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## Variables associated with communicative participation after head and neck cancer

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### Abstract

**Importance**—For patients with head and neck cancer (HNC), communication difficulties often create substantial barriers in daily life, affecting a person’s ability to return to work, establish or maintain relationships, or participate in everyday activities.

**Objective**—The purpose of this study is to examine variables significantly associated with communication in everyday activities, or “communicative participation,” in adult survivors of HNC. We hypothesized these variables would extend beyond overt communication symptoms.

**Design**—From 2008–2011, participants completed questionnaires about specific experiences and symptoms associated with their health and communication. Seventeen variables were considered in relation to communicative participation.

**Setting**—Data were collected from community-dwelling adult survivors of HNC. Participants completed questionnaires, in English, either online or using paper forms according to their preference.

**Participants**—One hundred ninety-seven adults (121 males, 76 females, average age = 61.5 years) participated, all at least 6 months post-treatment for HNC with no additional medical conditions affecting speech. Participants were recruited through support groups, professional email lists, and professional contacts.

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**Author Contributions:** Ms. Bolt and Dr. Baylor had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

*Study concept and design:* Eadie, Yorkston, Baylor

*Acquisition, analysis, or interpretation of data:* Bolt, Eadie, Baylor, Amtmann

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**Main Outcome(s) and Measures**—Communicative participation and predictor variables were measured using a variety of validated patient-report scales and demographic information. Multiple linear regression analysis was conducted with predictors entered using a backward stepwise regression procedure. Variables with regression coefficients significant at  $P < .05$  were retained in the model.

**Results**—The final model contained 4 significant variables ( $R^2 = 0.462$ ): self-rated speech severity, cognitive function, laryngectomy status, and time since diagnosis. In sum, better communicative participation was associated with less severe speech and cognitive problems; together, these two variables accounted for 42.0% of the variance in the model. To a lesser extent, better communicative participation also was associated with not having undergone total laryngectomy surgery and longer time since diagnosis.

**Conclusions and Relevance**—These results suggest that communicative participation in adults with HNC is associated with self-rated speech severity, cognitive function, whether or not a person has undergone total laryngectomy, and time since diagnosis. Clinicians can use these results to inform their practice in pretreatment counseling, patient education, and rehabilitation for survivors of HNC.

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## Introduction

According to the American Cancer Society,<sup>1</sup> an estimated 59,000 new cases of head and neck cancer (HNC) were diagnosed in the United States in 2015. Treatments for HNC often result in alterations to structures of the speech/voice mechanism. Consequently, survivors of HNC frequently experience difficulties with verbal communication. In fact, among HNC survivors, speech outcomes have been identified as the strongest predictor of overall health related quality of life,<sup>2</sup> inhibiting a person's ability to return to work, establish or maintain relationships, or participate in everyday activities. Communication in everyday activities, or "communicative participation," has emerged in recent years as a meaningful patient-reported outcome.<sup>3</sup>

*Communicative participation* has been defined as "taking part in life situations where knowledge, information, ideas, or feelings are exchanged."<sup>4</sup> The most obvious barriers to communicative participation in patients with HNC may relate to changes in voice quality and reduced speech intelligibility. However, research has shown clinician ratings of these factors are only weakly to moderately related to communicative participation in this population.<sup>5</sup> In fact, communicative participation has been linked to many factors beyond speech and voice function. For example, treatment-related variables, such as tumor site (e.g., laryngeal and hypopharyngeal), as well as physical symptoms, such as xerostomia, hearing loss, and poor dentition, may negatively affect communication in HNC.<sup>6,7</sup> A few studies also have shown that factors related to the person, such as changes in body image, and factors related to the environment, such as social support, affect communication after HNC.<sup>6,7</sup>

Research in other patient populations, such as multiple sclerosis, have revealed the effect of multiple environmental (e.g., social support, familiarity of communication partners, background noise) and personal (e.g., age, gender, educational background, coping strategies; cognitive function) factors on communicative participation.<sup>8</sup> Together, the results

suggest that communicative participation is a complex construct with many potential contributing variables. Yet, to our knowledge, there are no quantitative studies exploring the many variables that may contribute to communicative participation in survivors of HNC. This is an especially important area of investigation in HNC, where there is a wide range of concerns.<sup>9</sup> Identifying these variables would have implications for counseling as well as providing targets for rehabilitation.

The purpose of this study, therefore, was to examine variables that are significantly associated with communicative participation in adults with HNC. We hypothesized that for survivors of HNC, communicative participation would be significantly related to multiple variables that include, but also extend beyond overt communication symptoms. These variables include demographic (e.g. age, education), personal (e.g. emotional distress, speech usage), and physical/functional symptoms (e.g. swallowing difficulties, hearing loss, speech severity) known to be of concern in HNC.<sup>9</sup>

## Methods

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

### Participants

Participants were recruited through support groups, professional email lists, and professional contacts as part of a larger investigation of the Communicative Participation Item Bank (CPIB).<sup>10</sup> All participants were community-dwelling adults, aged 18 years or older, who had completed treatment for HNC at least 6 months prior to their participation. The 6 month inclusion criterion was selected to ensure that all participants had lived with the consequences of HNC long enough to have experienced a wide range of communication situations and how it impacted daily communication, as well as to avoid the fluctuation in scores that may occur immediately post-treatment.<sup>11</sup> They were all able to complete the questionnaires in English and reported no additional medical conditions (beyond HNC) that affected their speech. Participants were paid \$20 for completing a series of questionnaires.

### Data Collection

Through a battery of self-report questionnaires, participants answered questions about specific experiences and symptoms associated with their health and communication, known to influence outcomes in HNC survivors.<sup>12</sup> Questionnaires were administered either using paper forms or online through a secure website according to participant preference. Participants who did not complete the questionnaires within three weeks were contacted once for follow-up. Seventeen variables, described below, were included in the analysis as they relate to communicative participation.

*Communicative participation* was measured using the *Communicative Participation Item Bank (CPIB)*.<sup>10</sup> The CPIB asks participants to rate how much their “condition” (i.e. HNC) interferes with communication in everyday situations (e.g., making a phone call to get information). Ratings range from *not at all* to *very much* on a four point Likert-type scale. The CPIB was calibrated using Item Response Theory (IRT) which, as the name implies,

draws upon the properties of individual items to measure latent traits.<sup>13</sup> Summary scores are converted either to logits, with scores typically ranging from  $-3.0$  to  $3.0$  logits ( $M = 0$ ), or to T-scores ( $M = 50$  and  $SD = 10$ ). In both scoring systems, the mean is the mean of the calibration sample used when developing the CPIB. Higher scores represent better communicative participation. The CPIB has been shown to possess strong psychometric properties in multiple communication disorders, including HNC.<sup>3,10</sup>

Variables related to demographic information and medical history consisted of *age, gender, living situation, education, employment status, cancer location, time since diagnosis, laryngectomy status, and history of hearing loss.*

*Self-rated speech severity* was reported using a single item from the Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised (ALSFRS-R).<sup>14</sup> While originally designed to measure physical function in the daily lives of patients with ALS, the questions pertain to a range of issues common to a variety of patient populations, including HNC.

*Speech usage* was measured with the Levels of Speech Usage rating scale.<sup>15,16</sup> Consisting of a single item, participants choose one of five categories to describe the demands placed on their speech in daily activities. Full descriptions of these categories were provided (see Baylor, et al, 2008, for details).

*Fatigue, pain, physical activity, and emotional distress* were measured with single items from the Patient-Reported Outcome Measurement Information System Global Health instrument (PROMIS; [www.nihpromis.org](http://www.nihpromis.org)).<sup>17</sup> These items are detailed in Table 2.

*Cognitive symptoms* were measured using a custom set of eight items from the NeuroQOL item bank ([www.neuroqol.org](http://www.neuroqol.org)); these items were used with permission prior to publication of the finalized Cognitive Function instrument.<sup>18</sup> Participants rated the level of difficulty associated with tasks related to memory, reading, writing, and problem solving. Ratings were made on a five point Likert-type scale, ranging from *none* to *cannot do*. Scoring for custom sets of items from NeuroQOL item banks is not currently available. Summary scores are reported here (possible range 8 – 40), with higher scores reflecting a higher level of self-reported cognitive function.

*Swallowing difficulties* were described using a single item from the University of Washington Quality of Life Questionnaire (UW-QOL).<sup>19</sup> Designed specifically to measure health-related QOL in people with HNC, swallowing difficulties are categorized in four ways: normal, cannot swallow certain foods, can swallow only liquids, or cannot swallow.

## Data Analysis

Prior to conducting the regression analyses, correlation analyses were performed to rule out potential multicollinearity among communicative participation and the 17 predictor variables. Any variables with correlations greater than 0.70 would be considered for removal. Pearson correlations were used for the continuous (interval) level data, while Spearman correlations were used for the categorical data (ordinal and nominal; see Table 3). Because no correlations were greater than the cut-off of 0.70, all variables were retained for entry into the regression analysis.

The associations of the 17 predictor variables with communicative participation were examined through multiple linear regression analysis in SPSS Version 18.0. Communicative participation, age, time since diagnosis, and self-reported cognitive function were continuous variables; all others were categorical variables. Throughout the process of backward stepwise regression, model fit was analyzed with an overall regression F statistic. Individual variables with regression coefficients significant at the .05 level were retained in the model.

## Results

### Participants

Of 242 questionnaires provided to potential participants, 197 were completed and returned (response rate of 81.4%). The mean age of the respondents was 61.47 years ( $SD = 12.32$ ) with a range of 24 – 86 years. The mean time since cancer diagnosis was 8.38 years ( $SD = 8.14$ ) with a range of 0 – 45 years. The majority of participants were male (61.4%) which is consistent with HNC prevalence data.<sup>1</sup> Additional demographic information is shown in Table 1.

### Predictors of Communicative Participation

The mean logit score for communicative participation in this sample was 0.330 ( $SD = 0.948$ ). The range was  $-2.503$  to  $2.607$  logits, suggesting a broad range of experiences across the participants. The mean summary score for cognitive function in this sample was 35.22 ( $SD = 4.89$ ), with a range of 16 to 40. Descriptive results for categorical variables included in this study are described in Table 2.

Initial analysis with backwards stepwise linear regression resulted in a model containing only self-rated speech severity and cognitive function ( $R^2 = 0.425$ ). A histogram of the residuals approximated a normal distribution, showing random distribution of the residuals. A scatter plot comparing Cook's distance and centered leverage values revealed three potential outliers. These three data points were removed and the regression analysis was repeated. During the subsequent analysis, variables were removed from the model in the following order: education, cancer location, physical activities, pain, fatigue, gender, speech usage, employment, living situation, swallowing problems, emotional distress, age, and hearing loss. The resulting model contained four variables: self-rated speech severity, self-rated cognitive function, laryngectomy status, and time since diagnosis ( $R^2 = 0.462$ ; see Table 4). A histogram of the residuals again approximated a normal distribution. Consistent with the initial analysis, better communicative participation was associated with less severe speech and cognitive problems; together, these two variables accounted for 42.0% of the variance in the model. To a lesser extent, but still statistically significant, better communicative participation was also associated with not having undergone total laryngectomy surgery and longer time since diagnosis.

## Discussion

The results of this study suggest that communicative participation in adults with HNC is associated with self-rated speech severity, self-rated cognitive function, time since diagnosis,

and whether or not a person has undergone total laryngectomy surgery. Three of these variables were hypothesized a priori as being potential predictors of communicative participation. First, self-rated speech severity and laryngectomy status are directly linked to speech function and quality, and prior research has shown that speakers with increased speech difficulties show poorer communicative participation in other patient populations.<sup>8</sup> In HNC, speech and voice difficulties are commonly encountered as a result of surgical resection or radiation effects on the function of structures in the vocal tract.<sup>9</sup> Several researchers also have noted poorer functioning after total laryngectomy for voice-related QOL when compared to laryngeal preservation or partial laryngectomy procedures, which is consistent with the present results (laryngectomy status as the final, albeit weak, predictor).<sup>20,21</sup> In addition, self-rated difficulties in speech and voice have been found to more strongly relate to communicative participation than clinician-rated severity.<sup>5</sup> Thus, results from the present study are consistent with prior research, and demonstrate the direct association between speech severity and communicative participation, predicting 22.7% of the variance in scores.

Beyond speech and voice impairments, we also predicted that time since diagnosis would be associated with communicative participation outcomes. Prior research supports the idea that quality of life improves over time as people adapt to a “new normal.”<sup>22</sup> This variable also has been shown to be positively associated with other outcomes in HNC.<sup>22</sup>

Finally, it is notable that self-reported cognitive function emerged as the second strongest predictor of communicative participation, with 19.3% of the variance predicted. This variable was not hypothesized to be an a priori predictor because cognitive symptoms have not traditionally been considered in HNC. To date, only one study<sup>23</sup> has investigated and found objective evidence of cognitive dysfunction in this population.

Cognitive changes related to HNC are not well understood but have been well established in other cancer populations. For example, in women with breast cancer the most commonly reported cognitive deficits occur in the areas of memory, attention, executive function, and processing speed.<sup>24</sup> Together, these constitute the phenomenon that patients and survivors frequently refer to as “chemo brain.”<sup>25</sup> Although commonly attributed to side effects of various chemotherapeutic agents, cognitive decline has been reported in patients with various types of cancer who did not receive chemotherapy, suggesting that cognitive changes may result from radiation, surgery, and even the body’s natural response to the cancer itself.<sup>26,27</sup> As a result, the term “cancer-related cognitive impairment” (CRCI) has emerged. Deficits in memory, word finding, and processing speed may lead to difficulty following conversations, particularly in groups, and may result in avoidance of conversations in multiple contexts.<sup>8,28,29</sup> This can create a substantial barrier for survivors as they return to work and participate in other activities post-treatment. The possibility of struggle with cognitive symptoms is also of considerable importance for the rehabilitation process after HNC. Patients often are managing complex medical routines and are provided with much information to understand and remember without concern for cognitive status because HNC is not typically associated with cognitive problems. The results of this study, however, suggest that patients may indeed be struggling with cognitive issues more than previously appreciated.

Because HNC is most commonly diagnosed in people over the age of 55,<sup>30</sup> it may be difficult to differentiate CRCI from typical age-related cognitive changes. While the average age of participants in this study (61.47) is consistent with population data reported by the National Cancer Institute,<sup>30</sup> the rate of HNC related to human papillomavirus (HPV) continues to rise in an increasingly younger population. No inferences should be made from the summary scores reported here with regard to population norms of cognitive function. Further study is needed, including measures before and after treatment, to explore the nature and prevalence of cognitive change in this population.

It should be noted that 62% of the participants in this study indicated that they had undergone total laryngectomy surgery. While this may limit the ability to generalize these results to the larger HNC population, laryngectomy status accounted for only 0.7% of the variance in the final model. In addition, cancer site did not enter as a significant predictor variable. Together, these results suggest that at least among the current participants, results were representative. Another limitation of this study is that speech severity, along with several other potential predictor variables, was measured using a single item. In all cases, these single items were “global” items which correlate with multi-item scales. These items evaluate function in broad yet essential terms. They provide insight into the participants’ core perceptions, but further research is needed to examine the nature of these perceptions and identify potential therapeutic targets. This study utilized only self-report data. Future research should investigate the relationship between communicative participation and variables such as speech or cognitive severity when measured objectively or through other perspectives such as clinician-directed measures, and how these modalities compare. In addition, other variables that predict communicative participation need to be identified. These could include severity of comorbid ailments or even social factors. For example, while living alone did not emerge as a predictor in the present study, other factors related to the environment, such as social support, have been found to be important for HNC survivors.<sup>7</sup> In addition, personal factors such as coping strategies may be stronger predictors of communicative participation than age or gender, as explored in the present study. All of these factors warrant further consideration in future research.

The results of this study underscore the importance of speech function and quality on communicative participation outcomes after HNC. These results also show a strong relationship between cognitive function and communicative participation in this population. Clinicians can use these results to inform their practice in pretreatment counseling, patient education, and rehabilitation for survivors of HNC. Future research may lead to development of new interventions to maximize communication outcomes and help survivors of HNC fulfill their life goals.

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**Table 1**

## Demographic Characteristics (N = 197)

Variable	No. (%)	Mean (SD)	Range
Age		61.47 (12.32)	24 – 86
Time since cancer diagnosis (in years)		8.38 (8.14)	0.5 – 45
Gender			
Male	121 (61.4)		
Female	76 (38.6)		
Education			
Elementary / Junior high	5 (2.5)		
Some high school	9 (4.6)		
High school graduate	18 (9.1)		
Vocational / technical training	7 (3.6)		
Some college	66 (33.5)		
College graduate	49 (24.9)		
Post-graduate (masters; PhD)	42 (21.3)		
No response	1 (0.5)		
Employment			
Employed	58 (29.4)		
No response	2 (1.0)		
Living Situation			
Alone	60 (30.5)		
Family	132 (67.0)		
Friends / Roommate	2 (1.0)		
Other	2 (1.0)		
No response	1 (0.5)		
History of hearing loss			
Yes	81 (41.1)		
No	113 (57.4)		
No response	3 (1.5)		
Cancer location			
Larynx	105 (53.3)		
Pharynx	15 (7.6)		
Tongue	31 (15.7)		
Mouth (other than tongue)	8 (4.1)		
Palate	2 (1.0)		
Sinus	2 (1.0)		
Multiple sites	28 (14.2)		
No response	6 (3.0)		
Total laryngectomy			
Yes	123 (62.4)		
No	55 (27.9)		

<b>Variable</b>	<b>No. (%)</b>	<b>Mean (SD)</b>	<b>Range</b>
No response	19 (9.6)		

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**Table 2**

Summary of categorical variables (N = 197)

Variable	Instrument/Scoring	No. (%)
Self-rated speech severity	ALSFERS-R: <i>Which statement best describes your speech?</i>	
	Normal	34 (17.3)
	Sounds different but people understand me	61 (31.0)
	Sometimes have to repeat words to be understood	92 (46.7)
	Use gestures, writing or drawing to help people understand my speech	6 (3.0)
	Not understandable	2 (1.0)
	No response	2 (1.0)
Speech usage	Levels of Speech Usage: <i>Which of the five categories best describes how you typically use your speech?</i>	
	Undemanding	43 (21.8)
	Intermittent	66 (33.5)
	Routine	60 (30.5)
	Extensive	18 (9.1)
	Extraordinary	7 (3.6)
Fatigue	PROMIS Global Health: <i>In the past 7 days, how would you rate your fatigue on average?</i>	
	None	18 (9.1)
	Mild	75 (38.1)
	Moderate	87 (44.2)
	Severe	15 (7.6)
	Very severe	2 (1.0)
Pain	PROMIS Global Health: <i>In the past 7 days, how would you rate your pain on average?</i> 0–10 scale re-coded to 1–5 scale	
	5 = No Pain	55 (27.9)
	4	90 (45.7)
	3	41 (20.8)
	2	10 (5.1)
	1 = Worst pain imaginable	0
Physical activities	PROMIS Global Health: <i>To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?</i>	
	Completely	85 (43.1)
	Mostly	58 (29.4)
	Moderately	37 (18.8)
	A little	15 (7.6)
Emotional distress	PROMIS Global Health: <i>In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?</i>	
	Never	20 (10.2)
	Rarely	70 (35.5)
	Sometimes	69 (35.0)
	Often	33 (16.8)
Swallowing	UW-QOL: <i>Which statement best describes any problems you have with swallowing?</i>	
	Swallowing is normal	63 (32.0)
	Cannot swallow certain foods	122 (61.9)

Variable	Instrument/Scoring	No. (%)
	Can only swallow liquid food	8 (4.1)
	Cannot swallow	3 (1.5)
	No response	1 (0.5)

*Note.* ALSFRS-R = Amyotrophic Lateral Sclerosis Functional Rating Scale-Revised; PROMIS = Patient-Reported Outcome Measurement Information System; UW-QOL = University of Washington Quality of Life Questionnaire

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Table 3

Correlation Analyses

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	
1. Communicative participation	-																		
2. Age	<b>-.004</b>	-																	
3. Time since diagnosis	<b>.108</b>	<b>.354*</b>	-																
4. Gender	.097	.279*	.060	-															
5. Living situation	.038	-.099	-.139	.000	-														
6. Speech severity	<b>.600*</b>	<b>.065</b>	<b>.015</b>	<b>.099</b>	<b>.087</b>	-													
7. Speech usage	<b>.308*</b>	<b>-.106</b>	<b>-.077</b>	<b>-.079</b>	<b>.177*</b>	<b>.327*</b>	-												
8. Fatigue	.219*	.123	.046	.265*	-.021	.118	.046	-											
9. Pain	.159*	.037	.029	.031	.010	.027	-.011	.280*	-										
10. Cognitive function	<b>.335*</b>	<b>.045</b>	<b>.046</b>	<b>.143*</b>	<b>-.046</b>	<b>.268*</b>	<b>.069</b>	<b>.333*</b>	<b>.311*</b>	-									
11. Education	.137	-.115	-.152*	.002	.025	.156*	.056	.114	.033	.093	-								
12. Employment	.067	-.356*	-.198*	-.108	-.007	.139	.237*	-.020	.005	-.002	.231*	-							
13. Physical activities	.209*	-.100	-.104	.102	-.005	.141*	.217*	.489*	.305*	.259*	.187*	.266*	-						
14. Emotional distress	.288*	.286*	.264*	.173*	.078	.217*	.037	.415*	.250*	.445*	.028	-.185*	.178*	-					
15. Swallowing problems	.256*	.183*	.226*	.180*	-.102	.247*	.098	.107	.134	.095	-.056	-.042	.122	.080	-				
16. Hearing loss	.020	.181*	.184*	.178*	-.050	.021	.004	-.012	-.150*	-.089	-.143*	.042	-.038	.069	-.034	-			
17. Cancer location	.008	-.401*	-.235*	-.349*	.071	-.037	.046	-.103	-.016	-.084	.213*	.195*	.115	-.122	-.340*	-.181*	-		
18. Laryngectomy status	.099	-.396*	-.430*	-.276*	.167*	.110	.150*	.058	.104	-.100	.363*	.343*	.223*	-.143	-.223*	-.127	.625*	-	

Note. Pearson correlations, indicated in bold, were used for the interval (continuous) level data, while Spearman correlations were used for the ordinal and nominal (categorical) data. The table above combines both with Pearson reported in bold for the appropriate variables.

\* denotes significant at p<.05.

**Table 4**

Coefficients for final regression model

Variable	Unstandardized coefficients (SE)	Standardized Coefficients	t value	Significance	R <sup>2</sup>
Speech severity	.551 (.065)	.498	8.542	.000	.227
Cognitive function	.063 (.011)	.318	5.505	.000	.193
Time since diagnosis	.015 (.006)	.137	2.319	.022	.035
Laryngectomy status	.285 (.117)	.146	2.434	.016	.007

*Note.* Adjusted R<sup>2</sup> = 0.462.