

The Role of Perceived Social Support, Resilience, and Depression on Communicative
Participation in Head and Neck Cancer Survivors

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A thesis

Submitted in partial fulfillment of the
requirements for the degree of

Master of Science

University of Washington

2016

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Program Authorized to Offer Degree:

Speech and Hearing Sciences

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Abstract

The Role of Perceived Social Support, Resilience, and Depression on Communicative Participation in Head and Neck Cancer Survivors

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Objectives: The purpose of this study was (1) to investigate the relationships among the psychosocial variables of perceived social support, resilience, and depression in adults diagnosed with head and neck cancer (HNC), and (2) to determine the unique contribution of these variables in predicting individuals' communication in everyday activities (i.e., communicative participation) above and beyond known factors (self-rated speech severity, cognitive function, time since diagnosis, and laryngectomy status).

Participants/Methods: Seventy-three adults (average age = 65.8 years) who were at least 2 years post-treatment for HNC participated in the study. Participants completed questionnaires consisting of demographic information and self-report scales measuring communicative participation and other variables of interest.

Results: With all variables considered, a total of 63% of the variance was predicted in communicative participation. Depression was found to uniquely predict communicative

participation, accounting for 12% of the variance. Perceived social support was weakly correlated with communicative participation, but was not found to be a significant unique predictor. Resilience did not significantly correlate with or uniquely predict communicative participation. Self-rated speech severity uniquely accounted for 28% of the variance in communicative participation.

Conclusions: These results suggest that, in addition to the known variable of self-rated speech severity, depression is a useful predictor of communicative participation. Implications for speech-language pathology service delivery and future research directions are discussed.

Introduction

Head and neck cancer (HNC) describes any cancer of the oral cavity, pharynx, larynx, nasal passages, or salivary glands (National Cancer Institute, 2013). It is estimated that there will be approximately 61,760 new diagnoses of HNC in the United States in 2016 (American Cancer Society, 2016), and it remains a serious health concern worldwide. This condition impacts many facets of the patient's life; communication especially may be profoundly affected. If the larynx is resected in its entirety (i.e., total laryngectomy), the patient will have to learn an alternate means of oral communication, including esophageal speech, tracheoesophageal speech, or the use of an electrolarynx. Even if the larynx is preserved, resection of part of the larynx can impact residual voice quality, and removal of oral structures can cause articulatory imprecision. Radiation treatments may similarly cause articulatory difficulties secondary to fibrosis of oral structures or dental decay. Radiation also may cause fibrosis and scarring of the vocal folds, resulting in poor voice quality and increased vocal effort (Colton, Casper, & Leonard, 2011; Jacobi, Molen, Huiskens, Rossum, & Hilgers, 2010; Stemple, Glaze, & Klaben, 2000). While these examples show the direct effect of standard HNC treatments on structures that are involved in voice and speech production, we must remember that there are many factors that affect the success of communication in everyday settings, or what is known as "communicative participation." For example, communication success might be affected by background noise, fatigue level, coping strategies used by the person with HNC, or attitudes and support of people surrounding the person with HNC. These factors are encompassed in a biopsychosocial model of health and disability outlined in the next section, and form the basis of this study's research questions.

Communicative Participation

In the past, therapeutic interventions for HNC and other health conditions have focused on directly treating the impairment, with the reasoning that treating the underlying impairment would ameliorate its effects on the patient's everyday life. For example, consider an adult female with a history of smoking who has a cancerous tumor on her vocal folds. Using a traditional biomedical model, we would expect the tumor to be treated by a radiation oncologist or a head and neck surgeon with the goal of eliminating/curing the cancer. After primary medical treatment, a speech-language pathologist might work with this patient to optimize residual voice quality. The biomedical model assumes that by targeting and improving voice quality, we would improve the patient's communication outcomes, which would also improve her quality of life. This model assumes a linear effect between the reduction of a speech or voice impairment and subsequent improvement of communication in everyday settings. Yet, this model does not take into account the fact that regardless of her voice quality and understandability, communication success may be affected by other factors. This is one place where the traditional biomedical model breaks down. For example, even with optimal voice quality, this woman may be depressed or have poor coping strategies, and may not resume her daily activities after her HNC treatment. She also may encounter communication partners who are impatient, or who may express negative attitudes about her voice and how her cancer was caused (i.e., smoking) that may affect her communication success. These factors undoubtedly affect her outcomes, but are ignored or poorly explained in traditional models of health.

More recent models of functioning and disability consider a person's health condition in a broader context. The World Health Organization's International Classification of Functioning, Disability, and Health (WHO-ICF) takes this approach in its model of disability (World Health

Organization, 2001). It considers the impact of the health condition not only in regards to body functions and structures (such as missing oral structures and how fibrosis may affect vibration of the vocal folds), but it also describes functioning in terms of its effect on the person and her function in daily activities (such as difficulty speaking clearly and efficiently—problems at the activity level). A third level of functioning includes the impact of the health condition on participation in life situations (such as how communication is affected in occupational and/or social settings). It is this level of functioning (i.e., participation) that we will focus on in this investigation. One difference between this biopsychosocial model and the biomedical model is the fact that there is not necessarily a direct linear relationship between the impairment (i.e., body functions and structure) and participation. There are multiple factors with bi-directional interactions to be considered. An additional difference in the WHO-ICF model (vs. the traditional biomedical model) is the inclusion of personal and environmental factors. These include factors such as the person's sex, age, and coping strategies (personal), as well factors in the physical and attitudinal environment that impact outcomes at all levels of functioning. Thus, the WHO-ICF provides a framework for understanding how factors such as social support, background noise, fatigue, or coping strategies affect communication in everyday life situations.

The construct of communicative participation considers communication disorders in the context of involvement in life situations. Eadie et al. (2006) define communicative participation as “taking part in life situations where knowledge, information, ideas, or feelings are exchanged” (p. 309). Communication disorders, such as those associated with HNC, can affect an individual's ability and/or satisfaction in participating in these life situations. Communicative participation is a very complex construct because it can be affected not only by the manifestation of the communication disorder itself, but also by personal and environmental factors, as the ICF

model suggests (Eadie, 2007). Wethington, Glanz, and Schwartz (2015) report that “individual appraisals, rather than objective characteristics, are key determinants of how the event or situation affects behavioral and health status” (p. 224). Therefore, we cannot predict how a communication problem will affect communicative participation based on the severity of symptoms or treatment effects alone. For example, prior research suggests that the severity of a speech problem or level of dysphonia evaluated by a clinician is only weakly related to patient-reported communicative participation (Eadie et al., 2016).

Consequently, recent research has sought to discover other factors that might predict an individual’s communicative participation in everyday life. For example, in a qualitative study examining communication after HNC, many participants reported that social support played an essential and beneficial role in their lives post-diagnosis (Fletcher, Cohen, Schumacher, & Lydiatt, 2012). Other researchers have sought to examine these relationships in individuals with health conditions other than HNC. For example, Baylor, Yorkston, Bamer, Britton, and Amtmann (2010) investigated the relationship between communicative participation and personal, environmental, and symptom variables in individuals diagnosed with multiple sclerosis. The study found that fatigue, slurred speech, depression, problems thinking, employment status, and social support were significantly related to self-reported measures of communicative participation. Baylor, Burns, Eadie, Britton, and Yorkston (2011) also performed a qualitative study that investigated factors that interfere with communicative participation in people with a variety of communication disorders, including those post-laryngectomy. Many participants reported that they experienced participation restrictions not only due to the functional limitations of their impairments, but also because of negative emotions they felt as a

result of their difficulties. Their ability to cope and react to stressful circumstances had an impact on their communicative participation.

One recent study (Bolt, Eadie, Yorkston, Baylor, & Amtmann, 2016) investigated factors that predicted communicative participation in people at least 6 months post-diagnosis of HNC. Demographic information and patient-report scales were gathered for 197 participants. Regression analysis revealed that self-rated speech severity, self-rated cognitive function, laryngectomy status, and time since diagnosis predicted communicative participation, accounting for 46% of the variance in scores. Better communicative participation was predicted by lower self-rated speech severity, higher self-rated cognitive function, no laryngectomy surgery, and a longer period of time post-diagnosis. Self-rated speech severity and cognitive function were particularly strong predictors, uniquely accounting for 22.7% and 19.3% of the variance in communicative participation, respectively. While this study accounted for almost half of the variance in communicative participation, other predictors remain unknown. More research is needed to determine other factors that impact communicative population in this population. In particular, the authors suggested that future research address the influence of psychosocial factors such as social support. These findings help justify the need for the current study.

This emerging research has begun to investigate the effects of communication disorders on individuals' participation in life situations that require communication. Reflecting back on the ICF model of disability, participation is influenced by a variety of variables, including personal characteristics of the individuals with the disorder, as well as environmental factors that make up the world in which they live. More research is needed to better describe the interactions among these variables, especially in the context of individuals diagnosed with HNC. The aim of this study is to address this research gap by examining the relationship between communicative

participation and three psychosocial factors— social support (an ICF environmental factor), depression (an ICF body functions and structures factor), and resilience (an ICF personal factor). These variables and the rationale for their inclusion in this study are described in detail in the following sections.

Social Support

Social support is a multidimensional construct that can be defined as “information from others that one is cared for, loved, esteemed, and part of a mutually supportive network” (Holt-Lunstad & Uchino 2015, p. 186, citing Cobb, 1976). In the ICF framework, social support is an environmental factor that may impact participation. This support or assistance might be tangible (e.g., meals, money, or a ride to a doctor’s appointment), but it can also come in the form of a resource of information, emotional support, or a sense of belonging (Holt-Lunstad & Uchino, 2015). Social support does more than just contribute to emotional well-being. Research has found that strong social support is related to better health habits and even lower mortality rates (DiMatteo, 2004; Holt-Lunstad, Smith, & Layton, 2010; Uchino, 2006).

Two different types of social support include perceived and received support. Perceived support is described as an individual’s *perception* that they have people to whom they can turn if they need assistance. Received support, on the other hand, is described as the *actual* assistance that an individual receives (Holt-Lunstad & Uchino, 2015). Though these two concepts are related, they measure two distinct constructs. Past research has shown perceived support to be a better predictor of mental and physical health than received support (Wills & Shinar, 2000). As a result, this study will examine the effect of perceived social support on communicative participation.

Though limited, there is a body of research examining the role of perceived social support in populations with communication disorders. First, Boyle (2015) examined the relationship of social support, empowerment, self-help support group participation, and group identification to quality of life in 249 adults who stutter. Social support was measured using the Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988). This scale was broken down to determine the relative contributions of social support from family, friends, and significant others. The results indicated that all three were significantly related to quality of life: social support from family ($r = 0.54$), friends ($r = 0.46$), and significant others ($r = 0.37$). Furthermore, participation in support groups also was important, although these variables showed weaker relationships with quality of life. For example, involvement in support groups in the past three years ($r = 0.22$), level of participation ($r = 0.32$), consistency of attendance ($r = 0.22$), and number of years participating in support groups ($r = 0.17$) were all related to quality of life. However, after controlling for demographic factors and stuttering related variables, the regression model revealed that empowerment and social support from family significantly predicted quality of life, with 38.1% of the variance predicted (vs. 18% for age, gender, and stuttering severity). These results also show the importance of perceived social support in communication disorders.

Second, Baylor et al.'s (2010) study examined how perceived social support (among other variables) was associated with communicative participation in individuals diagnosed with multiple sclerosis (MS). Four hundred ninety-eight individuals diagnosed with MS completed a series of questionnaires assessing these variables. The Communicative Participation Item Bank (CPIB; Baylor, Yorkston, Eadie, Miller, & Amtmann, 2009) was used to measure communicative participation, and perceived levels of social support were measured using the

Multidimensional Scale of Perceived Social Support (Zimet et al., 1988). They reported a significant, but somewhat weak relationship between the two factors ($r = 0.281$), with a higher degree of social support corresponding to a higher reported level of communicative participation.

Several other studies have also examined the role of social support in HNC populations. One such study sought to explore how social support was related to health-related quality of life in 394 recently diagnosed HNC patients (Karnell, Christensen, Rosenthal, Magnuson, & Funk, 2007). Perceived social support was measured using the Social Provisions Scale (SPS), and health-related quality of life was judged using the Head and Neck Cancer Inventory (HNCI), the Beck Depression Inventory (BDI), and the Medical Outcomes Study Short Form 36 (SF-36). These researchers found that perceived social support was significantly related to quality of life one year post-diagnosis. They reasoned that this relationship occurred because “increased social support enhances patients’ ability to adjust to changes in their post-treatment function” (p. 146).

Birkhaug, Aarstad, Aarstad, and Olofsson (2002) also examined the relationship between health-related quality of life and social support in 104 participants treated for laryngeal cancer. Social support was measured using a 15-item questionnaire created for the study; health-related quality of life was determined using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Head and Neck Cancer (EORTC QLQ H&N35). These researchers found that social support was not significantly related to health-related quality of life. Social support, however, was defined as extent of contact with neighbors, family, and friends (otherwise known as social networks), rather than the perceived support gained from those interactions. As a result, it is unknown whether perceived social support would have been a stronger predictor.

Finally, Llewellyn, McGurk, and Weinman (2005) conducted a systematic review investigating the relationship between quality of life and various psychosocial and behavioral factors in the HNC population. The researchers concluded that the role of social support is currently unclear, and emphasized that large differences may occur due to different ways of measuring social support as well as different definitions of social support. Research investigating the relationship between social support and quality of life appears to be equivocal; however, results indicate that *perceived* social support may be a strong predictor of quality of life. While quality of life outcomes are not synonymous with patient-rated communicative participation, they have been found to be positively related (Eadie et al., 2014). Therefore, we might hypothesize that increased perceived social support might also be associated with increased communicative participation in those with HNC.

Resilience

Like social support, resilience is a multidimensional concept that may attenuate the effects of stressors in individuals' lives (Wethington, Glanz, & Schwartz, 2015). Richardson (2002) defines resilience as “the process of coping with adversity, change, or opportunity in a manner that results in the identification, fortification, and enrichment of resilient qualities or protective factors” (p. 308). Wethington, Glanz, and Schwartz (2015) define it as “resistance to the negative impacts of stress” (p. 223). Numerous authors have proposed different qualities that make up resilience over the years; however, these typically fall into the themes of psychological and dispositional attributes, family support and cohesion, and external support systems (White, Driver, & Warren, 2008). Therefore, resilience could be conceptualized as both a personal and environmental factor in the ICF model—it consists of characteristics both intrinsic to the person (the psychological and dispositional attributes) and those outside his or her control (family and other external support). Though many sources consider social support as a component of

resilience, resilience will be considered solely a personal, intrinsic factor for purposes of this study. This conceptualization is supported by most basic definitions of resilience; for example, White, Driver, and Warren (2010) define it as “an individual’s personal qualities and skills that enable that person to flourish in the face of adversity or a disruptive event” (p. 23). This viewpoint is supported by Richardson (2002), who describes the source as being within one’s self.

Research on resilience is somewhat limited at this time, but shows great promise as a predictor of health outcomes. In 2001, the Committee on Future Directions for Behavioral Health and Social Science Research at the National Institutes of Health urged increased research on positive health, defined as the “biological, behavioral and psychosocial factors that contribute to resilience, disease resistance, and wellness” (p. 3). As a result, much research has been focused on this construct since 2001, and has continuously shown resilience to be positively related to health-related outcomes. For example, Anderson and Anderson (2003) showed that factors associated with resilience such as good relationships, optimism, and the ability to find meaning after a stressful event are associated with greater life expectancy. White, Driver, and Warren contributed to this body of research with their two studies focusing on individuals after traumatic disabilities (2008, 2010). They examined the consistency of resilient characteristics in 42 adults completing inpatient rehabilitation stay following a spinal cord injury (2010). Resilience was measured using the Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003), a 25-item questionnaire that asks participants to judge how much they agree with statements describing them as having resilient qualities in the first week of admission. Resilience was shown to be significantly and positively correlated with spirituality ($r = 0.35$) and satisfaction with life ($r = 0.54$); it was negatively correlated with depression

($r = -0.35$). This overall trend was also evident at the end of the patients' stays. Resilience was not shown to change significantly throughout the stay, suggesting that these characteristics are better described as intrinsic traits rather than based on current states. The authors, however, proposed that these resilient characteristics can be facilitated through intervention. Resilience may not have changed throughout this study because there was no intervention undertaken and therefore no catalyst for change.

While resilience has been explicitly studied in those with varied health conditions, it has limited study in those with cancer. A “resilience in illness” model for young adults with cancer recently was developed. It revealed that resilience is related to several variables, such as courageous coping, family environment, social integration, and how individuals derive meaning that is hopeful (Haase, Kinter, Monahan, & Robb, 2014). Two studies report the effect of resilience on outcomes in HNC, although one study relates to characteristics of caregivers (Simpson et al., 2015). The other study is an unpublished investigation that reported a positive, moderate correlation ($r = .427$) between resilience and patient-reported quality of life outcomes in 94 individuals treated for HNC (Asiedu, 2014). The resilience research is even more lacking in the communication disorders literature. Craig, Blumgart, and Tran (2011) discussed resilience in the context of people who stutter—their study found that higher levels of resilience in this population were predicted by a more supportive social network. Though we might hypothesize from previous work that resilience and perceived social support will be positively, but perhaps weakly correlated in individuals treated for HNC, this relationship needs further discussion. White et al. (2008) emphasize that resilient characteristics are ordinary (or “not heroic”) and therefore can be found or trained in almost anyone. Luthar and Cicchetti (2002) also stress that resilience can be fostered, and discuss methods of intervention in their article. As a result, this

construct has important implications for rehabilitation because it has been proposed that it may be amenable to change.

Depression

Depression is a mood disorder that may be manifested in many different ways. Symptoms range from mild to severe and can include a depressed mood, loss of interest or pleasure, significant weight loss/gain, insomnia, fatigue, guilt, or feelings of worthlessness (Haisfield-Wolfe, McGuire, Soeken, Geiger-Brown, & De Forge, 2009). In a retrospective study of depression in HNC patients, 10.6% of people with HNC were diagnosed with depression during the two years before their cancer diagnosis, and an additional 8.9% were diagnosed within a year after their cancer diagnosis (Rieke et al., 2016). Therefore, it is evident that depression is not uncommon in this population.

Depression may be construed as an ICF body functions and structures factor, but may manifest across all dimensions of the WHO ICF model. Similar to resilience and social support, it has been shown to affect health outcomes. A study by Onitilo, Nietert, and Egede (2006) demonstrated that at an 8-year follow-up of individuals diagnosed with cancer, depressed individuals were more likely to have died than their non-depressed counterparts. DiMatteo and Haskard-Zolnieriek (2011) suggest that this may be related to difficulty with adherence to medical recommendations. They state that “depression can interfere with a patient’s ability to adhere to medical regimens including both the desire and the ability to manage behavior change that is vital when facing chronic conditions such as cancer” (p. 107). Just as a patient often needs to change behaviors for medical reasons (e.g., stopping smoking or exercising more), the patient with a history of HNC may also need to adjust to communication changes, possibly learning a new method of communication and/or adjusting to new communication obstacles they had not

experienced before. If the individual is not motivated or able to change his/her communication behaviors, adjustment difficulties will likely arise. Therefore, it is hypothesized in this study that depression levels will be related communicative participation, with higher levels of depression predicting lower levels of communicative participation.

No known studies have investigated the relationship between depression and communicative participation in individuals diagnosed with HNC. There is precedent in the communication disorders literature, however. In Baylor et al.'s (2010) study of variables related to communicative participation in individuals with multiple sclerosis, depression (as measured by the short form of the Center for Epidemiological Studies Depression Scale [CES-D]) was shown to be significantly and negatively related to communicative participation ($r = -0.560$, $p \leq 0.01$). As a result, one purpose of this study was to determine whether this relationship also exists in individuals diagnosed with HNC.

Research Questions

Communicative participation is a complex construct that may potentially be affected by many different variables, including the psychosocial factors of social support, resilience, and depression. Resilience and social support have been associated with improved health status and health behaviors (Newman, 2005; Holt-Lunstad & Uchino, 2015), as well as quality of life outcomes in different populations (Boyle, 2015; Llewellyn, McGurk, & Weinman, 2005). Perceived social support has been positively associated with communicative participation in individuals with multiple sclerosis (Baylor et al., 2010), and was found to be a meaningful contributor to communication in a qualitative study of HNC survivors (Fletcher et al., 2012). Measures of social support and resilience are also related as supported by theoretical discussion (Cobb, 1976; White, Driver, & Warren, 2008) and empirical research (Blood et al., 1994;

Blumgart, Tran, & Craig, 2014), although, for the purposes of this study, they will be considered as distinct. Depression, on the other hand, has been linked to poorer health outcomes (DiMatteo and Haskard-Zolnierrek, 2011), reduced quality of life in HNC (Howren, Christensen, Karnell, & Funk, 2013), and reduced communicative participation in individuals with multiple sclerosis (Baylor et al., 2010). The limited research on social support and resilience after disability indicate that these factors may be important to adjustment after a diagnosis of HNC, and may predict important outcomes such as communicative participation. Research also supports the hypothesis of a negative relationship between depression and communicative participation. However, these relationships are yet unstudied in this important clinical population. Therefore, the research questions this study seeks to answer are as follows:

1. What are the relationships among perceived communicative participation, social support, resilience, and depression in individuals treated for HNC? How do these factors relate to other variables already shown to predict communicative participation in this population (self-rated speech severity, perceived cognitive function, time since diagnosis, laryngectomy status)?
2. To what extent do the variables of perceived social support, resilience, and depression together predict communicative participation above and beyond known factors?
3. Of the variables of interest in this study and the factors already known, which measures uniquely predict communicative participation, holding all other variables constant?

The answers to these questions may have significant clinical implications. If resilience, depression, and/or social support are found to predict communicative participation in this population, this may enable speech-language pathologists to make better prognostic judgments about communication success in life activities. If social support is found to be an important

predictor, it would highlight the importance of including family, friends, and significant others in the education and treatment process. If the level of depression predicts communicative participation, the importance of including psychological services in the rehabilitation process would be emphasized. Finally, if resilience is an importance predictor and is indeed amenable to change as researchers propose, this would also indicate a benefit to referring patients treated for HNC to counseling services to foster this trait.

Methods

Overview and Design

Procedures in this study were approved by the University of Washington Institutional Review Board. This study is an observational study that is exploratory in design, and investigates correlations among perceived social support, resilience, depression, and communicative participation, as well as how these factors uniquely predict variance in communicative participation. Factors found previously to relate to communicative participation in individuals diagnosed with HNC (Bolt et al., 2016) were also included in the study (i.e., self-rated speech severity, self-perceived cognitive status, time since diagnosis, and laryngectomy status). All data were collected using self-report measures. Participants provided this information through a web-based procedure or a paper-based format of the same questionnaires.

Participants

Seventy-three individuals previously diagnosed with head and neck cancer completed questionnaires that included measures of self-reported communicative participation, perceived social support, depression, and resilience after giving their consent to participate in the study. Demographic information, such as age, gender, years post onset of diagnosis, living situation, location of cancer, and primary communication methods was gathered for each participant.

Participants also completed additional questionnaires, which were included as part of a larger study examining communication outcomes after head and neck cancer. Participants needed to be at least 18 years old and must have been diagnosed and treated for any type of head and neck cancer (oral cavity, pharynx, larynx, nasal passages, or salivary glands). They must have lived at home at the time of completion and been able to speak, read, and write English. Finally, participants must have been at least 2 years post-treatment for their cancer. According to a qualitative study by Isaksson, Salander, Lilliehorn, and Laurell (2016), 64% of participants who were 2-2.5 years post-HNC treatment rated their everyday lives at least as good as their lives prior to diagnosis. This suggests an adjustment to the effects of the HNC and its treatment. Therefore, a 2-year time period was chosen for this study, giving participants time to adjust to any new patterns developed after treatment (e.g., involvement in a support group, adjustment to using a new communication strategy).

Procedures

Participant recruitment was achieved by contacting various clinicians and support groups throughout the United States who serve individuals treated for HNC. Interested participants were mailed a packet of questionnaires and a demographic survey or were given a link to complete them online through Assessment Center (assessmentcenter.net), based on the participant's preference. Therefore, questionnaires could be filled out online or completed on paper. Paper questionnaire responses were entered into the database by a research assistant.

Questionnaires

Communicative Participation. Self-reported communicative participation was gathered using the Communicative Participation Item Bank— General Short Form (CPIB; Baylor et al., 2013). This questionnaire includes 10 questions. Participants are asked to judge how much their

condition interferes with various communication tasks, such as talking with people they know, talking with people they don't know, communicating in small groups, and getting a turn in fast-moving conversations. Participants rate interference on a scale of 0-3, with 0 indicating that their condition interferes with this activity very much, and 3 indicating not at all. The scores are then transformed to standard scores (T-scores; mean of calibration sample = 50, SD = 10). The CPIB has been shown to have strong psychometric properties, and the developers concluded that it can be useful "to develop theoretical models of participation, to understand the roles that various contributing factors play in communicative participation, and to understand the impact of various types of intervention on participation" (Baylor et al., 2009, p. 1318). A sample of individuals diagnosed with HNC (n = 197) was included as part of the validation study that included development of the short form used in this study (Baylor et al., 2013). The normative data for this measure also included participants with multiple sclerosis (n = 216), Parkinson's disease (n = 218), and amyotrophic lateral sclerosis (n = 70).

Social Support. Perceived social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS), developed by Zimet, Dahlem, Zimet, and Farley (1988). This questionnaire consists of 12 questions that ask participants about their perceptions of availability of social support from family, friends, and a significant other. Participants read each statement and then rate it on a scale of 1-7, with 1 indicating very strong disagreement, and 7 indicating very strong agreement. It included statements such as "There is a special person who is around when I am in need" and "I can talk about my problems with my friends." 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. Total scores range from 12 (lowest level of social support) to 84

(highest level of social support). The developers indicate good internal and test-retest reliability, and moderate construct validity. Osman, Lamis, Freedenthal, Gutierrez, and McNaughton-Cassill (2014) confirmed strong internal reliability and stated that their study indicated “strong support for the use of the MSPSS as a unidimensional instrument” (p. 111).

Resilience. Self-reported resilience was measured through the Connor-Davidson Resilience Scale, Short Form (CD-RISC, Connor & Davidson, 2003). Participants are asked to rate a series of 10 statements as not true, rarely true, sometimes true, often true, or true nearly all the time. This measure includes statements such as “I can deal with whatever comes my way” and “I think of myself as a strong person when dealing with life’s challenges and difficulties.” The total score is the total summed score across all of the responses (out of a total possible of 40), with higher scores being better. The developers reported good psychometric properties of the original form, including test-retest reliability and internal consistency. They also found that scores were sensitive to change, improving after psychological treatment in individuals with post-traumatic stress disorder (PTSD). The short form, used in this study, has also demonstrated good internal consistency and construct validity (Campbell-Sills, Cohan, & Stein, 2007). White et al. (2008) advocated the use of the CD-RISC, stating that it is “the most promising measure of resilience, with the 10-item short form offering potential as a valid and reliable measure that is easy to administer” (p. 15).

Depression. Self-reported measures of depression were gathered using the depression subscale of the Hospital Anxiety and Depression Scale (HADS-D; Zigmond & Snaith, 1983). This scale includes 7 questions, and participants rate their perspectives regarding certain feelings or situations on a Likert scale of 0-3. Higher scores indicate higher self-perceived levels of depression. The measure includes statements such as “I still enjoy the things I used to enjoy” and

“I look forward with enjoyment to things.” A meta-analysis of this tool with cancer oncology and palliative care patients suggested that this measure has been determined to have suitable specificity and sensitivity levels to serve as part of a screening tool for depression (Mitchell, Meader, & Symonds, 2010).

Known factors. The factors determined to contribute to communicative participation in Bolt et al.’s (2016) study were also included in the data analysis. Identical measures were used except for speech severity; the previous study used a Likert scale to judge severity. Laryngectomy status (binary) and time since diagnosis (a continuous variable) were gathered as demographic variables. Self-perceived cognitive status was measured using the Neuro-QoL Cognition Function- Short Form questionnaire (Cella et al., 2012). This questionnaire consists of 8 questions and statements, which participants were asked to rate on a scale of 1-5. Higher scores are related to higher self-perceived cognitive function. Finally, self-perceived speech severity was rated using a 100 mm visual analog scale. The question asked participants to rate their speech intelligibility from *easily understandable* to *extremely difficult to understand* by marking the appropriate part of the line. Scores were determined by measuring the mark’s distance from the beginning of the line in millimeters, with higher scores indicating higher perceived severity.

Data Analysis

Data were entered into SPSS Version 13.0. The CPIB short form T-scores were used to measure communicative participation. Z-scores (standard scores) were derived for each of the MSPSS, CD-RISC 10, HADS-D, and Neuro-QoL to measure perceived social support, resilience, depression, and cognitive function, respectively. Time since diagnosis was retained as a continuous variable measured in years, and laryngectomy status was effect coded. To determine the relationships among the variables, a correlational Pearson analysis was first

performed. Multiple regression with sequential predictor entry was then performed to determine how strongly and uniquely the variables of interest predicted communicative participation. Sequential predictor entry allows for testing specific incremental variance accounted for as one or more predictors are added to the model. To ensure that linear regression model assumptions were tenable, normality, linearity, and homoscedasticity of residuals were examined for each model. The significant predictor variables from Bolt et al. (2016) formed block 1 (self-perceived speech severity and cognitive status, laryngectomy status, and years post-diagnosis). The new variables of interest in this study (focal predictors) formed block 2 (perceived social support, resilience, and depression). The interactions of these three variables formed block 3. The final model was as follows:

$$\begin{aligned} \text{Communicative Participation} = & b_0 + b_1 * \text{Laryngectomy status} + b_2 * \text{Time since} \\ & \text{diagnosis} + b_3 * \text{Speech severity} + b_4 * \text{Cognitive Function} + b_5 * \text{Social support} + \\ & b_6 * \text{Resilience} + b_7 * \text{Depression} + b_8 * \text{Depression} \times \text{Social support} + \\ & b_9 * \text{Depression} \times \text{Resilience} + b_{10} * \text{Depression} \times \text{Social support} \times \text{Resilience}. \end{aligned}$$

In the model above, communicative participation is equal to the conditional mean (b_0), plus the unique effects of laryngectomy status, time since diagnosis, perceived severity of speech symptoms, and perceived cognitive function ($b_1 - b_4$), plus the unique effects of perceived social support, resilience, depression, and the interaction terms ($b_5 - b_{10}$). Change scores reveal how strongly each block of variables uniquely contribute to the overall model. Partial correlations and partial correlations squared (effect size) are used to show the unique contribution of each variable with all others being held constant.

Results

Participant Demographics

Of the 79 questionnaires provided to potential participants, 73 were completed and returned (response rate = 92 %). The mean age of all participants was 65.8 years ($SD = 9.5$), and the mean time since diagnosis was 13 years ($SD = 9$ years, range= 2 – 56 years). The mean age and predominance of male participants are consistent with the demographics of those treated for head and neck cancer (American Cancer Society, 2016; Ries et al., 2007). Most individuals were Caucasian/White and lived with family. Sixty percent of the participants had undergone a total laryngectomy. Additional demographic information is presented in Table 1 below.

Table 1. Demographic data of participants

| Demographic variable | | Frequency | Percent |
|----------------------|--------------------------------|-----------|---------|
| Gender | Male | 48 | 65.8 |
| | Female | 22 | 30.1 |
| | Unknown | 3 | 4.1 |
| Race | White | 71 | 97.3 |
| | Asian | 1 | 1.4 |
| | American Indian/Alaskan Native | 1 | 1.4 |
| Ethnicity | Not Hispanic | 64 | 87.7 |
| | Unknown | 9 | 12.3 |
| Living situation | With Family | 59 | 80.8 |
| | Live Alone | 13 | 17.8 |
| | Other | 1 | 1.4 |
| Primary comm. method | TEP | 26 | 35.6 |
| | Natural speech | 23 | 31.5 |
| | Electrolarynx | 14 | 19.2 |
| | Esophageal speech | 6 | 8.2 |
| | AAC | 2 | 2.7 |
| | Writing | 2 | 2.7 |
| Cancer location | Larynx | 39 | 53.4 |
| | Pharynx | 15 | 20.5 |
| | Multiple locations | 11 | 15.1 |
| | Tongue | 4 | 5.5 |
| | Mouth | 3 | 4.1 |

| | | | |
|---------------------|---|----|------|
| | Unknown | 1 | 1.4 |
| Relationship status | Married/committed | 54 | 74.0 |
| | Single/widowed/divorced | 19 | 26.0 |
| Work status | Not working | 44 | 60.3 |
| | Working full-time | 11 | 15.1 |
| | Working part-time | 6 | 8.2 |
| | Unknown | 5 | 6.8 |
| | Volunteer | 4 | 5.5 |
| | Home-based business | 3 | 4.1 |
| Laryngectomy status | Total laryngectomy | 44 | 60.3 |
| | No laryngectomy | 26 | 35.6 |
| | Unknown | 3 | 4.1 |
| Treatment type | Surgery and radiation | 30 | 41.1 |
| | Surgery, radiation, & chemotherapy | 22 | 30.1 |
| | Radiation and chemotherapy | 7 | 9.6 |
| | Surgery | 6 | 8.2 |
| | Surgery, radiation, & other | 4 | 5.5 |
| | Surgery, radiation, chemotherapy, & other | 3 | 4.1 |
| | Radiation | 1 | 1.4 |

Descriptive Results

Table 2 presents a summary of the descriptive results for the instruments included in this study. The mean CPIB short form T-score for the participants was 49.3 (SD = 11.6), suggesting

that this group of participants was similar to the group on which the CPIB was normed (average = 50; SD = 10; Baylor et al., 2013).

Table 2. Descriptive summary of results, including variable of interest, instrument and scoring format, average score (SD), range (min – max), and number of participants with complete data in sample (n).

| Variable | Instrument and scoring format | M (SD) | Range | Sample (n) |
|-------------------------------|--|---------------|-------------|------------|
| Communicative participation | CPIB short form; scores reported in T-scores with 50 as average (SD = 10); higher scores more desirable | 49.26 (11.61) | 24.2 - 71 | 70 |
| Self-reported speech severity | Visual analog scale; 0 = easily understandable, 100 = extremely difficult to understand; high scores worse | 34.18 (30.07) | 0 – 95 | 73 |
| Cognitive function | Neuro-QoL short form; T- scores reported; 50 = average (SD = 10); higher scores indicate higher perceived function | 49.77 (8.10) | 29.1 – 64.2 | 73 |
| Depression | HADS-D; depression domain based on 7 items with 4 point Likert scale from 0 = “not at all” to 3 = “most of time”; total ranges from 0-21, higher scores indicate more depression | 4.08 (3.60) | 0 – 18 | 72 |
| Perceived Social Support | MSPSS: total score ranges from 1-7 based on average; higher scores indicate more perceived social support | 5.56 (1.25) | 2.08 – 7.00 | 71 |
| Resilience | CD-RISC 10 item short form scores ranges from 0 – 50 based on average; higher scores indicate higher resilience | 32.25 (5.85) | 13-40 | 73 |

Table 3. Zero-order correlations among the measures included in the regression

| Measure | M | (SD) | 1. CPIB | 2. SRSS | 3. Time since dx | 4. Laryng. status | 5. Neuro-QoL | 6. HADS-D | 7. MSPSS | 8. CD-RISC | 9. HADS-D x MSPSS | 10. HADS-D x CD-RISC |
|-----------------------------|--------|---------|---------|---------|------------------|-------------------|--------------|-----------|----------|------------|-------------------|----------------------|
| <i>Outcomes</i> | | | | | | | | | | | | |
| 1.CPIB | 49.10 | (11.63) | -- | -- | -- | -- | -- | -- | -- | -- | -- | -- |
| <i>Block 1 Predictors</i> | | | | | | | | | | | | |
| 2.SRSS | 34.87 | (29.90) | -.64*** | -- | -- | -- | -- | -- | -- | -- | -- | -- |
| 3.Time since dx | 12.78 | (9.25) | .072 | .084 | -- | -- | -- | -- | -- | -- | -- | -- |
| 4.Laryng. status | .24 | (.98) | .059 | .001 | .10 | -- | -- | -- | -- | -- | -- | -- |
| 5.Neuro-QoL | -.014 | (.98) | .20* | -.058 | .14 | .19 | -- | -- | -- | -- | -- | -- |
| <i>Block 2 Predictors</i> | | | | | | | | | | | | |
| 6.HADS-D | .019 | 1.03 | -.44*** | .15 | -.18 | -.11 | -.55*** | -- | -- | -- | -- | -- |
| 7.MSPSS | -.0029 | 1.01 | .29** | -.060 | .13 | .017 | .19 | -.43*** | -- | -- | -- | -- |
| 8.CD-RISC | .013 | .98 | .12 | -.051 | .054 | -.035 | .51*** | -.67*** | .10 | -- | -- | -- |
| <i>Block 3 Predictors</i> | | | | | | | | | | | | |
| 9.HADS-D x MSPSS | -.44 | 1.02 | -.004 | -.032 | -.011 | .025 | .126 | -.40*** | .36** | .22 | -- | -- |
| 10.HADS-D x CD-RISC | -.67 | 1.76 | -.009 | .063 | .11 | .067 | .33** | -.56*** | .12 | .48*** | .37** | -- |
| 11.HADS-D x CD-RISC x MSPSS | .21 | 1.70 | -.069 | .017 | -.055 | -.11 | -.27* | .55*** | -.34** | -.51*** | -.51*** | -.78*** |

Note. N=68 (complete data). * $p < .05$, ** $p < .01$, *** $p < .001$

Variables Related to Communicative Participation

Zero-order correlations. Table 3 presents the means (CPIB short form T scores, self-reported speech severity (SRSS), time since diagnosis) and standardized means/Z-scores (Neuro-QoL, HADS-D, MSPSS, CD-RISC), standard deviations, and zero-order correlations for the measures of interest in this study. Only those participants with complete data ($n = 68$) were included in the final analysis.

Several variables were shown to be significantly related to the main outcome measure of communicative participation. Significant, but weak, positive correlations were found between communicative participation and perceived cognitive function ($r = 0.20, p = 0.047$) as well as between communicative participation and perceived social support ($r = 0.29, p = 0.008$). In other words, increased perceived cognitive function and perceived social support were associated with better communicative participation. Communication participation was also significantly and moderately related to depression ($r = -0.44, p < 0.001$) and was moderately to strongly related to self-reported speech severity ($r = -0.64, p < 0.001$). Both of these relationships were negative; increased depression (worse scores) and increased speech severity (worse scores) were associated with lower communicative participation. Finally, resilience was not found to be significantly related to communicative participation ($r = 0.12, p = 0.176$).

Other significant relationships found among the variables of interest included a significant and moderate positive relationship between resilience and perceived cognitive function ($r = 0.51, p < 0.001$), as well as significant, moderate, negative relationships between depression and perceived cognitive function ($r = -0.55, p < 0.001$) and between depression and resilience ($r = -0.67, p < 0.001$). Depression also was found have a significant, but low to moderate negative correlation with perceived social support ($r = -0.43, p < 0.001$). That is, as depression increased, perceived social support decreased.

Regression

The first block of predictors involved in the regression analysis included variables previously linked with communicative participation: self-rated speech severity, self-rated cognitive function, laryngectomy status, and time since diagnosis (Bolt et al., 2016). Regression analysis revealed that this block of predictors accounted for significant variance in communicative participation, $R^2 = 0.45$ (Adjusted $R^2 = 0.42$), $F(4, 63) = 13.01$, $p = 0.001$ (see summary in Table 4). Therefore, these variables accounted for 45% of the variance in communicative participation. The second block of predictors included the measures of particular interest in this study: depression, perceived social support, and resilience. Together, the main effect of these variables significantly accounted for an additional 12% in variance in communicative participation above and beyond variables in block 1; $R^2_{\text{change}} = 0.12$, $F_{\text{change}}(3, 60) = 5.82$, $p = 0.001$ ($R^2_{\text{total}} = 0.58$ and $R^2_{\text{adjusted}} = 0.53$). Finally, the third block consisted of interactions between the measures included in block 2. The interactions demonstrated an additional 6% increase in variance accounting for communicative participation above variables in blocks 1 and 2; $R^2_{\text{change}} = 0.06$, $F_{\text{change}}(3, 57) = 2.93$, $p = 0.041$ ($R^2_{\text{total}} = 0.63$ and $R^2_{\text{adjusted}} = 0.57$). In total, the three blocks of variables accounted for 63% of the variance in CPIB scores.

Table 4. Model Summary

| Model | <i>R</i> | <i>R</i> ² | Adj. <i>R</i> ² | SE Est | <i>R</i> ² Change | <i>F</i> Change | df 1 | df 2 | Sigt. F Change (<i>p</i> value) |
|-------|----------|-----------------------|-------------------------------|--------|---------------------------------|--------------------|------|------|-------------------------------------|
| 1 | .67 | .45 | .42 | 8.87 | .45 | 13.01 | 4 | 63 | .001 |
| 2 | .76 | .58 | .53 | 8.00 | .12 | 5.82 | 3 | 60 | .001 |
| 3 | .80 | .63 | .57 | 7.64 | .057 | 2.93 | 3 | 57 | .041 |

Results from the final block, with all predictors entered in the model (see Table 5) showed that self-rated speech severity uniquely predicted communicative participation, holding all else constant, with 28% of the variance uniquely predicted ($b = -0.214$, $SE = 0.033$, $t(61) = -6.57$, $p < 0.001$, $sr^2 = 0.28$). Second, depression also uniquely predicted communicative participation, holding all else constant ($b = -7.03$, $SE = 1.66$, $t(61) = -4.24$, $p < 0.001$, $sr^2 = 0.12$), with 12% of the variance uniquely predicted. Unlike the prior study (Bolt et al., 2016), laryngectomy status ($b = -0.31$, $SE = 1.01$, $t(57) = -0.13$, $p = 0.897$), years post-diagnosis ($b = 0.030$, $SE = 0.11$, $t(57) = 0.28$, $p = 0.777$), or self-reported cognitive function ($b = 0.015$, $SE = 1.66$, $t(57) = 0.012$, $p = 0.990$) did not account for significant unique variation in communicative participation, holding all else constant. In addition, resilience was not found to be a significant unique predictor ($b = -2.79$, $SE = 1.50$, $t(57) = -1.86$, $p = 0.068$), nor was perceived social support ($b = 1.06$, $SE = 1.20$, $t(57) = 0.877$, $p = 0.384$).

Table 5. Standardized/unstandardized coefficients and correlations for Model 3

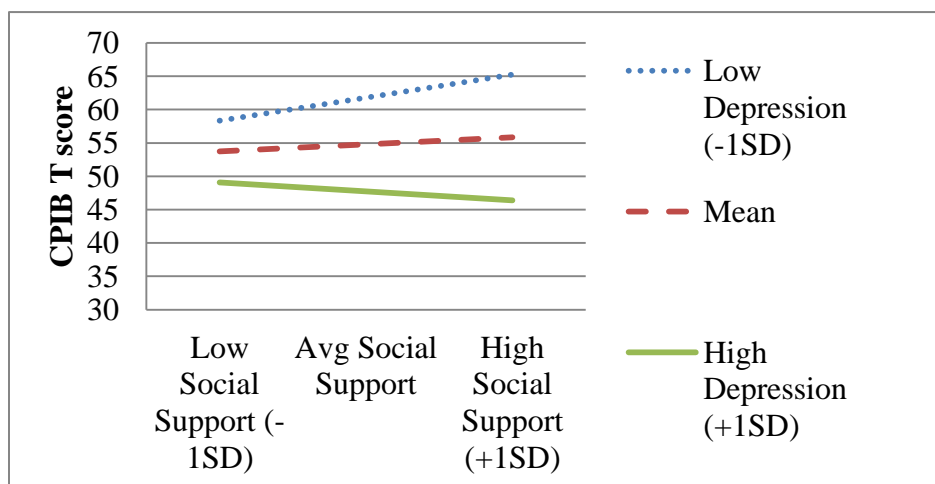
| Coefficients (a) | | | | | | | | |
|---|----------------------------|-----------------------------|------------|---------------------------|--------|-------|--------------|--------|
| | | Unstandardized Coefficients | | Standardized Coefficients | | | Correlations | |
| Model | | B | Std. Error | Beta | t | Sig. | Partial | Part |
| 3 | (Constant) | 54.589 | 2.057 | | 26.543 | 0 | | |
| | Laryngectomy status | -0.132 | 1.013 | -0.011 | -0.13 | 0.897 | -0.017 | -0.01 |
| | Years post-dx | 0.03 | 0.105 | 0.024 | 0.284 | 0.777 | 0.038 | 0.023 |
| | Zscore(NeuroQoL) | 0.015 | 1.217 | 0.001 | 0.012 | 0.99 | 0.002 | 0.001 |
| | Self-rated speech severity | -0.214 | 0.033 | -0.55 | -6.572 | 0 | -0.657 | -0.527 |
| | Zscore(HADSD) | -7.032 | 1.66 | -0.621 | -4.237 | 0 | -0.489 | -0.34 |
| | Zscore(CDRISC) | -2.79 | 1.501 | -0.235 | -1.859 | 0.068 | -0.239 | -0.149 |
| | Zscore(MSPSS) | 1.055 | 1.204 | 0.091 | 0.877 | 0.384 | 0.115 | 0.07 |
| | ZHADSD x ZMSPSS | -2.4 | 1.119 | -0.21 | -2.145 | 0.036 | -0.273 | -0.172 |
| | ZHADSD x ZCDRISC | -1.249 | 0.958 | -0.189 | -1.304 | 0.197 | -0.17 | -0.105 |
| | ZHADSD x ZMSPSS x ZCDRISC | -0.419 | 1.058 | -0.061 | -0.396 | 0.693 | -0.052 | -0.032 |
| a. Dependent Variable: CPIB short form T-score | | | | | | | | |

Finally, there was a significant interaction between self-reported depression and perceived social support ($b = -2.40$ ($SE = 1.12$), $t(57) = -2.15$, $p = 0.036$, $sr^2 = 0.03$). Specifically, this interaction term uniquely accounted for 3% ($sr^2 = 0.03$) of the variance in communicative participation, holding all else constant. To understand the nature of the interaction, predicted

values were plotted for each group (high, average, and low self-reported depression) by three levels of perceived social support (low = -1 *SD*, mean, and high = +1 *SD*). As illustrated in Figure 1 below, the interaction was disordinal and indicated that the effect of depression was greater for patients with a higher level of perceived social support. At high levels of social support (+1 *SD*), participants at one standard deviation below average in perceived depression had a predicted advantage of 18.86 points in communicative participation compared to participants who scored one standard deviation above in self-reported depression. At low levels of social support (-1 *SD*), however, participants at one standard deviation below in self-reported depression had a predicted advantage of 9.26 points in communicative participation compared to those one standard deviation above in perceived depression.

The hypothesis that social support would have a positive relationship with communicative participation was supported for individuals with low and average levels of depression. As seen in Figure 1, increasing levels of perceived social support corresponded to an increased in communicative participation for these participants. However, an opposite trend was seen for individuals with high levels of depression. In this group, increasing levels of perceived social support were related to a decrease in communicative participation.

Figure 1. The relationship between low vs. high depression and social support on CPIB scores



Discussion

This study sought to identify variables useful in predicting communicative participation in individuals treated for HNC. Specifically, this investigation focused on the possible unique contribution of several psychosocial variables, including perceived social support, depression, and resilience. Overall, results from this study were consistent with those reported previously (Bolt et al., 2016), with 45% of the variance accounted for in communicative participation by self-reported speech severity, perceived cognitive function, laryngectomy status, and time since diagnosis. With the addition of the psychosocial variables and their interactions included in the model, an additional 18% of the variance in communicative participation was predicted. In total, 63% of the variance in communicative participation was predicted by the variables in this study. These results highlight the importance of considering psychosocial variables in models of communicative participation, and have future clinical and research implications in this population.

Descriptive Summary

Participants in this study reported mean CPIB short form T-scores of 49.3 ($SD = 11.6$), suggesting that this group of participants was similar to the group on which the CPIB was normed (average = 50; $SD = 10$; Baylor et al., 2013). In addition, the mean age of all participants was 65.8 years ($SD = 9.5$), and the mean time since diagnosis was 13 years ($SD = 9$ years), which is similar to other studies investigating outcomes in HNC survivors (Bolt et al., 2016). Participants reported mild to moderate speech severity (mean = 34.18, with 0 = easily understandable to 100 = extremely difficult to understand), and average perceived cognitive function (mean T-score on NeuroQoL = 49.77). On average, the participants reported overall good perceived social support (mean MSPSS = 5.56), which is consistent with scores from a group of individuals with multiple sclerosis in a previous study (mean = 5.49; Baylor et al.,

2010). Results also showed that participants' perceived resilience was average (mean = 32.35) and comparable to a general American adult population of similar age (mean = 30.8 – 32.1; Jeste et al., 2013). Finally, the participants reported an average level of perceived depression within the normal range (mean = 4.08; a cut-off of 8 has been established as having a specificity of 0.79 and sensitivity of 0.83 for the HADS-D; Bjelland, Dahl, Haug, & Neckelmann, 2002). However, it must be noted that 11 participants (15%) of the participants reported a score of 8 or above on the HADS-D, consistent with perceived depression. This value is consistent with Rieke et al.'s (2016) study, which found that 10.6% of patients with HNC were diagnosed with depression two years prior to cancer diagnosis, and an additional 8.9% developed depression within a year after the cancer diagnosis. How these variables relate to one another, including communicative participation, will be discussed next.

Relationships Among Variables

Relationships among variables investigated in this study revealed many interesting results. First, self-rated speech severity had a moderately strong negative relationship with communicative participation among HNC survivors in our study ($r = -0.64$, $p < .001$). It is not surprising that increased speech severity (worse scores) were associated with reduced perceived function in everyday communication situations. This relationship has been shown previously; for example, in 197 HNC patients, Bolt et al. (2016) also reported a moderately strong relationship ($r = 0.600$) between self-rated speech scores with communicative participation. This result also is consistent with other studies in other populations; Baylor et al. (2010) found a moderate correlation ($r = -0.474$) between perceived severity of slurred speech and reduced communicative participation in individuals with multiple sclerosis. Eadie et al. (2016) also found that there was a moderately strong correlation ($r = 0.596$) between patient-rated speech

acceptability and communicative participation in a group of 36 individuals who had undergone total laryngectomies.

Next, depression was found to be negatively and significantly correlated with several variables, including a moderate relationship with communicative participation ($r = -0.44$). This result is consistent with findings reported by Baylor et al. (2010), who noted a similar relationship ($r = -0.56$) in individuals with multiple sclerosis. The moderate relationship between depression and communicative participation is important to consider. One possible explanation for this link is that depression may be associated with reduced motivation and social participation (DiMatteo & Haskard-Zolnieriek, 2011). This, in turn, may lead to decreased willingness to overcome communication difficulties and therefore decreased participation in life events where communication is required (i.e., decreased communicative participation). However, a causal link cannot be determined in the present study; it is unknown whether depression causes reduced communicative participation, or if reduced communication in everyday settings leads to depression. The direction of this relationship needs study in future investigations.

Depression was also found to have a significant, negative, and moderate correlation ($r = -0.55$) with perceived cognitive status. A connection between depression and cognitive skills has been recognized in previous research; individuals with depression may experience deficits in aspects such as memory and executive functioning (Austin, Mitchell, & Goodwin, 2001). This study also revealed a significant, moderately strong, negative relationship between depression and resilience ($r = -0.67$); that is, higher levels of depression were related to lower levels of resilience. The results of this study revealed a stronger relationship between depression and resilience than that found in a study that included 42 individuals who had spinal cord injuries ($r = -0.35$; White et al., 2010). Given that the participants in that study were in the acute phase of

their stay in hospital and had different types of disabilities, it is difficult to make a comparison across the studies. Yet, it is consistent with the construct of resilience: it is impacted by a person's affect and well-being.

Depression also was shown to have a significant, moderately negative correlation with perceived social support ($r = -0.43$). As depression increased, perceived social support decreased. This finding is supported by a previous study, which found that depression (as measured by the HADS) was significantly and negatively related to perceived social support in a sample of over 40,000 Norwegians (Grav, Hellzèn, Romild, & Stordal, 2012). Social isolation and withdrawal, as well as reduced use of community resources, were common symptoms of depression reported by DiMatteo and Haskard-Zolnierrek (2011), which lends further support to this relationship. Finally, this relationship has also been reported by some individuals with depression themselves—a qualitative study researching depression in people treated for HNC revealed that some participants have perceived rejection from family and friends (Lang, France, Williams, Humphris, & Wells, 2013).

Though no known studies have examined the relationships between resilience and communicative participation, it was predicted that these two factors would be positively correlated with each other. The results, however, demonstrated that resilience was not significantly correlated with communicative participation ($r = 0.12$, $p = 0.176$). In contrast, resilience was demonstrated to be significantly and moderately related to perceived cognitive function ($r = 0.51$), and it showed a moderately strong negative relationship with depression ($r = -0.67$). How these variables interact and may influence outcomes will be discussed in the next section.

Finally, as predicted, perceived social support was significantly related to communicative participation, demonstrating a weak correlation ($r = 0.29, p = 0.008$). These findings mirror those of Baylor et al. (2010), who reported social support to be weakly related to communicative participation ($r = 0.28, p \leq 0.01$). Therefore, results suggest a comparable relationship between these two variables in both the HNC and multiple sclerosis populations.

The conceptualization and definition of resilience is disparate in the literature; as discussed previously, some consider social support as an important contributing factor to this construct. For example, White, Driver, and Warren (2008), among other researchers, posit that that resilience includes family support and cohesion as well as external support systems. These factors have also been linked in previous studies, such as Craig, Blumgart, and Tran (2011), who found that higher levels of social support significantly predicted higher levels of resilience, with social support contributing to approximately 2% of the variance in resilience scores. In this study, however, resilience and social support were not found to be significantly related ($r = 0.10, p = 0.204$). Together, these results suggest that the MSPSS and CD-RISC are measuring different constructs, at least among participants in this study, and that these two factors can legitimately be considered distinct (one as a personal factor in the ICF model, and one as an environmental factor; World Health Organization, 2001).

Predicting Communicative Participation

The primary purpose of this study was to examine the extent to which the variables of perceived social support, resilience, and depression together predicted communicative participation beyond factors already established. Bolt et al. (2016) found that self-rated speech severity, self-rated cognitive function, laryngectomy status, and time since diagnosis all predicted communicative participation, with these variables accounting for 46.2% of the

variance. These factors were included in this study as block 1, and analysis indicated that these four variables accounted for 45% of the variance in communicative participation, corroborating results from Bolt et al.'s (2016) study. Specifically, Bolt et al. (2016) found that self-rated speech severity was the single variable that contributed most to variance in communicative participation scores, contributing to 22.7% of the variance. In this study, self-rated speech severity contributed to 28% of the variance in communicative participation, holding all else constant. As discussed previously, these two variables had a negative relationship, with greater perceived speech severity being related to poorer communicative participation scores. This trend was also noted by Eadie et al. (2016), who found a significant correlation between participants' perceptions of their speech acceptability and communicative participation. Interestingly, listener ratings of intelligibility and acceptability in that study did not have a significant relationship with communicative participation. It is understandable that individuals' own assessments of the severity of their speech may be associated with how they view their success or interference in life activities that require communication.

The other three variables from Bolt et al. (2016) that were found to uniquely predict communicative participation included laryngectomy status, time since diagnosis, and self-perceived cognitive status. None of these variables were found to uniquely predict communicative participation in the current study. In the case of time since diagnosis or laryngectomy status, the results of this study were not surprising; they were only weak predictive factors in the previous study (predicting 0.7% and 3.5% variance in communicative participation, respectively; Bolt et al., 2016). Given slightly different inclusion criteria (e.g., this study included individuals at least 2 years post-diagnosis, whereas the Bolt et al. (2016) study included those who were 6 months or greater post-diagnosis), these differences might be expected.

Results from this study indicated that cognitive function did not uniquely predict communicative participation; however, in Bolt et al.'s (2016) study, it did uniquely predict communicative participation, accounting for 19% of the variance. It is not clear why this disparity occurred; one possible reason is the difference in inclusion criteria for time post-treatment of head and neck cancer. Bolt et al. (2016) included individuals at least 6 months post-treatment, but this study only accepted participants who were 2 or more years post-treatment. It is possible that cognitive functioning was perceived to be more of a barrier directly after treatment. After at least two years had elapsed, individuals may have felt that their cognitive functioning had improved or that they had learned to adapt to their new cognitive status. This is speculation and needs to be tested using more rigorous research designs.

The variables of interest in this study, perceived social support, resilience, and depression, made up block 2 of the analysis. Results showed that these factors accounted for an extra 12% in variance in communicative participation. Block 3, consisting of interactions between variables in block 2, added an additional 6% in variance. Thus, an additional 18% of the variance was accounted for with psychosocial variables, which support the contention that these variables significantly contribute to the multidimensional construct of communicative participation.

Specifically, the final model included not only self-reported speech severity, but also depression, which alone accounted for 12% of the variance in communicative participation, with all other variables held constant. These findings are particularly important because of the high risk of depression in HNC (Rieke et al., 2016). Studies have shown that HNC patients are at higher risk for suicide compared to other cancers and the general population (Zeller, 2006), and that depression is associated with poorer quality of life and survival (Lazure, Lydiatt, Denman, &

Burke, 2009; Satin, Linden, & Phillips, 2009). As already reported, 15% of the participants in this study reported a score of 8 or above on the HADS-D, which is consistent with perceived depression. Howren, Christensen, Karnell, and Funk (2013) proposed some reasons why depression is prevalent in this population, stating that it “may be a function of the diagnosis itself, the presence of burdensome disease and treatment sequelae, declines in HRQOL [health-related quality of life], and/or the possibility of disease progression [or] recurrence” (p. 301). In other words, the causal nature of depression in this population is difficult to determine; establishing the directionality of these relationships is important for future interventions, such as psychosocial or pharmacological interventions.

In addition, it is important to consider how depression relates to other areas of functioning such as cognition, as well as factors that make up resilience. While resilience alone did not significantly account for unique variability in communicative participation in this study, it is notable that depression and resilience also were moderately to strongly correlated ($r = -0.67$). Because those who are less depressed are also likely to be able to adapt to the lived experience of HNC treatment, this may be a strong confounding factor in determining relationships with outcomes such as communicative participation. This relationship deserves future study.

Finally, one interesting relationship captured by the regression analysis was a significant interaction between depression and perceived social support, which uniquely predicted 3% of the variance in communicative participation. Upon further analysis of this interaction, it was revealed that while increased social support overall had a positive impact on communicative participation, this benefit was maximally experienced by individuals who had low depression (1 *SD* below the mean). In contrast, in participants with high levels of depression (1 *SD* above the

mean), increased social support actually decreased their communicative participation scores. Individuals with depression scores around the mean received some benefit, though less so compared to their less depressed counterparts. Therefore, social support had an enhancing effect on communicative participation only in individuals with low or average levels of depression. At high levels of depression, it might be hypothesized that the more others encourage the person to communicate or participate in everyday settings, the more that person might resist and become further isolated. This result suggests that while social support may be a generally positive influence, one needs to consider involving a professional who can identify and aid patients with depression before outcomes may be maximized. Establishing the nature (causality) of these relationships is key area for future research.

Limitations and Future Research Directions

One of the main limitations of this study was the paucity of diversity in the sample. For example, 60% of the participants in the study had a total laryngectomy. Their results may not necessarily be similar to those with other types of HNC. However, results showed that laryngectomy status was not significantly correlated with communicative participation in this sample. It is hypothesized, therefore, that their experiences were similar enough so as to not influence the external validity of the results. In addition, a large majority of the participants in this study were White (97%) and non-Hispanic (at least 87%). This is not representative of the population of individuals with head and neck cancer, which is much more racially and ethnically diverse (National Cancer Institute, 2014). Finally, the majority of the participants in this study were recruited from physical and online support groups. Individuals who do not take part in such groups may have completely different experiences not necessarily reflected by the results in this study. For example, perceived social support was a major variable in this study, and those who

do not belong to support groups may report different levels of support. Because this sample does not necessarily reflect the diversity of the HNC population, these results should be interpreted with caution. It may be very difficult to overcome this sampling bias, but future research may add to our knowledge by describing the perceptions of individuals underrepresented in this study.

An additional limitation of this study was its cross-sectional nature. Participants were on average 13 years post-diagnosis, and therefore, the majority of individuals had a significant amount of time to adapt to any existing physical changes, as well as psychological side effects. Participants had to be at least two years post-treatment; how these results might differ with those undergoing a treatment regimen and how these variables might change over time remain questions for future research.

The small sample size of this study is also a potential limitation. The N:p ratio was 73:10 \approx 7.3:1 instead of the recommended 15:1, meaning that the power levels for testing the model coefficients were inadequate. In addition, this study used only self-reported data. As such, future research should investigate the association between communicative participation with other variables that are measured objectively, such as speech severity, depression, or cognitive function measured by clinicians. While ratings from listeners have not been shown to relate strongly to communicative participation in past research (Eadie et al., 2016), other metrics of impairment, such as listener effort should be considered.

Finally, the variables in this study accounted for 63% of the variance in communicative participation scores. It is evident that while this study has made strides in identifying contributing factors to this construct, much of the variance still remains unaccounted for. This area may benefit from future research to discover more variables that can be used to predict communicative participation. For example, it may be interesting to study the relationship

between duration and/or perceived usefulness of speech-language pathology treatment sessions on communicative participation in patients with a diagnosis of HNC. Establishing better relationships between the health care provider and the patient may also enhance coping mechanisms and self-management strategies, which may also relate to communicative participation. All of these areas should be investigated in the future.

Implications

The results of this study support the contention that communicative participation is indeed a multidimensional construct, and includes variables that span the ICF model (World Health Organization, 2001). Specifically, this study showed that self-reported speech severity and depression (both body functions and structures measures) were found to be the strongest unique predictors of communicative participation scores. In addition, perceived social support (an environmental factor) was found to predict communicative participation when its interaction with depression was considered. Thus, communicative participation is not solely affected by speech or voice impairments, but also other variables inherent to the individual and his or her environment.

This study has implications for speech-language pathologists (SLPs) who are working with clients who have a history of head and neck cancer. Education may play an important role when working with this population. For example, many patients will likely be comparing their current speech/voice to their pre-HNC state. SLPs can help these patients manage their expectations by working with them to identify their communication strengths and giving them ways to compensate for their deficits. Patients may then be more willing to go out and communicate in their life activities even if their communication has drastically changed. The

nature of these social relationships as well as their impact on a person's resilience must also be a focus of future research.

These results also emphasize the value of referring patients to external resources such as support groups and counselors when warranted. Depression status and social support were shown to be significantly related to communicative participation. Though SLPs can help the patient break down speech and language-related barriers to communicative participation, these psychosocial factors will likely need to be addressed to help the patient make maximal progress towards their goals. For example, including families and caregivers in all stages of recovery is necessary to promote better support and expectations. In addition, it may be beneficial to include other models of intervention such as group therapy to help patients cope emotionally. Ultimately, it is imperative that we consider patients' needs individually in order to find the best ways to help them maximize their communicative participation potential.

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