Published in final edited form as:

Ann Otol Rhinol Laryngol. 2014 April ; 123(4): 257–264. doi:10.1177/0003489414525020.

Communicative Participation and Quality of Life in Head and Neck Cancer

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Abstract

Objectives—The purpose of this study was to determine how a new self-report outcome measure of communicative participation, the *Communicative Participation Item Bank* (CPIB), related to disease- and discipline-specific quality of life outcomes in a head and neck cancer (HNC) population.

Methods—One hundred ninety-five individuals treated for HNC completed the *Communicative Participation Item Bank* (CPIB), the *University of Washington Quality of Life* (UW-QOL) questionnaire, and the *Voice Handicap Index-10* (VHI-10).

Results—Results revealed moderate QOL scores across the UW-QOL (mean scores: global QOL = 66; physical subscale = 70; social-emotional subscale = 73) and VHI-10 questionnaire (mean = 16). Correlations between the CPIB and the UW-QOL scores were statistically significant ($p < .001$), but relatively weak ($r = .37 - .38$). As hypothesized, a stronger correlation was found between the CPIB with the VHI-10 ($r = -0.79$; $p < .001$).

Conclusions—Clinicians may consider adopting the CPIB to complement existing tools in assessing communication outcomes after HNC.

Keywords

quality of life; head and neck cancer; speech; communication; outcome measures

Introduction

One of the greatest difficulties experienced by head and neck cancer (HNC) patients relates to verbal communication. Its loss may lead to withdrawal and social isolation, and can negatively impact an individual's quality of life (QOL).¹ Difficulties in communication may result from alterations of structures of the speech/voice mechanism associated with primary

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Note: Portions of this paper were presented at the 8th International Conference on Head & Neck Cancer in July 2012, in Toronto, Ontario, Canada.

HNC treatment (e.g., surgical removal of tumors on the tongue, larynx, palate), as well as secondary effects (e.g., radiation effects on dental health; facial disfigurement).

Traditional methods of assessing communication after HNC include use of speech intelligibility or voice quality measures performed by clinicians, as well as patient-reported QOL measures.² Patient-reported measures may be disease-specific (i.e., investigating the influence of specific HNC symptoms on well-being) or discipline-specific (i.e., measuring characteristics of interest within a discipline of study, such as how vocal function affects well-being). Some studies have indicated that use of HNC-specific questionnaires in clinical research masks some voice- or speech-related concerns, suggesting that discipline-specific questionnaires, or even population-specific questionnaires,³ might be more sensitive for assessing communication difficulties.^{4,5} However, no tools are solely dedicated to measuring communication in everyday activities, or what is called communicative participation.⁶ Communicative participation is defined as taking part in life situations where knowledge, information, ideas or feelings are exchanged.⁶ For example, communicative participation includes talking to strangers, ordering a meal in a restaurant, or discussing end-of-life care wishes with family members.

While the concept of communicative participation is reflected in several QOL instruments used in the HNC population, the construct is intertwined with other dimensions such as emotional, physical, and social functioning. This is the nature of multidimensional constructs such as QOL. While QOL instruments are useful for measuring overall performance, they confound the measurement of participation and limit the ability to study how variables such as treatment type, tumor site, coping, or environmental conditions may independently affect communicative participation.

An additional difficulty for HNC survivors is that there is current lack of self-report instruments that measure functional *speech* difficulties, as opposed to *voice-related* function. While voice-related QOL measures may sensitively capture difficulties in those with laryngeal cancer, those with oral and oropharyngeal-based tumors may have more difficulty in *speech-related* tasks.⁷ This leaves a large gap in our ability to evaluate functional communication outcomes in this growing group of patients. While one group has proposed a *Speech Handicap Index*,⁵ it was not developed using best practices in patient-reported measures, such as initial inquiry using qualitative approaches to ensure the face and content validity of the instrument.⁸

In the past few years, our multidisciplinary research team has begun to develop the *Communicative Participation Item Bank* (CPIB).^{9,10} Items in the CPIB were developed on the basis of a literature review,⁶ qualitative studies of people with communication disorders that included those with HNC,¹¹ and initially validated on a large sample of individuals with a neurogenic voice disorder (spasmodic dysphonia).⁹ Recently, construct validity of the CPIB was demonstrated using a large sample (N=701), including 197 HNC patients.¹⁰ The results of this series of studies^{6,9-11} suggest that the CPIB might be a promising HNC outcome measure when communicative participation is a primary outcome of interest. However, the next step in developing a patient-reported outcome measure is to examine how the new tool relates to typical HNC measures.⁸ Specifically, the objective of this study was

to determine how this newly validated measure of communicative participation related to global QOL, HNC-specific QOL, and discipline-specific QOL measures in a HNC population. A voice-specific QOL instrument was chosen as a discipline-specific measure in this study because it is the most frequently used tool in research and clinical settings, and has demonstrated psychometric properties.¹² It was hypothesized that the discipline-specific QOL measure that assessed a similar construct as communicative participation would demonstrate the strongest relationship with the new CPIB measure, and that HNC-specific and global QOL measures would demonstrate weaker relationships. Results have implications for adopting the CPIB for clinical and research practice.

Methods

Subjects

Individuals in this study previously participated in a large scale investigation calibrating the CPIB across populations.¹⁰ Subjects were recruited through support groups, professional email lists, and professional contacts. Individuals had undergone HNC treatment at least six months prior to participation to avoid the fluctuation of QOL scores that occur immediately post-treatment.¹³ Subjects included adults with no additional medical conditions (beyond HNC) that affected speech. They all used speech as their primary method of communication, and were able to complete questionnaires in English. Individuals were paid \$20 for their participation.

Data Collection

The University of Washington Institutional Review Board approved the procedures in this study. Subjects were either sent a login to a secure website or mailed a packet, and were given three weeks to complete the questionnaires before being contacted once for follow-up.

Demographic measures—Demographic information included age, sex, marital status, and primary speech method (i.e., natural or alaryngeal speech method, if applicable). Medical history included site of cancer diagnosis, date of diagnosis, and type(s) of treatment. Other demographic information is reported elsewhere.¹⁰

Communicative Participation Item Bank (CPIB)—The CPIB was developed to measure communicative participation in community-dwelling adults with a range of speech-related communication disorders.^{9,10} A previous study showed strong psychometric properties (unidimensionality, local independence, item fit and measurement precision) in a HNC population.¹⁰ The items ask individuals to rate how much their condition (e.g., HNC) interferes with participation in a wide range of daily speech communication activities using a four-point Likert scale (Not at all = 3, A little = 2, Quite a bit = 1, and Very much = 0). For example, items include interference talking to people you do not know, making a telephone call to get information, ordering a meal in a restaurant, talking in groups of people, and having a conversation in a noisy place.^{9,10} There are a total of 46 items in the final item bank.

The CPIB was validated using the modern measurement methods of Item Response Theory (IRT). IRT-based latent trait scores are expressed in a common scale (logits). Scores typically range from -3.0 to $+3.0$ logits, with 0 representing the mean of the sample used for item bank calibration. Higher scores on the CPIB represent higher levels of communicative participation. The reader is referred to Baylor et al^{9,10} for details related to the psychometric properties, specific items, and scoring details for the CPIB, and to Hays et al¹⁴ for further information related to development of item banks using IRT analyses.

University of Washington Quality of Life (UW-QOL) questionnaire—The UW-QOL (V4)^{15,16} was used to measure disease-specific QOL. The UW-QOL consists of 12 items measuring health-related domains. Recently, Rogers et al¹⁷ recommended that outcomes from the UW-QOL be reported using 2 subscales of physical and social-emotional function in lieu of a composite score. Each subscale is based on the average of 6 items that are used to derive a QOL score ranging from “0” (worst health-related QOL) to “100” (best health-related QOL). The second part of the UW-QOL consists of three questions related to global QOL. Each item is calculated independently to represent a global QOL score, ranging from “0” (worst QOL) to “100” (best QOL). Because the first 2 global questions measure QOL and similarly relate to the subscales, only the general QOL question was included for analysis in this study. Thus, global QOL was derived from the question: “Considering everything in your life that contributes to your personal well-being, rate your overall quality of life during the past 7 days”.

Voice Handicap Index-10 (VHI-10)—The VHI-10¹⁸ is a frequently used, validated 10-item questionnaire that measures the impact of voice disorders, including those secondary to HNC, on voice-related quality of life.¹⁹ Participants respond to each item indicating how frequently they have had each experience using a 5-point Likert scale. Responses are added to determine a VHI-10 total score that ranges from “0” (no voice handicap) to “40” (high voice handicap).

Data Analysis

Descriptive analyses were completed for the demographic data. Means, ranges and standard deviations were calculated for continuous variables such as age and time since diagnosis. Frequencies were calculated for categorical variables such as location of cancer.

The Graded Response Model (GRM)²⁰ was selected for the IRT analyses of the CPIB using IRTPRO software.²¹ For the purposes of this investigation, CPIB person (trait/ability) scores were derived to reflect levels of communicative participation in each individual. Disease- and discipline-specific QOL scores were calculated for each participant using the physical and social-emotional subscales from the UW-QOL, one global UW-QOL score, and the VHI-10 total score. Relationships between each of the test scores with CPIB were determined using Pearson Correlation Coefficients.

Results

Subject Characteristics

Two hundred forty-two questionnaires were provided to individuals treated for HNC. One hundred ninety-seven questionnaires were completed and returned (81.4% response rate). Two respondents indicated that they used non-speech methods as their primary method of communication, and were therefore excluded, leaving 195 participants in the data set. Participants (119 males, 76 females) were on average 61 years old (age range=24–86 y), and were on average 9 years (range = 0.5–46 y) post-diagnosis. Other participant demographics are shown in Table 1.

CPIB and QOL Scores

Overall, results showed moderate QOL scores for the disease- and discipline-specific QOL scales. The mean score for the entire sample was 70 ($SD=16$) for the UW-QOL physical subscale, 73 ($SD=16$) for the UW-QOL social-emotional subscale, and 66 ($SD=21$) for the global UW-QOL score. The mean VHI-10 score was also moderate at 16 ($SD=8$). Scores also are reported as a function of the sex, cancer site, and speech method in Table 2. CPIB scores appeared to vary with site of diagnosis, with more interference in communicative participation reported for individuals with tumors across multiple sites or for those with laryngeal cancer, and better scores for those with oral and oropharyngeal cancers (see Table 2). No statistical comparisons were made as a function of cancer site due to non-normal distributions in the sample.

All correlations between the CPIB and the UW-QOL scores were statistically significant ($p < .001$), but relatively weak (see Figures 1, 2, and 3; CPIB vs. UW-QOL physical subscale scores, $r = 0.37$; CPIB vs. UW-QOL social-emotional subscale scores, $r = 0.37$; CPIB vs. UW-QOL global scores, $r = 0.38$). One item on the UW-QOL includes a speech domain. A post-hoc correlation was performed between the CPIB with the participants' speech domain scores to determine whether overall or subscale scores masked the strength of relationships with communicative participation. Results revealed a significant, but moderate, correlation between the two measures ($r = 0.50$; $p < .001$). In contrast to relationships between the CPIB with the UW-QOL scores, a moderate to strong significant correlation was found between the CPIB with the VHI-10 ($r = -0.79$; $p < .001$; see Figure 4).

Discussion

This study investigated how communicative participation, as measured by the CPIB, related to commonly used QOL measures in HNC. Results revealed relatively weak relationships between CPIB scores with all disease-specific QOL scores (UW-QOL). However, as hypothesized, a stronger, moderate relationship was found between CPIB scores with a discipline-specific scale measuring voice-specific QOL (VHI-10). Results suggest that the CPIB measures a construct that makes a unique contribution in assessment in HNC. Findings have implications for research and clinical practice.

CPIB as a HNC Outcome Measure

HNC is not only a life-threatening disease, but it is also associated with drastic functional problems in speech, swallowing, airway protection, and pain, to name a few areas. As a result, patient-reported outcomes, including both disease- and discipline-specific QOL scales, are increasingly being used to document effects of both HNC and its treatment.^{1,2,7} Overall, results from this study revealed moderately severe disease-specific QOL scores after HNC treatment, consistent with previous literature.^{17,22} In addition, voice-related QOL scores were also moderate in severity, consistent with previous findings in HNC patients.^{23,24}

The present study investigated the relationship between the CPIB with typical patient-reported outcomes in HNC. The relatively weak relationships found between CPIB scores and the global and subscales of the UW-QOL suggest that the CPIB is indeed measuring a unique construct that is not currently represented on typical disease-specific tools. One possible reason why relationships were weak to moderate between the CPIB with the UW-QOL global QOL and other subscales may relate to the multidimensional nature of quality of life. Composite scores derived from QOL scales may sometimes mask concerns in particular areas (i.e., high function in one domain combined with low function in another domain may result in cancelling effects).¹⁷ Yet, even the speech domain of the UW-QOL (related to perceived intelligibility) was only moderately ($r = 0.50$) related to communicative participation, suggesting that intelligibility may not strongly predict how individuals communicate in social contexts. Results are similar to previous research showing a moderate ($r = 0.52$) relationship between the UW-QOL speech domain and speech intelligibility in those with oropharyngeal cancer.²⁴ Examining how clinician-measured speech impairments such as disordered voice quality or reduced speech intelligibility relate to communicative participation should be the focus of future investigations.

The most obvious reason why relationships between CPIB and disease-specific QOL scores were generally weak in this study may be because particular areas of social functioning, such as communication in context, are generally not well represented on current HNC tools.^{4-6,25} Combined with the results of this study, this might suggest that there is a general lack of sensitivity of these types of scales for adequately capturing broader communication issues. For example, several reviews of outcome measures have found that these tools generally focus on physical and psychological well-being, with a paucity of instruments or items on existing tools that measure the social dimension of QOL in cancer-specific²⁶ or HNC-specific QOL scales.²⁵ This area is critical to consider because both patients and health professionals²⁷ recognize that factors in the environment (e.g., background noise, social support) as well as participation in life roles are as important areas of rehabilitation as traditional approaches that focus on improving or restoring body structures and functions.²⁸

While the relationships between the CPIB and the UW-QOL scores were weak to moderate, a moderate to strong relationship ($r = -0.79$) was found between the CPIB and voice-specific QOL, as measured by the VHI-10. Baylor et al⁹ reported a similar moderate relationship ($r = -0.68$) between CPIB scores and VHI scores for individuals with a neurogenic voice disorder (spasmodic dysphonia). These findings are consistent with

qualitative research suggesting that individuals with different communication disorders experience similar types of participation restrictions.¹¹ The moderate to strong relationship demonstrated between the CPIB and voice-related QOL supports the concurrent validity of the CPIB, while similarly highlighting the contributions of the CPIB above and beyond voice-specific QOL (with 62.9% of the variance predicted; see figure 4).

Results of this study must be considered in light of the sample of HNC patients who participated, including a large number of individuals from online support groups who were paid for their participation. In addition, individuals in the present study were on average 9.4 years post-diagnosis. All outcomes need to be interpreted with these demographics and potential biases in mind.

In addition to these factors, the sample also included a large proportion of individuals who had undergone total laryngectomy. While this sample may not be representative of HNC patients as a whole, the group included those who exhibited a large range of communication abilities (demonstrating a range of CPIB scores; see Table 2), suggesting that the CPIB might be a sensitive outcome measure for individuals with a variety of HNC who received different treatments. For example, CPIB scores appeared to vary with site of diagnosis, with more interference in communicative participation reported for individuals with tumors across multiple sites or for those with laryngeal cancer, and better scores for those with oral and oropharyngeal cancers. Thus, one potential advantage of the CPIB over a voice-specific QOL tool relates to its ability to capture difficulties that are either voice- or speech-specific, as one might expect in a broad HNC population. These results mirror what have been shown for speech-related QOL outcomes,²⁹ and lend strength to the validity and potential use for the CPIB. The significance of these results should be interpreted and replicated in more controlled longitudinal studies that include a larger proportion of individuals with oral and oropharyngeal-based tumors.

Directions for Future Research and Clinical Implications

The CPIB was developed using best practice methods for developing self-reported outcome measures.⁸ The advantage of a measure based on IRT is that it results in item-level properties instead of scale-level properties.¹⁴ Once an instrument is developed using IRT, one can estimate a particular person's trait level (e.g., communicative participation) based on responses to even a subset of items, as opposed to entire test. Thus, a key advantage of IRT-based instruments is that it permits dynamic test administration (e.g., computerized adaptive testing), in that very few items need to be administered before determining that person's exact "level" of the latent trait. This is a substantial departure from existing protocols that require that an entire test be administered, which burdens the patient, and lengthens the time of administration for clinicians. A second advantage of this approach beyond standard protocols is that because the CPIB is based in IRT, it may be directly compared with other latent traits based in IRT. Use of this approach will facilitate meta-analyses and performance of systematic reviews in measuring treatment efficacy after HNC, as well as comparisons with outcomes across other populations. A final advantage of the CPIB is because it measures a unidimensional construct, communicative participation, it

allows the study and identification of mediating variables that might be important for future interventions and counseling when communication is the primary outcome of interest.

Future investigations will focus on establishing minimal important differences (clinically significant changes)³⁰ for the CPIB, as well as development of computer adaptive testing methods. Until then, a 10-item CPIB short form¹⁰ with corresponding IRT-derived scores is available for clinical and research use, which will promote better understanding of communication outcomes in the HNC population.

Conclusions

This study investigated how the CPIB, a newly validated self-reported outcome measure, related to typical QOL measures in the HNC population. Results revealed relatively weak relationships between CPIB scores with disease-specific QOL scores, and stronger relationships with voice-specific QOL scores. Results suggest that the CPIB may complement existing tools, while offering some potential advantages over tools typically used in HNC research and clinical practice.

Acknowledgments

Funding: National Institutes of Health/National Cancer Institute (1R03CA132525-01A1; PI: Eadie) and National Institute on Deafness and Other Communication Disorders (NIDCD: 1R03DC010044) (PI: Baylor).

We gratefully acknowledge funding support from the National Cancer Institute (NCI: 1R03CA132525-01A1; PI: Eadie) and the National Institute for Deafness and other Communication Disorders (NIDCD: 1R03DC010044; PI - Baylor). We also would like to thank the participants, clinicians and support group leaders who helped with recruitment, and student research assistants for their efforts in data collection and entry including Brittney Skrupky, Christina Gray, Tiffany Elliott, Brianne Bowker, Kathy Nagle, and Devon Sawin.

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Figure 1.

CPIB person scores (in logits) as a function of UW-QOL physical subscale scores. Negative CPIB scores = more interference with communicative participation (worse); for UW-QOL, 0 = worst QOL and 100 = best QOL. The line of best fit and variance predicted are included in the lower right.

Figure 2.

CPIB person scores (in logits) as a function of UW-QOL social-emotional subscale scores. Negative CPIB scores = more interference with communicative participation (worse); for UW-QOL, 0 = worst QOL and 100 = best QOL. The line of best fit and variance predicted are included in the lower right.

Figure 3.

CPIB person scores (in logits) as a function of UW-QOL global scores. Negative CPIB scores = more interference with communicative participation (worse); for UW-QOL, 0 = worst QOL and 100 = best QOL. The line of best fit and variance predicted are included in the lower right.

Figure 4. CPIB person scores (in logits) as a function of VHI-10 scores. Negative CPIB scores = more interference with communicative participation (worse); for VHI-10, 0 = normal and 40 = most severe handicap. The line of best fit and variance predicted are included in the lower right.

Table 1

Selected Demographic Characteristics (N = 195 subjects).

Characteristic	No. (%)	Mean (SD)	Range
Sex			
Female	76 (38)		
Male	119 (62)		
Age (y)		61.3 (12.3)	24–86
Marital Status			
Married/committed relationship	119 (61)		
Single/widowed/divorced	74 (38)		
Not reported	2 (1)		
Cancer site			
Larynx	105 (54)		
Oropharynx/Hypopharynx	16 (8)		
Oral Cavity	40 (21)		
> 1 site	17 (9)		
Not reported/unclear	17 (9)		
Cancer treatment			
Surgery	30 (15)		
Radio(chemo)therapy	59 (30)		
Surgery and radio(chemo)therapy	98 (50)		
Not reported/unclear	8 (4)		
Speech Method			
Natural Speech	73 (37)		
Tracheoesophageal speech	66 (34)		
Esophageal speech	16 (8)		
Electrolaryngeal speech	40 (21)		
Time Since Diagnosis (y)		9.4 (8.2)	0.5–46

Table 2

QOL and CPIB Scores as a function of sex, cancer site, and speech method.

		UW-QOL Physical		UW-QOL Social-Emotional		UW-QOL Global		VHL-10		CPIB	
	n	M (SD)		M (SD)		M (SD)		M (SD)		M (SD)	
Sex											
Female	76	66 (17)		70 (17)		64 (23)		17 (9)		0.21 (1.07)	
Male	117	73 (14)		75 (15)		68 (19)		16 (7)		0.42 (0.85)	
Cancer Site											
Larynx	105	75 (14)		74 (16)		67 (19)		19 (7)		0.32 (0.90)	
Oropharynx/hypopharynx	16	68 (13)		78 (18)		66 (27)		12 (6)		0.64 (0.82)	
Oral Cavity	40	63 (16)		71 (13)		67 (22)		14 (9)		0.55 (1.17)	
>1 site	17	56 (15)		63 (19)		61 (23)		19 (7)		0.02 (0.66)	
Not reported	17										
Speech Method											
Natural Speech	73	63 (17)		71 (15)		65 (23)		12 (8)		0.55 (1.04)	
Tracheoesophageal	66	74 (12)		73 (16)		67 (18)		19 (7)		0.20 (0.82)	
Esophageal	16	80 (12)		78 (21)		71 (21)		17 (9)		0.48 (0.94)	
Electrolarynx	40	71 (15)		72 (16)		64 (21)		19 (6)		0.12 (0.90)	