patrick, 1994). The short form of the CESD contains ten items that ask participants to rate how often they have experienced different feelings during the past week. Examples of the items include: I was bothered by things that usually don't bother me; I felt that everything I did was an effort; and I was happy. Participants rate the frequency of experiencing these feelings on a four-point scale ranging from “Rarely or none of the time” (less than 1 day per week) to “Most or all of the time” (5-7 days per week).

Fatigue—The Modified Fatigue Impact Scale (MFIS) (Multiple Sclerosis Council for Clinical Practice Guidelines, 1998) is a shortened version of the Fatigue Impact Scale (FIS) (Fisk *et al.*, 1994). The MFIS is a 21-item self-report instrument that asks participants to rate the frequency that they have experienced the impact of fatigue over the past four weeks. The rating scale is a five-point scale from 0 = never to 4 = almost always. The MFIS yields an overall score as well as scores for three sub-domains reflecting the impact of fatigue on cognitive (sample item: I have difficulty paying attention for long periods of time); physical (sample item: I have had to pace myself in my physical activities); and psychosocial functioning (sample item: I have been less motivated to participate in social activities). For the current study the overall MFIS score was used.

Social support—The Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, Dahlem, Zimet, & Farley, 1988) contains twelve items asking participants to rate their perception of the availability of social support. An example item is, “There is a special person who is around when I am in need.” Participants express their level of agreement with the statements on a 1 (very strongly disagree) to 7 (very strongly agree) scale. Three subscale scores differentiating sources of support from friends, family and a significant other are available in addition to the total score. The total score (which is the average rating across all items) was used for this study.

Demographic information—Participants were asked to report their age, gender, ethnicity, duration of MS symptoms, type of MS, education level and employment status. Education was coded in six categories ranging from “less than high school” to “graduate or professional school.” Employment was coded as a binary variable as either currently involved or not involved in paid employment.

Data analysis—Data were entered into SPSS Version 12.0 (SPSS, 2003) for analysis using multiple linear regression. Communicative participation was the dependent variable and was scored using IRT which results in a continuous variable scored on an interval scale. Thirteen variables were selected as candidate variables for the multivariate model. Age and MS duration were continuous variables. Problems thinking, slurred speech, vision loss, pain, mobility (EDSS), depression (CESD), fatigue (MFIS), social support (MSPSS) and education were ordinal categorical variables. Gender and work status were nominal categorical variables. All variables were included in the initial model and backwards stepwise regression was completed.

Model fit was analyzed with an overall regression F statistic. Individual variables with regression coefficients significant at the 0.05 level were retained in the model.

Results

Participants

The mean age of the 498 participants was 51.51 (sd 11.0) years with a range of 20 – 85 years. The mean duration of MS symptoms was 13.13 (sd 9.9) years with a range of less than one year to 60 years. The sample was predominately female and Caucasian which is consistent with MS prevalence data (Joy & Johnston, 2001). Additional demographic information is available in Table 1.

Variables related to communicative participation

Table 2 presents a summary of descriptive results for the instruments included in this study. The mean of the communicative participation scores for this sample was -0.05 (sd 0.87) logits. The range was -3.21 to 1.22 logits suggesting that most participants reported communicative participation below the mean. The concentration of participants in the lower end of the scale suggests that in general the participants in this study reported that they experienced considerable interference with communicative participation. Table 3 shows the Pearson correlations among communicative participation and the original thirteen independent variables. Table 4 presents the multivariate regression coefficients and significance levels for the variables included in the final regression model. When all thirteen variables were entered into the regression analysis the model accounted for just under half of the variance (adjusted $R^2 = 0.488$ with a significance level of <0.001). Seven variables had significant regression coefficients ($> .05$) and were removed in the following order starting with the least significant variable: gender, pain, duration of MS symptoms, vision loss, education level, mobility and age. The final model contained the following variables listed in order of their strength of association with communicative participation from greatest to least: fatigue impact, slurred speech, depression, problems thinking, employment and perceived social support. For this final set of variables the adjusted R^2 was 0.487 with a significance level of <0.001 .

A histogram of the residuals closely approximated a normal distribution verifying the assumption of normality for error in the model. There are concerns about possible multicollinearity involving the variables of depression and fatigue as the variance inflation factor was greater than 2.0 on both of these variables (SPSS, 2003). The correlation between these two variables was 0.701. Three potentially influential cases were identified on a scatterplot comparing Cook's Distance and Centered Leverage Values. When these three cases were removed from the analysis there was no change in the final set of variables selected for the model. The four variables with the strongest associations with communicative participation (fatigue, slurred speech, depression and problems thinking) maintained their relative order while social support had a slightly stronger association than work status. The adjusted R^2 improved minimally to 0.494 after removing the three extreme cases. The results presented in Table 4 are the original results with the three cases included.

In summary, the variables that were significantly associated with communicative participation listed in order from strongest to weakest associations were fatigue, slurred speech, depression, problems thinking, employment and perceived social support. The first four variables in this list had relatively stronger associations with participation while the latter two variables had notably weaker associations. Increased problems thinking, slurred speech, depression and fatigue were associated with lower scores on the communicative participation items (indicating more interference in participation). Increased social support and involvement in paid

employment were associated with higher scores on the communicative participation items (indicating less interference in participation).

Discussion

The results of this study suggest that self-reported communicative participation is statistically significantly associated with self-reported fatigue, slurred speech, depression, problems thinking, employment status and social support in this sample of adults with MS. Perhaps the most notable finding is that communicative participation is not associated solely with communication disorder characteristics but that other variables, particularly fatigue, depression and social support are also significantly related to participation.

The results of this study support the findings of prior qualitative studies in that communicative participation appears to be shaped by multiple variables, only some of which are communication disorder symptoms (Bringfelt et al., 2006; Yorkston et al., 2007; Yorkston et al., 2001). Qualitative studies have documented a number of issues related to communicative participation that were important to people living with MS. The current study has added quantitative evidence of the associations between communicative participation and fatigue, depression, social support and employment status as well as with speech and cognitive symptoms.

Prior quantitative research has also identified multiple variables related to communicative participation. For example, in their study with typically aging adults Cruice and colleagues (2005) found that the frequency of communication activities was significantly associated with age, education level and vision. Measures of participation (network size and number of social activities) in Cruice et al. (2005) were associated with the frequency of communication activities, education level and depression. Depression was the only variable found to be significantly related to communicative participation in both the current study and the study by Cruice et al. (2005). Other variables such as age, education and vision that were included in the model in the Cruice et al. (2005) study were not included in the final model in the current study.

While both of these studies document that communicative participation is likely shaped by a variety of influences, comparisons of the models from these two studies need to take into account the differences in populations and methodologies that might contribute to different findings. For example, the Cruice et al. (2005) study was completed with typically aging adults whereas the current study was completed with adults with MS. There is not yet enough research on this topic to know how variables contributing to communicative participation might vary across different medical conditions or communication disorders. Other differences across studies such as methods for measuring communicative participation and related variables may contribute to the generation of different models. Cruice et al. (2005) used tallies of communication activities and social networks as measures of participation while the current study used an IRT score of a subjective self-report measure asking people to report how much they felt MS interfered with their communicative participation. The differences in these studies may suggest that frequency and interference measure different aspects of communicative participation. Cruice et al. (2005) used objective measures of verbal performance (e.g., Boston Naming Test (Kaplan, Goodglass, & Weintraub, 2001)) and visual acuity while the current study used self-reported ratings of the extent to which variables such as speech, thinking and vision were problems. Comparisons of these two studies highlight that as this line of research progresses, clinicians and researchers will need to consider the different possible ways to measure each construct and how these different methods might influence our understanding of participation. Objective measures such as tallies of activities inform us as to *what* people do, but subjective measures tell us the *meaning* or the *adequacy* of those activities for the

individuals who live with communication disorders and need to fulfill particular life roles. This subjective information is critical to understanding the life impact of conditions and the adequacy of participation (Brown *et al.*, 2004; Hemmingsson & Jonsson, 2005; Johnston, Goverover, & Dijkers, 2005; Perenboom & Chorus, 2003).

The current study and future related studies will have important research and clinical implications in terms of how broadly we view rehabilitation efforts related to communication disorders. Traditional approaches for evaluating communication disorders have focused heavily on the nature and extent of impairments and on the performance of isolated speech or language activities (Eadie *et al.*, 2006; Threats, 2002; Worrall, McCooey, Davidson, Larkins, & Hickson, 2002). Intervention strategies have followed suit with an emphasis on improving performance of basic communication skills. One of the primary goals of intervention however, should be to reduce participation restrictions associated with communication disorders. In their qualitative study of individuals with MS, Bringfelt *et al.* (2006) reported that, "Participants did not consider talking or making themselves understood as a goal per se. Instead, communication and related problems were mentioned in a context such as initiating, maintaining, developing or finishing personal interactions or relationships" (p.136). This focus on participation as the primary intervention goal is a position that has been advocated in other communication disorder populations such as in the Life Participation Approach to Aphasia (Chapey *et al.*, 2000). Many questions remain regarding the intervention strategies that would best help individuals improve their communicative participation. Traditional speech and language interventions may yet contribute directly to improved participation and therefore should continue to be a key consideration in intervention. Nonetheless, the results of this study suggest that when we focus specifically on participation we become aware of many more variables beyond speech, language or cognitive abilities that may influence communicative participation and may be considered in intervention programs.

This study did not investigate the effects of intervention on participation, but possible hypotheses for future research might be drawn from the findings. For example, interventions directly targeting fatigue (Finlayson & Holberg, 2007; Matuska, Mathiowetz, & Finlayson, 2007), depression (Mohr, Boudewyn, Goodkin, Bostrom, & Epstein, 2001), and social support (Williams *et al.*, 2004) may help facilitate greater communicative participation by either reducing symptoms of fatigue or depression, or by providing individuals with better strategies for managing symptoms and utilizing social resources. At this early stage of developing a model of communicative participation caution is warranted in formulating these hypotheses. For example, pharmacologic interventions for pain or fatigue may actually interfere with cognitive function (Pierson & Griffith, 2006; Sliwa & Cohen, 1998). The directionality of associations should also be tested in prospective longitudinal studies to determine the causal relationships among variables. Does treating depression improve communicative participation, does enhanced participation lead to reduced depression, or both? These and related questions will need to be explored carefully by multi-disciplinary teams whose members are experts in the different health issues associated with MS.

This study has several limitations that need to be addressed in future research. First, the Communicative Participation Item Bank is still under development, and while the preliminary psychometric findings are very encouraging, additional research is needed to provide further evidence regarding the reliability and validity of the instrument. Second, more comprehensive measurement of some of the constructs included in this study is warranted. The usefulness of self-report of cognitive function is not well established and formal assessment of cognitive function is time consuming, expensive and impractical for survey research. The term "problems thinking" used in this study likely does not adequately reflect the nature, complexity and diversity of cognitive issues in people with MS. Validated self-report questions related to

cognitive function are needed to better measure the influence of various cognitive issues in communicative participation for this population.

Third, additional variables should be included in these investigations to explore their relationships with communicative participation. Individual differences will certainly account for some variability, particularly because different people have different priorities and goals with regard to life activities and the role of communication in those activities. However, additional constructs may also make systematic contributions to the model. These possibilities need to be explored. Additional variables to include in future research might be drawn from the various categories of the ICF including impairment, activity and contextual factors. More detailed information about the nature and severity of the communication disorder as well as clinical measures of communication function may provide insight into the roles of impairment and activity in participation. Contextual factors may include information about the individual participants as well as information about the environment. For example, information about individuals' personal coping strategies or personal perspectives on disability may provide insight into their participation. One possibility is to include a measure of self-efficacy defined as individuals' confidence in their ability to participate in activities (Yorkston *et al.*, 2008b). Environmental variables might include information about both the physical and the social context. For example, background noise is one aspect of the physical environment that might influence communicative participation. The social environment may be affected greatly by the supportiveness of communication partners. Communication partners who are willing to take more time for communication and to share the responsibility for constructing messages may provide more communicative social support for participation than someone who is not as receptive.

One of the challenges in moving forward with this research will be finding instruments that provide psychometrically sound and clinically meaningful measurement of the various constructs of interest. The construct of social support will be used here as an illustration. The MSPSS (Zimet *et al.*, 1988) was used in this study to measure social support, but this questionnaire does not contain questions about the type of support that people with communication disorders may need from communication partners to facilitate participation. Social support for people with communication disorders may include the willingness of communication partners to co-construct messages with the individual, or the willingness of communication partners to remain patient with a conversation long enough to repair communication breakdowns. Additional instruments may need to be developed for social support and other constructs to obtain more valid measurement of issues as they directly pertain to people with communication disorders.

Finally, this research needs to be replicated in other populations to determine whether the variables that are associated with communicative participation are similar across disorders.

Conclusion

In conclusion, this study provides quantitative evidence that self-reported restrictions in communicative participation are statistically significantly associated with multiple variables, only some of which are direct symptoms of cognitive-communication or speech disorders. Other variables including other MS symptoms (fatigue, depression), environmental variables (social support), and demographic variables (work status) were also significantly associated with communicative participation in this sample of people with MS. This study provides a starting point for formulating and testing a model of communicative participation from which to pursue future research to build a stronger understanding of the biopsychosocial factors that shape communicative participation for people living with MS and for people with other healthcare conditions.

Acknowledgments

The authors wish to thank the participants for their time and efforts in this study, as well as the staff at the Multiple Sclerosis Research and Rehabilitation Training Center (MSRRTC) in the Department of Rehabilitation Medicine at the University of Washington who collected the data. This research was supported by grants from the National Institute on Disability and Rehabilitation Research, Department of Education (Grants H133B031129); the National Institute of Arthritis and Musculoskeletal and Skin Diseases, National Institute of Health (Grant 5U01AR052171-03); and training grants from the National Center for Medical Research and Rehabilitation, National Institute of Health (Grant T32-HD-00742416A1), and National Institute for Disability and Rehabilitation Research (H133PO80008).

References

- Andresen EM, Malmgren JA, Carter WB, Patrick DL. Screening for depression in well older adults: Evaluation of a short form of the CES-D. *American Journal of Preventive Medicine* 1994;10(2):77–84. [PubMed: 8037935]
- Baylor, CR. Initial psychometric testing of the Communicative Participation Scale using Item Response Theory in a spasmodic dysphonia sample. University of Washington; Seattle: 2007. Unpublished Dissertation
- Baylor CR, Yorkston KM, Eadie TL, Miller RM, Amtmann D. Developing the Communicative Participation Item Bank: Rasch analysis results from a spasmodic dysphonia sample. *Journal of Speech Language and Hearing Research*. in press.
- Bond, TG.; Fox, CM. Applying the Rasch Model: Fundamental Measurement in the Human Sciences. Mahwah, NJ: Lawrence Erlbaum Associates; 2001.
- Bowen J, Gibbons L, Gianas A, Kraft GH. Patient administered Expanded Disability Status Scale (EDSS-S). 1999
- Bowen J, Gibbons L, Gianas A, Kraft GH. Self-administered Expanded Disability Status Scale with functional system scores correlates well with a physician-administered test. *Multiple Sclerosis* 2001;7:201–206. [PubMed: 11475445]
- Bringfelt PA, Hartelius L, Runmarker B. Communication problems in Multiple Sclerosis: 9-year follow-up. *International Journal of MS Care* 2006;8:130–140.
- Brown M, Dijkers MPJM, Gordon WA, Ashman T, Charatz H, Cheng Z. Participation Objective, Participation Subjective: A measure of participation combining outsider and insider perspectives. *Journal of Head Trauma Rehabilitation* 2004;19(6):459–481. [PubMed: 15602309]
- Chapey R, Duchan JF, Elman RJ, Garcia LJ, Kagan A, Lyon J, et al. Life participation approach to aphasia: A statement of values for the future. *The ASHA Leader*. 2000
- Cook KF, O'Malley KJ, Roddey TS. Dynamic assessment of health outcomes: time to let the CAT out of the bag? *Health Services Research* 2005;40(5, Part II):1694–1711. [PubMed: 16179003]
- Cruice M, Worrall L, Hickson L. Personal factors, communication and vision predict social participation in older adults. *Advances in Speech-Language Pathology* 2005;7(4):220–232.
- Eadie TL, Yorkston KM, Klasner ER, Dudgeon BJ, Deitz J, Baylor CR, et al. Measuring communicative participation: a review of self-report instruments in speech-language pathology. *American Journal of Speech-Language Pathology* 2006;15:307–320. [PubMed: 17102143]
- Embretson, SE.; Reise, SP. Item Response Theory for Psychologists. Mahwah, NJ: Lawrence Erlbaum Associates, Inc.; 2000.
- Finlayson M, Holberg C. Evaluation of a teleconference-delivered energy conservation education program for people with multiple sclerosis. *Canadian Journal of Occupational Therapy* 2007;74(4):337–347.
- Fisk JD, Ritvo PG, Ross L, Haase DA, Marrie TJ, Schlech WF. Measuring the functional impact of fatigue: initial validation of the Fatigue Impact Scale. *Clinical Infectious Diseases* 1994;18(Suppl 1):S79–83. [PubMed: 8148458]
- Fraser C, Stark S. Cognitive symptoms and correlates of physical disability in individuals with multiple sclerosis. *Journal of Neuroscience Nursing* 2003;35(6):314–320. [PubMed: 14713097]
- Fries JF, Bruce B, Cella D. The promise of PROMIS: using item response theory to improve assessment of patient-reported outcomes. *Clinical and Experimental Rheumatology* 2005;23(Suppl. 39):S53–S57. [PubMed: 16273785]

- Hartelius L, Svensson P. Speech and swallowing symptoms associated with Parkinson's Disease and Multiple Sclerosis: A survey. *Folia Phoniatrica et Logopedica* 1994;46:9–17.
- Hemmingsson H, Jonsson H. An occupational perspective on the concept of participation in the International Classification of Functioning, Disability and Health - some critical remarks. *The American Journal of Occupational Therapy* 2005;59(5):569–576. [PubMed: 16268024]
- Johnston MV, Goverover Y, Dijkers M. Community activities and individuals' satisfaction with them: quality of life in the first year after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation* 2005;86:735–745. [PubMed: 15827926]
- Joy, JE.; Johnston, J.; R, B. Multiple Sclerosis: Current Strategies and Strategies for the Future. Washington DC: National Academy Press; 2001.
- Kagan A, Simmons-Mackie N, Rowland A, Huijbregts M, Shumway E, McEwen S, et al. Counting what counts: A framework for capturing real-life outcomes of aphasia intervention. *Aphasiology* 2008;22(3):258–280.
- Kaplan, E.; Goodglass, H.; Weintraub, S. Boston Naming Test. Lippincott Williams & Wilkins; 2001.
- Kurtzke JF. Rating neurologic impairment in multiple sclerosis: An Expanded Disability Status Scale (EDSS). *Neurology* 1983;33:1444–1452. [PubMed: 6685237]
- Kurtzke JF. Epidemiology and etiology of multiple sclerosis. *Physical Medicine and Rehabilitation Clinics of North America* 2005;16:327–349. [PubMed: 15893675]
- Lublin FD, Reingold SC. Defining the clinical course of multiple sclerosis: Results of an international survey. *Neurology* 1996;46(4):907–911. [PubMed: 8780061]
- Matuska K, Mathiowetz V, Finlayson M. Use and perceived effectiveness of energy conservation strategies for managing multiple sclerosis fatigue. *American Journal of Occupational Therapy* 2007;61(1):62–69. [PubMed: 17302106]
- Mohr DC, Boudewyn AC, Goodkin DE, Bostrom A, Epstein L. Comparative outcomes for individual cognitive-behavior therapy, supportive-expressive group psychotherapy, and sertraline for the treatment of depression in multiple sclerosis. *Journal of Consulting and Clinical Psychology* 2001;69(6):942–949. [PubMed: 11777121]
- Multiple Sclerosis Council for Clinical Practice Guidelines. Fatigue and multiple sclerosis: Evidence-based management strategies for fatigue in multiple sclerosis. 1998. Retrieved January 24, 2008, from <http://www.pva.org/site/DocServer/fatigue1.pdf?docID=662>
- Perenboom RJM, Chorus AMJ. Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). *Disability and Rehabilitation* 2003;25(11-12):577–587. [PubMed: 12959331]
- Pierson SH, Griffith N. Treatment of cognitive impairment in multiple sclerosis. *Behavioural Neurology* 2006;17:53–67. [PubMed: 16720960]
- Reeve BB, Hays RD, Bjorner JB, Cook KF, Crane PK, Teresi JA, et al. Psychometric evaluation and calibration of health-related quality of life item banks. *Medical Care* 2007;45(5 Suppl 1):S22–S31. [PubMed: 17443115]
- Shevil E, Finlayson M. Perceptions of persons with multiple sclerosis on cognitive changes and their impact on daily life. *Disability and Rehabilitation* 2006;28(12):779–788. [PubMed: 16754575]
- Sliwa, JA.; Cohen, BA. Multiple Sclerosis. In: DeLisa, JA.; Gans, BM., editors. *Rehabilitation Medicine: Principles and Practices*. Third. Philadelphia: Lippincott-Raven; 1998. p. 1241-1257.
- SPSS. SPSS 12.0 for Windows. Chicago: SPSS, Inc.; 2003.
- Thissen, D.; Chen, WH.; Bock, RD. *Multilog (Version 7)*. Lincolnwood, IL: Scientific Software International; 2003.
- Threats TT. Evidence-based practice research using a WHO framework. *Journal of Medical Speech-Language Pathology* 2002;10(3):xvii–xxiv.
- Von Korff M, Ormel J, Keefe FJ, Dworkin SF. Grading the severity of chronic pain. *Pain* 1992;50(2):133–149. [PubMed: 1408309]
- Ware JE, Gandek B, Sinclair SJ, Bjorner JB. Item response theory and computerized adaptive testing: Implications for outcomes measurement in rehabilitation. *Rehabilitation Psychology* 2005;50(1):71–78.

- Williams RM, Turner AP, Hatzakis M, Chu S, Rodriguez AA, Bowen JD, et al. Social support among veterans with multiple sclerosis. *Rehabilitation Psychology* 2004;49(2):106–113.
- World Health Organization. International classification of functioning, disability and health: ICF. Geneva: World Health Organization; 2001.
- Worrall L, McCooley R, Davidson B, Larkins B, Hickson L. The validity of functional assessments of communication and the activity / participation components of the ICIDH-2: Do they reflect what really happens in real-life? *Journal of Communication Disorders* 2002;35:107–137. [PubMed: 12036147]
- Yorkston KM, Baylor CR, Deitz J, Dudgeon BJ, Eadie TL, Miller RM, et al. Developing a scale of communicative participation: a cognitive interviewing study. *Disability and Rehabilitation* 2008a;30(6):425–433. [PubMed: 17943516]
- Yorkston KM, Baylor CR, Klasner ER, Deitz J, Dudgeon BJ, Eadie TL, et al. Satisfaction with communicative participation as defined by adults with multiple sclerosis: a qualitative study. *Journal of Communication Disorders* 2007;40:433–451. [PubMed: 17125785]
- Yorkston KM, Johnson K, Klasner ER, Amtmann D, Kuehn CM, Dudgeon BJ. Getting the work done: A qualitative study of individuals with multiple sclerosis. *Disability and Rehabilitation* 2003a;25(8):369–379. [PubMed: 12745946]
- Yorkston KM, Klasner ER, Bowen J, Ehde DM, Gibbons L, Johnson K. Characteristics of multiple sclerosis as a function of the severity of speech disorders. *Journal of Medical Speech-Language Pathology* 2003b;11(2):73–85.
- Yorkston KM, Klasner ER, Swanson KM. Communication in context: A qualitative study of the experiences of individuals with multiple sclerosis. *American Journal of Speech-Language Pathology* 2001;10:126–137.
- Yorkston KM, Kuehn CM, Johnson KL, Ehde DM, Jensen MP, Amtmann D. Measuring participation in people living with multiple sclerosis: a comparison of self-reported frequency, importance, and self-efficacy. *Disability and Rehabilitation* 2008b;30(2):88–97. [PubMed: 17852211]
- Zimet GD, Dahlem NW, Zimet SG, Farley GK. The Multidimensional Scale of Perceived Social Support. *Journal of Personality Assessment* 1988;52(1):30–41.

Sample item format:

Does MS interfere with communicating with others where and when you choose?

- ☐ Not at all
- ☐ A little
- ☐ Quite a bit
- ☐ Very much

Other Sample Item Stems

Does MS interfere with visiting with others in a public place (e.g., park, restaurant, sports activity)?

Does MS interfere with communicating about household management?

Does MS interfere with having a conversation while riding in a car?

Does MS interfere with talking to family or friends on the phone?

Does MS interfere with making a telephone call to get information?

Figure 1.
Sample item format from Communicative Participation Item Bank and additional sample item stems.

Table 1
Demographic Characteristics of the Sample

Demographic variable		Frequency	Percentage (N = 498)
Gender	Male	90	18.1%
	Female	408	81.9%
Ethnicity	Caucasian	482	96.8%
	Black	9	1.8%
	American Indian / Native Alaskan	17	3.4%
	Asian	5	1.0%
	Hispanic	13	2.6%
Education Level	Less than high school	5	1.0%
	High school graduate / GED	64	12.9%
	Vocational / Technical School	46	9.2%
	Some college	145	29.1%
	Undergraduate degree	138	27.7%
	Graduate or Professional school	100	20.1%
Paid employment	Yes	198	39.8%
	No	300	60.2%
MS Type	Relapsing Remitting	280	56.2%
	Secondary Progressive	100	20.1%
	Primary Progressive	62	12.4%
	Progressive Relapsing	46	9.2%
	No response	10	2.0%

Table 2
Summary of Descriptive Results for Instruments included in the Study

Variable	Instrument and scoring format	Results: mean (SD) range
Communicative Participation	Communicative Participation Item Bank: Scores reported in logits centered at 0 as average. Typical standardized range -3 to +3 with higher scores more desirable.	-.05 (0.87) -3.21 – 1.22
Problems thinking	Single Likert-scale item. 0 = not a problem to 4 = very much a problem	1.58 (1.15) 0-4
Slurred speech	Single Likert-scale item. 0 = not a problem to 4 = very much a problem	0.64 (0.89) 0-4
Vision loss	Single Likert-scale item. 0 = not a problem to 4 = very much a problem	0.99 (1.13) 0-4
Pain	Single Likert-scale item. 0 = no pain to 10 = pain as bad as could be	3.51 (2.86) 0 - 10
Mobility	EDSS- ^a . Raw scores recoded as 1 – 9 with 1 = raw score of 4.0 or lower, 9 = raw score of 8.0 or higher, and each number between representing an increase of 0.5 on the EDSS scale. Lower scores indicate better mobility function.	4.17 (2.79) 1-9
Depression	CESD ^b . 0 – 30 with lower scored indicating less depression	9.32 (6.17) 0 - 29
Fatigue	MFIS ^c . 0 – 84 with lower scores indicating lower impact of fatigue	43.28 ^b (17.77) 0 - 84
Social Support	MSPSS ^d . 1 – 7 representing average of scores with lower scores indicating less perceived support	5.49 (1.39) 1-7

^aSelf-administered Expanded Disability Status Scale

^bCenter for Epidemiological Studies Depression Scale

^cModified Fatigue Impact Scale

^dMultidimensional Scale of Perceived Social Support

Table 3
Pearson Correlations for the Variables included in the Regression Analysis

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1	1.000													
2	-0.536*	1.000												
3	-0.474*	0.366*	1.000											
4	-0.336*	0.301*	0.347*	1.000										
5	-0.316*	0.346*	0.218*	0.235*	1.000									
6	-0.300*	0.149*	0.255*	0.281*	0.193*	1.000								
7	-0.560*	0.521*	0.361*	0.326*	0.441*	0.246*	1.000							
8	-0.627*	0.685*	0.406*	0.369*	0.473*	0.395*	0.701*	1.000						
9	0.281*	-0.198*	-0.183*	-0.126*	-0.221*	-0.104*	-0.373*	-0.249*	1.000					
10	0.019	-0.041	-0.045	0.051	0.104*	0.351*	-0.050	0.085	-0.021	1.000				
11	0.045	-0.139*	-0.006	-0.106*	-0.077	-0.146*	-0.118*	-0.116*	0.037	-0.049	1.000			
12	0.254*	-0.215*	-0.133*	-0.219*	-0.133*	-0.490*	-0.134*	-0.314*	0.069	-0.382*	0.136*	1.000		
13	0.028	0.056	-0.103*	-0.068	0.090	-0.100	-0.002	-0.019	0.050	-0.073	-0.065	0.040	1.000	
14	-0.020	-0.046	-0.003	0.095	0.025	0.374*	-0.089	0.035	0.010	0.516*	-0.023	-0.368*	-0.016	1.000

Note. Variables are: 1. Communicative participation, 2. Problems thinking, 3. Slurred speech, 4. Vision loss, 5. Pain, 6. Mobility, 7. Depression, 8. Fatigue, 9. Social support, 10. Age, 11. Education, 12. Paid work, 13. Gender, 14. MS duration,

* Significant at $p \leq .01$

Table 4
Regression Coefficients and Results of Significance Tests for Final Regression Model

Variables	Unstandardized coefficient	Standardized coefficient	t value	Significance
Problems thinking	-0.111	-0.147	-3.310	0.001
Slurred speech	-0.217	-0.224	-6.253	0.000
Depression	-0.025	-0.177	-3.704	0.000
Fatigue	-0.013	-0.268	-4.838	0.000
Social support	0.045	0.073	2.099	0.036
Paid work	0.141	0.080	2.345	0.019

Note. The adjusted R^2 for this final model was 0.487.