Research Note

Factors Associated With Communicative Participation in Amyotrophic Lateral Sclerosis

Kathryn Yorkston,[a] Carolyn Baylor,[a] and Helen Mach[a]

Purpose: People with amyotrophic lateral sclerosis frequently experience bulbar impairment and dysarthria that may restrict their ability to take part in everyday communication situations. The aim of this study is to examine selected variables that may contribute to restrictions in communicative participation.
Method: Community-dwelling participants with amyotrophic lateral sclerosis (N = 70) who reported communication changes but continued to use natural speech completed a survey, including the Communicative Participation Item Bank, demographics (age, sex, living situation, employment status, education, and time since diagnosis), and self-reported symptom-related variables (physical activity, emotional problems, fatigue, pain, speech severity, speech

usage, and cognitive and communication skills). To identify predictors of restrictions in communicative participation, these variables were entered into a backward stepwise multiple linear regression analysis.
Results: Three variables (speech severity, swallowing severity, and speech usage) were included in the final model and accounted for 55% of the variability.
Conclusions: Better speech and swallowing skills and higher speech usage are associated with better communicative participation in this sample. Thus, when making clinical decisions regarding intervention, clinicians should continue their efforts to target speech and swallow abilities, while recognizing other variables that have the potential of restricting communicative participation.

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Amyotrophic lateral sclerosis (ALS) is a relentless progressive neurologic condition that affects not only speech and swallowing but also motor function of the arms and legs (Hanson, Yorkston, & Britton, 2011; Kiernan et al., 2011). Bulbar impairment is common and has received considerable research attention (Makkonen et al., 2016; Yunusova et al., 2010). The relationship between these impairments and their impact on communication in daily activities, such as conversation, is unclear, but understanding these associations is important for tailoring interventions to meet the needs that are relevant to clients (Bloch & Tuomainen, 2016). The International Classification of Functioning, Disability and Health has provided a vocabulary for describing the consequences of health conditions, including the domain of

participation (World Health Organization, 2001). When applied to communication, participation has been defined as "taking part in life situations in which knowledge, information, ideas, or feelings are exchanged" (Eadie et al., 2006, p. 309).

The Communicative Participation Item Bank (CPIB) was developed as a patient-reported outcome following methods recommended by the National Institutes of Health initiative Patient-Reported Outcomes Measurement Information System (http://www.nihpromis.org; Hays, Bjorner, Revicki, Spritzer, & Cella, 2009). It is intended for use in community-dwelling adults and has been calibrated in several diagnoses, including ALS, multiple sclerosis (MS), Parkinson's disease (PD), and head and neck cancer (Baylor et al., 2013). The items ask about the extent to which the patient's condition interferes in typical speaking situations, such as talking with people the patient does not know, communicating in small groups, or making a phone call to get information. The short form and details of calibration can be found elsewhere (Baylor et al., 2013). The CPIB is a tool to guide speech-language pathologists in treatment approaches that address the participation component of the International Classification of Functioning, Disability and Health framework.

[a]University of Washington, Seattle

Correspondence to Kathryn Yorkston: yorkston@u.washington.edu

Restrictions in communicative participation might be associated with bulbar impairment or changes in speech adequacy but may also be associated with other factors. This research note is one in a line of research examining predictors of communicative participation in different populations with communication impairments, including MS (Yorkston, Baylor, & Amtmann, 2014), PD (McAuliffe, Baylor, Amtmann, & Yorkston, in press), and head and neck cancer (Bolt, Eadie, Yorkston, Amtmann, & Baylor, 2016). Although self-rated speech severity is commonly associated with communicative participation, other associations are also present, including self-reported problems with cognition, physical activity, and emotional problems. The purpose of this study was to explore variables that are significantly associated with communicative participation in individuals with ALS.

Methods

All procedures were approved by the institutional review board at the University of Washington. All participants were paid and provided written, informed consent.

Participants and Data Collection

Participants were recruited across the United States via LISTSERVs and websites as part of a larger study focusing on the validation of the CPIB (Baylor et al., 2013). Inclusion criteria were self-reported diagnosis of ALS (at least 3 months prior to testing), age (at least 18 years), residence (community dwelling), and self-reports of speech changes. They used natural speech for communication, although some supplemented this with writing or other augmentative communication strategies. Participants were excluded if they relied exclusively on assistive devices for communication.

Data Collection and Analysis

Data were collected either online or using paper forms according to participant preference. In addition to CPIB, 14 variables of interest were collected. These data included the demographic variables of age, time since ALS diagnosis, gender, living situation, employment, and education level. Self-reported data were available on several measures of health and symptoms, including speech severity, swallowing severity, level of physical ability, emotional problems, fatigue, pain, and cognitive symptoms (see Table 1). The final variable considered was that of speech usage, which is the extent and nature of speaking demands that individuals face in their daily activities (Baylor, Yorkston, Eadie, Miller, & Amtmann, 2008).

Due to a sample size of 70 participants, we narrowed the list of variables to five to be entered into the regression analysis. These five variables were chosen by evaluating the Pearson correlations between each candidate variable and the CPIB and selecting the five variables with the strongest correlations with the CPIB for entry into the regression analysis. The five variables chosen for the regression analysis were speech severity, swallowing severity, speech usage, employment, and education level (see Table 2 for the correlation table providing the associations between each of the 14 original variables and the CPIB). A backward stepwise regression analysis was conducted by using SPSS (Version 18; SPSS Inc., Chicago, IL). Variables with nonsignificant p values were removed one at a time until all remaining variables were significant at $p < .05$. A histogram of the residuals approximated a normal curve.

Results

Demographics of Participants

Seventy participants with ALS completed the battery of instruments. Demographic characteristics, summarized in Table 3, are typical of those with the condition (i.e., a mean age in the mid-50s, most were married, living with family, and reported at least some college education). The most common self-reported speech severity category was "sometimes have to repeat to be understood."

Variables Associated with Communicative Participation

For this study, the CPIB scores were reported as logits, which is a common unit used in item response theory. A logit score of $M = 0$ of the calibration sample, and $SD = 1$. An ideal range of scores providing good representation of a trait range would be from −3.0 to +3.0. In this sample, the mean logit score was –0.56 (SD 1.1), and the range was −3.47 to 2.59.

The variables most strongly correlated with communicative participation were entered into the regression model and were the following: self-reported speech severity ($r = .63$); self-reported swallowing severity ($r = .46$); speech usage ($r = .39$); being involved in paid employment ($r = .17$); and education ($r = −.21$). The final model contained three variables (speech severity, swallowing severity, and speech usage) and accounted for 55% of the variance (see Table 4).

Discussion

The results suggested that better speech and swallowing abilities and higher levels of speech usage were associated with better communicative participation for this sample of participants with ALS. The levels of speech usage reflect the complexity of the communication roles that participants currently take part in. It could be argued that participants with high levels of demands will report less interference because they feel that they continue to be able to take part in complex and demanding communication situations.

Results of this study are consistent with other studies (see Table 5) that suggest communicative participation is associated with speech severity and speech usage in MS and PD. However, unlike other studies, the variable of swallowing severity remained in the final regression model

Table 1. Battery of questionnaires available for analysis (*N* = 70).

Construct	Instrument	Source	Responses	Sample data
Communication participation	46-item Communicative Participation Item Bank Example item: Does your condition interfere with making a call to get information?	Baylor (2013)	Not at all A little Quite a bit Very much	Logit score: *M* (*SD*) = −0.56 (1.1); Range = −3.47 to 2.59
Speech severity, no. (%)	ALS Functional Rating Scale Revised	Cedarbaum et al. (1999)	Normal Sounds different but people understand me Sometimes have to repeat words to be understood Use gestures, writing, or drawing to help people understand my speech Not understandable	3 (4.3) 11 (15.7) 49 (70.0) 7 (10.0) 0
Swallowing severity, no. (%)	ALS Functional Rating Scale Revised	Cedarbaum et al. (1999)	No problem Occasional difficulty but can eat most foods Diet limited to soft foods Eat some food; also tube feeding Nothing by mouth	13 (18.6) 48 (68.6) 4 (5.7) 4 (5.7) 1 (1.4)
Speech usage, no. (%)	Levels of speech usage	Baylor (2008)	Undemanding Intermittent Routine Extensive Extraordinary	17 (24.3) 26 (37.1) 26 (37.1) 1 (1.4) 0
Emotional problems, no. (%)	PROMIS Global Health Scale: emotional problems item Item: In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?	Hays et al. (2009)	Never Rarely Sometimes Often Always	1 (1.4) 27 (38.6) 31 (44.3) 10 (14.3) 1 (1.4)
Physical activity, no. (%)	Rate your ability to carry out everyday physical activities, such as walking, climbing stairs, and so on.	Hays (2009)	Not at all A little Moderately Mostly Completely	20 (28.6) 27 (38.6) 13 (18.6) 4 (5.7) 6 (8.6)
Fatigue, no. (%)	PROMIS Global Health Scale Item: In the past 7 days, how would you rate your fatigue on average?	Hays et al. (2009)	None Mild Moderate Severe Very severe	2 (2.9) 17 (24.3) 33 (47.1) 18 (25.7) 0
Pain	PROMIS Global Health Scale Item: In the past 7 days, how would you rate your pain on average? (0 = *worst pain,* 10 = *no pain*)	Hays et al. (2009)	0 to 10 scale: 0 = *worst pain,* 10 = *no pain*	*M* (*SD*) = 3.9 (.91); Range = 1 to 5

(table continues)

Table 1. *(Continued).*

Construct	Instrument	Source	Responses	Sample data
Cognitive and communication skill	Eight items selected from the Neuro-QOL item bank. How much difficulty the subject has with tasks related to memory, reading, writing, and problem solving[a]		Difficulty on a 5-point scale; total score is summed; ranges 8–40, with 8 = *XXXX*, 40 = *no difficulty*	*M* (*SD*) = 35.1 (4.8); Range = 13 to 40
Education, no. (%)	What is your highest level of education completed?		Elementary or some high school	0
			High school graduate	10 (14.3)
			Vocational or technical school	5 (7.1)
			Some college	14 (20.0)
			College graduate	31 (44.3)
			Postgraduate degree	10 (14.3)
Age, years				*M* (*SD*) = 56.4 (10.0); Range = 35 to 80
Time since diagnosis, years				*M* (*SD*) = 3.4 (4.7); Range = < 1 to 30
Gender, no. (%)			Male	41 (58.6)
			Female	29 (41.4)
Currently in paid employment, no. (%)				10 (14.3)
Living situation, no. (%)			Alone	6 (8.6)
			With family (spouse; children)	61 (87.1)
			Friends or roommate	0
			Assisted living	1 (1.4)
			Other (not specified)	1 (1.4)
			Not reported	1 (1.4)

Note.   ALS = amyotrophic lateral sclerosis; PROMIS = Patient-Reported Outcomes Measurement Information System.

[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 2. Correlation matrix of variables (*N* = 70).

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14
CPIB														
Age	.12													
Duration of ALS	−.11	−.05												
Gender	.07	.04	.04											
Living situation	−.03	.13	−.13	**.26***										
Employment	.17	−.03	−.19	−**.33**	.00									
Education	−.21	−.05	−.08	.04	.12	.04								
Speech severity	**.63**	.10	.07	.19	−.04	.04	−**.27**							
Swallowing severity	**.46**	−.03	−**.40**	−.14	−.04	.17	−.15	**.24**						
Speech usage	**.39**	.05	.07	−.02	−.23	**.33**	−.17	.23	.08					
Physical activity	.13	−.01	−**.31**	−.22	.08	**.49**	.19	−.07	.09	.12				
Emotional problems	.14	−.08	−**.24**	−.11	.01	.09	.04	−.10	**.26**	−.04	.20			
Fatigue	−.03	−.12	−.01	−**.29**	.04	**.29**	.06	−.16	.17	.04	**.30**	**.29**		
Pain	−.01	−.11	−.18	−.10	−.03	.22	.22	−.18	.10	.04	.21	**.42**	**.27**	
Cognitive symptoms	.09	.04	−.08	−.13	−.20	.16	.04	−.13	**.27**	.05	.18	**.45**	**.27**	**.36**

Note. CPIB = Communicative Participation Item Bank; ALS = amyotrophic lateral sclerosis.

*Bold indicates significant at *p* < .05.

for ALS, perhaps because it reflects the severity of bulbar dysfunction and is closely associated with speech severity. Speech and swallowing function may be more disassociated in other conditions, such as MS or PD. Also, factors such as fatigue or cognitive problems were not included in the final regression model for ALS. For example, in MS, more favorable communicative participation scores were associated with fewer limitations in cognition and physical activity and lower levels of education. In PD, favorable scores were associated with fewer problems with fatigue, cognition, and emotions. In head and neck cancer, the longer time since diagnosis was associated with more favorable scores. Thus,

Table 3. Demographics of participants with ALS (*N* = 70).

Parameter	Value
Age (years)	
M (*SD*)	56.4 (10)
Range	35–80
Gender (%)	
Male	58.6
Time since diagnosis (years)	
M (*SD*)	3.4 (4.7)
Range	0–30
Living situation (%)	
With family	87.1
Marital status (%)	
Married	80
Employment (%)	
Full- or part-time paid	14.3
Education (%)	
At least some college	78.6
Self-reported speech severity (%)	
Normal	4.3
Sounds different but understandable	15.7
Sometimes have to repeat words to be understood	70
Uses writing, drawing to help understanding	10
Not understandable	0

Note. ALS = amyotrophic lateral sclerosis.

although each condition is characterized by restrictions with communicative participation, the factors responsible for these restrictions may vary.

The absence of cognition, fatigue, or other factors in the ALS regression model may be explained by some of the limitations of the current study. First, because the sample size was small, only a limited set of factors could be examined. If the sample size were larger, other variables might have been available to be tested and retained in the model. In addition, more potentially important factors, such as social support, should be examined and were not included in this study. Third, inclusion criteria allowed participation of only those who relied primarily on natural speech. This excluded many people with ALS who were experiencing severe dysarthria and depended on augmentative communication approaches. Thus, the complete range of severity was not represented in the sample. Fourth, to reduce participant burden, some of the variables were measured by a small number of items. For example, emotional problems, physical activity, and fatigue were all measured with a single item. A more extensive set of items may have resulted in a more precise measurement. Also, all measures were self-reported, and the relationship between these measures and performance-based measures cannot be established in this study.

The limitations of the current study point to future directions of this line of research. Increased sample size and use of a more comprehensive battery of questionnaires might yield more information. Extending the severity range to include those who report extensive use of augmentative communication devices is also an important next step. To date, the CPIB has not yet been validated for people who rely primarily on augmentative communication, and this would be an important step in the development of this instrument.

The current study has a number of clinical implications. The associations between speech and swallow function and communicative participation suggest that continued

Table 4. Predictors of communicative participation in participants with ALS.

Parameter	R^2_{total}	$R^2_{adjusted}$	$F(3, 66)$	p	b	p
Communication participation	.55	.53	28	< .000		
Self-reported speech severity					0.49	< .001
Self-reported swallowing severity					0.32	< .001
Speech usage					0.25	.004

Note. ALS = amyotrophic lateral sclerosis.

efforts to deliver high-quality, evidence-based interventions targeting speech and swallowing function may improve communicative participation. However, because continued degeneration must be expected in ALS, the exclusive focus on maintenance of understandable natural speech may not be a realistic treatment goal. Clinicians need to predict and prepare for declines in communicative participation. Thus, they need to not only track changes in speech adequacy over time but also identify when and to what extent these changes affect communicative participation. Appreciating the relationship between changes in speech adequacy and communicative participation will help clinicians develop appropriate and timely treatment plans. These plans would address both the maintenance of natural speech and the implementation of compensatory strategies to maintain participation in the face of declining speech function. Another potential clinical implication comes from acknowledging the presence of speech usage in the final model in this study. The inclusion of this variable suggests that the more communicatively active individuals feel, the better they rate their participation. This might suggest that pursuing multiple avenues to keep a person engaged in communication situations, such as via alternative modes of communication or environmental modifications and support, may have the potential to help preserve the individual's level of satisfaction with life participation, even as speech declines. This hypothesis warrants further investigation.

Acknowledgment

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Table 5. Factors and direction of association with more favorable communicative participation.

Factors	ALS	MS[a]	PD[b]	HNCa[c,d]
Less severe speech	•	•	•	•
Less severe swallowing	•			
Higher speech usage	•	•	•	
Longer duration				•
Less fatigue			•	
Fewer cognition problems		•	•	•
Less education	•			
Less physical activity	•			
Fewer emotional problems			•	
R^2	.55	.507	.43	.462

Note. Bullets indicate a positive association with communicative participation. ALS = amyotrophic lateral sclerosis; MS = multiple sclerosis; PD = Parkinson's disease; HNCa = head and neck cancer.
[a]Yorkston et al., 2014. [b]McAuliffe et al., in press. [c]Bolt et al., 2016. [d]Not having undergone total laryngectomy was also included in the model.

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