Late-Effect Symptoms, Tobacco and Alcohol Use, and Demoralization in Head and Neck Cancer Survivors

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Abstract

Worldwide, head and neck cancers are the sixth most common type of cancer and comprise the ninth most common forms of cancer in the United States. Estimates of U.S. adults diagnosed with head and neck cancer in 2017 exceeded 53,000. Head and neck cancers are located in areas of the body associated with essential life functions, which are key to one's quality of life. Depending on the location and stage of the tumor, current standard treatments for head and neck cancer include surgery, radiation, chemotherapy, or a combination of the aforementioned. These treatments may result in multiple late-effect physiological symptoms such as dry mouth, mouth sores, swallowing difficulties, pain, and fatigue. Late-effect symptoms cause physical and psychosocial distress and may be exacerbated by tobacco and alcohol use. Head and neck cancer survivors experience some of the highest rates of major depressive disorders. Demoralization is a psychological syndrome observed in patients with serious illness. It may be experienced as feelings of helplessness, hopelessness, loss of meaning and purpose in life and expressed as an inability to cope. Head and neck cancer survivors are at least two times more likely to commit suicide as compared to the general U.S. population.

A descriptive correlational design, supported by the theory of unpleasant symptoms, was used to examine the occurrence and relationship of late-effect physical symptoms such as but not limited to xerostomia, mucositis, dysphagia, pain and fatigue, tobacco and alcohol use, and demoralization among head and neck cancer survivors. Descriptive statistics were reported for the occurrence and intensity of late-effect physical and life interference symptoms, tobacco and alcohol use, and demoralization. A hierarchical multiple regression was completed to explain the relationship between demoralization, late-effect physical symptoms, and tobacco and alcohol use. This study found when controlling for age, a relationship between life interference (general activity, mood, work including work around the house, relations with other people, walking, and enjoyment of life) and demoralization, the dependent variable. Variables representing situational factors (tobacco and alcohol use), were not significant in the model, nor were the physiological factors of late-effect physical symptoms.

Further research and exploration regarding identification of demoralization in head and neck cancer survivors and its relationship to life interference could prove useful in identifying patients who may be experiencing distress. Furthermore, this identification could help support those who have a lower quality of life in survivorship and may promote referrals to appropriate supportive resources.

Keywords: head and neck cancer, cancer survivors, late-effect symptoms, demoralization, life interference, theory of unpleasant symptoms

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"You must do the thing you think you cannot do." Eleanor Roosevelt

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Chapter 1: Introduction

Survivors of head and neck cancer experience multiple distressing treatment-related symptoms. Furthermore, these individuals have an increased rate of suicide compared to the general population (Kam et al., 2015; Murphy & Deng, 2015). Head and neck cancers are the sixth most common type of cancers worldwide and the ninth most common type of cancer in the United States (American Society of Clinical Oncology, 2016). Head and neck cancers account for approximately 3% of all types of cancers in the United States (American Society of Clinical Oncology, 2016; Stenson, 2020; World Health Organization [WHO], 2014).

Johns Hopkins Medicine (2020) estimated that over 65,000 adults, in the United States, are diagnosed with head and neck cancer each year. The majority of head and neck cancer occur in men, with over 65% occurring in men between the ages of 50 and 70 (Ridge, Mehra, Lango, & Galloway, 2016). However, there is an increased prevalence of adults (men and women) developing human papillomavirus-associated head and neck cancer, with the largest subset in their 40s and 50s (Lewis, Kang, Levine, & Maghami, 2015).

With earlier detection, improved lifestyle behaviors, and advances in treatment, survival rates of cancer patients continue to increase. As of 2016, there were an estimated 15.5 million cancer survivors in the United States, representing 4.8% of the population (Bluethmann, Mariotto, & Rowland, 2016). By 2026, the number of U.S. cancer survivors is estimated to exceed 20 million (American Cancer Society, 2017; Bluethmann, Mariotto, & Rowland, 2016). For head and neck cancer patients, survival rates continue to increase with 64.5% surviving at least five years post-diagnosis (Howlader et al., 2017). As survival rates of cancer patients have increased, so has the emphasis on the importance of one’s quality of life. Quality of life refers to a patient’s well-being before treatment, during treatment, and after treatment (i.e., throughout survivorship; Kline et al., 2018).

Background and Significance

A diagnosis of cancer, the staging of the tumor, and the resulting types of treatment, combined with the resulting physical and psychological impacts, may be lifelong and life altering challenges (Holland, Breitbart, Jacobsen, Lederberg, Loscalzo, & McCorkle, 2010; Murphy & Deng, 2015). Interventions (e.g., surgery, chemotherapy, immunotherapies, and radiation therapy) to treat cancer are associated with multiple, potentially distressing experiences. These interventions can result in lifelong physical side effects, which may profoundly affect a patient's quality of life (Ganz, 2009; Holland et al., 2010; Murphy & Deng, 2015). Head and neck cancer are located in areas of the body involved with functions that are vital not only to living but to one's quality of life (e.g., breathing, chewing, tasting, swallowing, and communicating). Due to the location of head and neck tumors, combined with the often-debilitating treatments that these survivors may have had to endure, life post-treatment for these individuals may result in long-term, if not life-long, physical and psychological post-treatment sequelae (such as demoralization) affecting survivors' quality of life.

Howren et al. (2013) stated that head and neck cancer are psychologically the most traumatic type of cancer to experience. Head and neck cancer survivors who experienced ongoing symptoms or side effects, after finishing treatment, noted poor life quality, regardless of the site of the cancer (Mayer, Nasso, & Earp, 2017). Some research has shown survival in head and neck cancer patients has been predicted by quality of life scores in three domains: pain, eating, and speech (Karvonen-Gutierrez, Ronis, Fowler, Terrell, Gruber, & Duffy, 2008). Predictors of quality of life among head and neck cancer patients also may include: (a) health-related behaviors such as smoking and alcohol use (Ronis, Duffy, Fowler, Khan, & Terrell, 2008), (b) having a feeding tube (Terrell et al., 2004), (c) low socioeconomic status (Wells et al., 2016), and (d) comorbidities such as depression (Murphy, Ridner, Wells, & Dietrich, 2007; Terrell et al., 2004; Verdonck-de Leeuw et al., 2014).

Purpose and Research Questions

Demoralization is a psychological syndrome frequently observed in patients with serious illness which may be expressed as feelings of hopelessness, helplessness, caused by a loss of meaning and purpose in life and an inability to cope (Clark & Kissane, 2002; Robinson et al., 2015). To date, few studies have examined how late-effect symptoms and tobacco and alcohol use are related to symptoms of demoralization in head and neck cancer survivors. Therefore, the purpose of this descriptive, correlational quantitative study was to examine the occurrence and intensity of late-effect symptoms, tobacco and alcohol use, and their relationship to the level of demoralization in head and neck cancer survivors.

Using the theory of unpleasant symptoms (Lenz et al., 1997), which was the guiding theoretical framework for this study, the following research questions were explored:

1. What is the occurrence and intensity of late-effect symptoms, as measured by the M.D. Anderson Symptom Inventory – Head and Neck Module (MDASI-HN), and tobacco and alcohol use among head and neck cancer patients and survivors?
2. What is the occurrence and intensity of demoralization in head and neck cancer patients and survivors?
3. Controlling for age, do late-effect symptoms (Factor I: mouth sores, food tasting, constipation, teeth/gum problems, skin pain; Factor II: voice, choking/coughing, dysphagia [swallowing/chewing], and mucus and Part II: life interference scale) and tobacco and alcohol use in head and neck cancer patients and survivors explain the variance in demoralization?

Significance in Head and Neck Cancer Survivors

Chinn and Myers (2015) noted that survival rates for oral cancers vary depending on a patient’s age, race, stage and location of the cancer, and comorbidities. The current five-year survival rate for patients who are diagnosed with oral cavity or oropharyngeal cancers is 63%, with a ten-year survival rate of 52% (American Society of Clinical Oncology, 2016). The five-year survival rate for all types of head and neck cancer is approximately 60%. According to Haddad and Limaye (2018), in 2013, there were more than a half million head and neck cancer survivors in the United States. This finding noted by Haddad and Limaye (2018) is reflective of the research findings noted by Cohen et al. (2016) and Howren, Christensen, Karnell, and Funk (2013). Head and neck cancer survivors account for approximately 3% of all cancer survivors in the United States (Stenson, 2020).

Overwhelmingly, alcohol and tobacco use increase risk factors associated with head and neck cancer (Stenson, 2020). Use of alcohol and tobacco can distress individuals and can result in poor life quality among cancer survivors. Ridge et al. (2016) noted that tobacco use is closely associated with incidences of head and neck tumors. Furthermore, smokers are six times more likely to develop tumors than nonsmokers (Ridge et al., 2016). Haung et al. (2017) noted the high correlation between liquor consumption and head and neck cancer, as denoted in a study of 811 participants.

Depending on the tumor’s location and stage, the current standard treatments for head and neck cancer include surgery, radiation, chemotherapy, or a combination of the aforementioned options (National Cancer Institute [NCI], 2014). Cancer-related treatments can result in the development of multiple, late-effect physiological symptoms, which include xerostomia (i.e., dry mouth), mucositis (i.e., mouth sores), dysphagia (i.e., difficulty chewing/swallowing), pain, and fatigue. Late-effect physiological symptoms can result in physical and psychosocial distress (Lenz et al., 1997). Head and neck cancer survivors are three times more likely to commit suicide as compared to the general U.S. population (Kam et al., 2015).

As cancer survival rates have increased across many cancers, research has focused on survivorship issues. The Institute of Medicine and National Research Council (2006) panel was specifically convened to examine cancer survivorship issues and to make recommendations for improving patient-related care. One of the recommendations set forth by the IOM and NRC was to increase support for survivorship research, thereby resulting in improved guidelines associated with effective survivorship care. More specifically, the IOM and the NRC stated that additional research must be conducted to further understand the prevalence, risks, and mechanisms of sequelae experienced by cancer survivors. The overarching goal of the panel was to develop interventions to alleviate symptoms and improve functioning/quality of life among survivors, family members, and caregivers.

In 2015, the American College of Surgeons Commission on Cancer first required that cancer centers screen for psychosocial distress as one of the criteria for accreditation (Pirl et al., 2014). As Pirl et al. (2014) reported, identifying distress in cancer patients enhances one’s quality of life and can result in improved health-related outcomes. Further research regarding identification of psychological factors, such as demoralization, in head and cancer survivors could prove useful in identifying patients who experience a lower quality of life during treatment and into survivorship and promote referrals to appropriate supportive resources.

Theoretical Framework

The theory of unpleasant symptoms (TUS), which was created by Lenz, Pugh, Milligan, Gift, and Suppe (1997), served as the framework for this descriptive, correlational study. This study was conducted to examine the relationship of late-effect symptoms and tobacco and alcohol use to demoralization among head and neck cancer survivors. Symptoms are a key component of information in health care as indicators of changes in patients' normal functioning and are the focus of the TUS (Lenz et al., 1997). The primary focus of this study was related to the symptoms experienced by head and neck cancer survivors; therefore, the TUS was appropriate to utilize for this research study.

Liehr (2005) described that the original version of the TUS, that initially was proposed in 1995 by Lenz, Suppe, Gift, Pugh, and Milligan, and was revised and published by Lenz et al. (1997). The theory originally was based on two concepts of unpleasant physiologic symptoms, fatigue and dyspnea. The theory was expanded to describe other unpleasant symptoms (e.g., pain, nausea; Lenz et al., 1997).

Liehr (2005) described the two main assumptions of the TUS that include: (a) different symptoms have common threads, and (b) symptoms are considered subjective phenomena that primarily occurs in family and community settings. Lenz et al. (1997) noted while individual symptoms may differ from one another, dimensions are common and may overlap across symptoms (e.g., in terms of intensity, timing, quality, and level of perceived distress). The term *intensity* describes the severity or strength of the symptom. The term *timing* describes the frequency and duration of the symptom. The term *level of distress perceived* describes the degree of discomfort of the symptom. Symptoms are described as multidimensional experiences (Liehr, 2005). Symptoms do not exist in a vacuum and, instead, impact an individual’s whole life (i.e., physiologic, psychologic, and situational). Once treatment is complete, symptoms can impact an individual for the entirety of his/her life. Various symptom scales are used and operationalized to measure symptom assessment, management, and relief (Liehr, 2005).

Lenz et al. (1997) explained that the TUS theory includes three major components. The first component of this theory is the symptoms being experienced. The second component of this theory is the influencing factors that create or affect the experience of the symptom. The third component of this theory is the outcomes of the symptom experience. The TUS has three categories of variables: physiologic, psychologic, and situational, which may relate to one another and influence the symptom experience (Lenz et al., 1997).

The three categories (e.g., physiologic, psychologic, and situational) that comprised the original TUS are applicable to the experiences head and neck cancer survivors may undergo from diagnosis through treatment and beyond. Late-effect symptoms, caused by the various treatments head and neck cancer patients experience, may last for years, if not indefinitely (Murphy & Deng, 2015). A combination of radiation, surgery, and chemotherapy agents may be used to combat head and neck malignancies. However, these treatments may result in permanent damage to the areas directly treated, as well as to the mucous membranes, surrounding tissues, tongue, gums, lips, and structures (e.g., salivary glands, etc.). Damage resulting in scar tissue in and around these structures may result in physiologic conditions (e.g., loss of teeth, need for a permanent placement of a feeding tube) and physical conditions (e.g., xerostomia/dry mouth, mucositis, dysphagia/difficulty swallowing, pain, and fatigue; Cartmill, Ward, MacGinley, & Porceddu, 2016; Murphy & Deng, 2015).

Head and neck cancer survivors often experience psychological challenges, which may include demoralization. Psychological challenges can influence the survivor’s quality of life. In cancer care, particularly, Ringash (2016) reported that the outcomes historically were described and assessed only in terms of survival and tumor removal or response. In this study, demoralization was conceptualized as a performance indicator in the TUS, thereby contributing to the extension of the theory.

The situational component of the TUS, in this study, relates to the fact that many head and neck cancer survivors still use tobacco and alcohol (Stenson, 2020). In fact, various researchers continue to denote the correlation between tobacco and alcohol use and head and neck cancer (Beynon et al., 2018). Despite the issues associated with tobacco and alcohol use, in regard to increasing one’s recurrence of cancer, patients remain users. Thus, this research study addressed the use of tobacco and alcohol among head and neck cancer patients/survivors.

Liehr (2005) outlined a number of assumptions of the TUS. The two assumptions pertinent to this study include: (a) the perception of the patient is key, and (b) symptom management is a dynamic process. The TUS lends itself particularly well to examining the relationships between the negative, late-effect symptoms (i.e., xerostomia, mucositis, dysphagia, pain, and fatigue), lifestyle factors (i.e., tobacco and alcohol use), and the psychological factor (i.e., demoralization) experienced by head and neck cancer patients and survivors.

Definition of Terms

The following terms are defined for this study. These terms are related to the research questions being explored. Specifically, these terms are outlined as they relate to the study, which is aligned with how they are presented in research.

Cancer Survivor

The term cancer survivor references the individual from his/her time of diagnosis until the end of his/her life (National Cancer Institute, 2016).

Demoralization

The term demoralization references a person's feelings of having failed to meet the expectations set by the individual or those around the person. The term can also describe experiencing a general inability to cope with demands, feelings of helplessness, hopelessness, and a desire to give up (Robinson, Kissane, Brooker, & Burney, 2015).

Depressive Symptoms

Depressive symptoms references when an individual experiences sadness, grief, etc., which often occurs in response to stressful life events (i.e., a cancer diagnosis; Archer, Hutchison, & Korszun, 2008).

Distress

The term distress references emotionally unpleasant psychological, social, and/or spiritual experience. This unpleasant experience might interfere with a patient's ability to effectively cope with cancer, related physical symptoms, and pertinent treatment (National Cancer Institute, 2017; PDQ Supportive and Palliative Care Editorial Board, 2019).

Dysphagia

Dysphagia references the trouble an individual might experience passing food or liquid down his/her throat. Dysphagia often occurs when an individual swallows and experiences gagging, coughing, choking, or a sensation of food being lodged in the throat (American Society of Clinical Oncology, 2017).

Head and Neck Cancer

Head and neck cancer references cancer that occurs in the head or neck area (e.g., nasal cavity, sinuses, lips, mouth, salivary glands, throat, or larynx; National Cancer Institute, 2016).

Head and Neck Squamous Cell Carcinoma (HNSCC)

The term head and neck squamous cell carcinoma references the most common malignant cell type occurring in individuals with malignant tumors that are located in the oral cavity, oropharynx, hypopharynx, larynx, and/or nasopharynx (Marur & Forastiere, 2016).

Intensity-Modulated Radiation Therapy (IMRT)

Intensity-modulated radiation therapy references a type of three-dimensional radiation therapy, which uses computer generated images to show the size and shape of the tumor. When using this type of therapy, narrow beams of radiation of varying intensities are directed at the tumor from multiple angles, thereby reducing the damage to healthy tissue near the tumor (National Cancer Institute, 2016).

Late Effects

Late effects are side effects that occur months or years after cancer treatment. Late effects may include physical, psychological, and/or social difficulties and can include second cancers (American Society of Clinical Oncology, 2016; NCI, n.d.a.).

Long-term Side Effects

Long-term side effects reference residual problems caused by a disease or the treatment of the disease, which may continue after treatment. Examples of long-term side effects of cancer treatment may include pain, numbness, fatigue, dry mouth, hearing loss, etc. Furthermore, long-term side effects can result in heart, lung, and gastrointestinal problems (National Cancer Institute, n.d.b.).

Mucositis

Mucositis references the swelling that occurs inside the mouth and throat, which can result in ulcers and mouth sores. Mucositis often occurs due to radiation in the head and neck area and/or can be due to chemotherapy treatments (American Society of Clinical Oncology, 2016).

Quality of Life

The term quality of life is a multifaceted construct, which describes an individual’s physical health, psychological state, level of independence, social relationships, and relationship to their environment. The basic premise of the term quality of life is satisfaction with one’s well-being (Dunne et al., 2016; National Cancer Institute, 2016).

Radiation Therapy

Radiation is used to kill cancer cells and shrink tumors. Radiation may be delivered externally from a machine (i.e., external-beam radiation therapy) or from internal therapy (i.e., radioactive material placed in the body near cancer cells (National Cancer Institute, 2016).

Symptoms

The term symptoms references “perceived indicators of change in normal functioning as experienced by patients… [that] may occur alone or in isolation from one another but more often are experienced simultaneously” (Hegyvary, 1993, p. 146). Symptoms may be experienced separately or in combination with other symptoms. Although symptoms may differ among individuals, there are commonalities in duration, intensity, quality, and distress (Lenz et al., 1997).

Xerostomia

The term xerostomia references failure of the salivary glands to make enough saliva to keep the mouth moist. Talking, swallowing, chewing, and tasting may be more difficult as a result of xerostomia (American Society of Clinical Oncology, 2017).

Summary

In the United States, head and neck cancer account for approximately 3% of all types of cancers (Stenson, 2020). The location of head and neck cancer combined with the current multimodal nature of treatment (e.g., chemotherapy, radiation, and surgery) may result in an unfortunate and difficult array of late term physical, physiologic, and psychologic effects. These effects, which occur post-treatment, can extend throughout the remainder of a patient's life. Despite the relatively low prevalence of head and neck cancer, survivors have a significantly higher rate of suicide as compared to the general population. Furthermore, head and neck cancer survivors commit suicide at higher rates than that of many other cancer survivor populations. In this study a descriptive, correlational survey design, which was supported by the TUS, was used to explore the relationships between the occurrence and intensity of the late-effect symptoms and alcohol and tobacco use among head and neck cancer patients and survivors, and their impact on demoralization.

Chapter 2: Literature Review

The purpose of this literature review is first to provide a brief overview of the etiology and current treatment modalities of head and neck cancer. After the overview of the etiology and treatment modalities, information regarding late-effect symptoms experienced by head and neck cancer patients and survivors, as well as an overview of tobacco and alcohol use, is provided. Lastly, definitions and a discussion of demoralization and its relevance to cancer patients will be presented.

Overview of Head and Neck Cancer

The American Cancer Society (2017) described the word *cancer* as a group of diseases defined by abnormal cell growth that may result in death if left uncontrolled. Although the exact causes of many cancers remain unknown, numerous causes have been identified. Lifestyle factors such as physical inactivity, excess body weight, tobacco use, and excess alcohol consumption as well as non-modifiable factors such as genetic mutations, environmental conditions, and immune conditions have all been identified to initiate or promote cancer (American Cancer Society, 2017). Cancer is the second most common cause of death in the U.S. with approximately 600,920 Americans cancer deaths in 2017 (American Cancer Society, 2017). In 2015, 61,760 new cases of oral cavity, pharyngeal, and laryngeal cancer were diagnosed, and 13,190 deaths due to head and neck cancer occurred (American Cancer Society, 2016).

Head and neck cancer include multiple types of malignancies with the most common type being squamous cell carcinoma developing in the squamous cells in the mucous membranes of the mouth, throat, and sinus cavities. Squamous cell carcinoma begins in the cells that line the inside of the mucous membranes in the larynx, pharynx, esophagus, oral cavity, salivary glands, nasal cavity, and paranasal sinuses (Argiris et al., 2008; Pinna et al., 2015; see Appendix A). Salivary gland cancers account for 5% of head and neck cancer (Posner, 2016). The prevalence of human papillomavirus-related malignancies is increasing rapidly in younger adults. In fact, according to Lewis et al. (2015), up to 70% of all oropharyngeal cancers are HPV-mediated squamous cell carcinomas.

Types of Head and Neck Cancer

There are various types of head and neck cancer that impact individuals. These types include laryngeal cancer, hypopharyngeal cancer, nasal cavity and paranasal sinus cancer, nasopharyngeal cancer, oral cavity and oropharyngeal cancers, and salivary gland cancer. The various types of cancer are discussed below, specifically detailing information about the prevalence, survival rates, symptoms, risk factors, and more.

Laryngeal Cancer

According to the American Cancer Society (2020), 12,370 new cases of laryngeal cancer and 3,750 deaths due to laryngeal cancer are estimated to occur in 2020. The five-year survival rate for laryngeal cancer is 61% (American Society of Clinical Oncology, 2016). The larynx consists of the supraglottic larynx, the glottis, and the subglottic region, which includes structures such as the epiglottis and vocal cords. Symptoms of laryngeal cancers may include sore throat, painful swallowing and change in voice quality, enlarged neck nodes, and referred ear pain (National Cancer Institute, 2016). Two risk factors, smoking and excess alcohol consumption, have an established association with squamous cell cancers in this area (Spitz, 1994). Patients are at high risk of recurrence in the first two to three years with recurrence after five years being rare. Oncologists advise close regular follow-up examinations (National Cancer Institute, 2016).

Kam et al. (2015) conducted a study entitled “Surveillance, Epidemiology, and End Results (SEER),” that collected program registry data from head and neck cancer patients between 1973 and 2011. The researchers reported that the suicide rate, which was adjusted for age, sex, and race, was 37.9 out of 100,000 persons per years as compared to the U.S. general population suicide rate that was 11.8 out of 100,000 persons per years. In patients treated with radiation therapy, suicide rates were higher compared with those treated with surgery alone. The highest suicide risk was for patients with cancers of the hypopharynx and the larynx. The suicide risk using a standardized mortality ratio (SMR) for hypopharyngeal cancer and cancer of the larynx was 13.91 and 5.48 (Kam et al., 2015).

Hypopharyngeal Cancer

Hypopharyngeal cancer occurs in an area extending from the hyoid bone to the cricoid cartilage below. Hypopharyngeal cancer is rare in the U.S. with fewer than 2,500 new cases diagnosed each year (Mendenhall et al., 2011). The primary risk factors for hypopharyngeal cancers are tobacco and excessive alcohol use. The five-year survival rate is 33% (Blot et al., 1988; Mendenhall, Werning, & Pfister, 2011). Symptoms of hypopharyngeal cancer may include voice changes including hoarseness, a lump in the neck, difficulty swallowing, ear pain, and persistent sore throat. Treatment options for hypopharyngeal cancer include surgery, radiation therapy, and chemotherapy (American Society of Clinical Oncology, 2016).

Nasal Cavity and Paranasal Sinus Cancer

The nasal cavity is located in the space behind the nose, and the paranasal sinuses include maxillary sinuses, ethmoid sinuses, frontal sinuses, and the sphenoid sinuses. Both nasal cavity and paranasal sinus cancer are rare with approximately 2,000 people in the U.S. diagnosed annually. The five-year survival rates for early stage nasal and paranasal sinus cancers are over 60%. Stage III survival rates are approximately 50%, while stage IV survival rates decline to 35% (Mendenhall et al., 2011). Primary risk factors for nasal and paranasal sinus cancer are tobacco and alcohol use with tobacco use being the greatest risk factor. Other risk factors include human papillomavirus infection, age, gender, marijuana use, as well as exposure to air pollution and environmental substances when inhaled such as dust from wood, flour, nickel, asbestos, fumes from formaldehyde, glue, radium, and solvents (American Society of Clinical Oncology, 2017). Symptoms of nasal cavity and paranasal sinus cancers may include: (a) a lump on the face, nose, or inside the mouth or nose, (b) pain or swelling in the face, eyes, or ears, (c) chronic sinus infections that do not respond to antibiotic treatment, (d) persistent sinus congestion, (e) persistent tearing in the eyes, (f) decreased sense of smell, (g) frequent headaches or pain in the sinus region, (h) bulging of one of the eyes or vision loss, and (i) frequent nosebleeds. Treatment options for nasal cavity and paranasal sinus cancers include surgery, radiation, and chemotherapy (American Society of Clinical Oncology, 2016).

Nasopharyngeal Cancer

The nasopharynx is located at the upper part of the throat behind the nose. The Eustachian tubes are located on either side of the nasopharynx and lead into the middle ear on each side. Nasopharyngeal cancer is uncommon in the U.S. with less than one person out of 100,000 diagnosed annually. Major risk factors include alcohol and tobacco use. Other risk factors may include geography/ancestry, as occurrence is most common in people living in Hong Kong and Southeast China; exposure to the Epstein-Barr virus; consuming large amounts of salt-cured meats regularly; and frequent environmental exposure to dust and smoke (American Society of Clinical Oncology, 2016). The most common symptom is a lump in the neck. Other symptoms may include nasal obstruction/stuffiness, difficulty hearing or hearing loss, fullness or pain in the ear caused by middle ear fluid, frequent headaches, blurred or double vision, and persistent sore throat. The five-year survival rate is 60% for nasopharyngeal cancer. The primary treatment for nasopharyngeal cancer is radiation therapy, which is often combined with chemotherapy and surgery.

Oral Cavity and Oropharyngeal Cancers

Two of the most common types of head and neck cancer are oral cavity and oropharyngeal cancers (American Society of Clinical Oncology, 2016). The oral cavity includes the hard palate, the floor of the mouth under the tongue, the front two-thirds of the tongue, the upper and lower gums (gingiva), the lining of the lips and cheeks (buccal mucosa), and the lips (American Society of Clinical Oncology, 2016). The oropharyngeal area includes the base of the tongue, the tonsils, the part of the throat behind the mouth, and the soft palate at the back of the mouth. According to the American Society of Clinical Oncology (2018), in 2019, approximately 53,000 adults were projected to be diagnosed with oral or oropharyngeal cancer. Furthermore, in 2019, the American Society of Clinical Oncology found that the overall five-year survival rate for oral cavity and oropharyngeal cancers was 65%. Risk factors for oral cavity and oropharyngeal cancers include tobacco and alcohol use and may also include prolonged sun exposure and HPV (American Society of Clinical Oncology, 2016). Symptoms include persistent sore throat, hoarseness or change in voice quality, numbness of the tongue or mouth, pain or bleeding in the mouth, lump on neck, throat, mouth or lip, and difficulty chewing or swallowing. Treatment options for oral cavity and oropharyngeal cancers include surgery, radiation therapy, and chemotherapy.

Salivary Gland Cancer

Three pairs of salivary glands are referred to as the major salivary glands, the parotid, the submandibular, and the sublingual glands. The parotid glands are the largest of the pairs located below and in front of each ear with most malignant tumors starting here (American Society of

Clinical Oncology, 2016). Salivary gland cancer is rare in the U.S. with an estimated prevalence of one adult out of 100,000 diagnosed annually. The five-year survival rate for salivary gland cancer is 72%. Risk factors include older age; radiation exposure; and environmental exposure to sawdust and chemicals, pesticides, and solvents (American Society of Clinical Oncology, 2016). Symptoms of salivary gland cancer include: (a) a lump on the face, neck, or mouth, (b) facial numbness and progressive facial paralysis, (c) pain or swelling in the face, chin, neck, or jawbone, and (d) a difference in size between the right and left sides of the face and neck. Treatment options for salivary gland cancer include surgery and radiation therapy, as well as chemotherapy (American Society of Clinical Oncology, 2016).

Diagnosis and Staging

The American Society of Clinical Oncology (2016) described five main types of head and neck cancer, which are identified according to the area where they develop. These five main types of head and neck cancer include the following: (a) laryngeal and hypopharyngeal, (b) nasal cavity and paranasal sinus, (c) nasopharyngeal, (d) oral and oropharyngeal, and (e) salivary glands (see Appendix A). Once head and neck cancer are diagnosed, staging follows to determine the site of origin (location of the primary tumor) and the extent to which the cancer has spread throughout the body. Staging is based on four main factors including: (a) location of the primary tumor, (b) the size and extent of the tumor(s), (c) lymph node involvement, and (d) whether the cancer has metastasized or spread to other areas of the body (American Joint Commission on Cancer, 2016).

The American Joint Commission on Cancer (AJCC, 2018) and the Union for International Cancer Control (UICC, 2018) developed and have maintained the current staging system that commonly is utilized worldwide. The TNM classification system, which was created by the AJCC (2018), is based on the extent of the tumor (T), the spread to the lymph nodes (N), and whether the tumor has metastasized (M). An updated staging system was implemented on January 1, 2018, and included a new classification called prognostic staging, which can be used in patient-care as applicable. This new staging process creates a more complex and informative system according to guidelines from the American Joint Commission on Cancer (2018).

Treatment Overview for Head and Neck Cancer

Head and neck tumors occur in areas that are anatomically complex and many head and neck cancer patients have metastasis at the time of diagnosis (Ridge et al., 2016). The areas in which head and neck tumors occur are critical to performing important functional activities, which include, but are not limited to breathing, eating, and communicating.

Due to the aforementioned head and neck tumor-related complexities, treatments for these types of cancers often are multimodal and debilitating (Howren et al., 2013). Depending on tumor location and stage, the current standard treatments for head and neck cancer include surgery, radiation, chemotherapy, or a combination of the aforementioned options (National Cancer Institute, 2014). Treatments and their resulting toxicities frequently result in lifelong impairments, which also may result in major psychological effects. Toxicities resulting from treatment are of primary concern for head and neck cancer patients and their healthcare providers as these sequelae have a direct impact on quality of life during and after treatment (Murphy et al., 2009). Treatment for head and neck cancer also may result in permanent disfigurements, which are visible to the naked eye, thereby resulting in a host of social and psychological issues. Although disfigurement is not addressed in this study, it is an important post-treatment issue affecting head and neck cancer survivors.

Types of Treatment

There are various types of cancer treatments that can be used independently of each other or in combination with other treatments. The sections below detail information about surgery, radiation therapy, and chemotherapy. These three treatment options are most commonly used in Western medicine to treat head and neck cancer, as well as other types of cancers.

Surgery

Treatment approaches for head and neck cancer are based on the primary site of the malignancy as well as the extent of the disease. For the 30% to 40% of individuals who present with early stage squamous cell tumors, surgery and/or radiation therapy are the standard treatments used (Dirix et al., 2006; Marur & Forastiere, 2016). Multimodal approaches are required for locally advanced malignancies, starting with surgery, and then followed by adjuvant radiation and/or chemotherapy dependent upon nodal involvement.

Surgery for head and neck cancer differ. Surgery options may include the removal of the tumor and/or the potential removal of the surrounding lymph nodes. Surgery may involve a partial, modified radical, or radical neck dissection. Partial neck dissection involves the removal of few lymph nodes, while modified radical neck dissection involves more extensive removal of lymph nodes on one side of the neck. During radical neck dissection, lymph nodes, nerve tissue, and some muscle, between the collarbone and jawbone, are removed. Neck dissection may cause injury to a variety of nerves, which may result in numbness of the ear, weakness of facial muscles, and weakness when raising the arm above the head. Further issues such as an accumulation of lymphatic fluid, which can result in lymphedema, may occur (Marrs, 2007; NCI, 2016). Lymphedema also may be caused by radiation treatments, which may disrupt the lymphatic drainage system, thereby causing excess fluid to accumulate in the interstitial space (Marrs, 2007).

Radiation Therapy

External beam radiation therapy is a standard treatment used for those who present with most head and neck cancer. In fact, external beam radiation therapy is used in over half of cases (Hutcheson, 2013). External beam radiation is delivered from a machine located outside the body, which generates x-ray or photon beams directed at the location of the tumor (Radiological Society of North America, 2016). Radiation doses are measured in gray (Gy) units, which is the amount of radiation absorbed by one kilogram of tissue. Standard dosage of radiation therapy for head and neck cancer treatment is daily fractions of 1.8 to 2.0 Gy over six or seven weeks for a total of 66 to 70 Gy (Manikantan et al., 2009). When external beam radiation used in combination with chemotherapy, the related effects are intensified.

There are several types of external beam radiation therapies. Current types of radiation therapy include: (a) intensity modulated radiotherapy (IMRT), (b) image-guided radiotherapy (IGRT), and (c) adaptive radiotherapy (ART; Hutcheson, 2013). These therapies can be used to treat head and neck cancer. The goals of beam radiation therapy are: (a) to completely eradicate the cancer with the least amount of exposure possible to radiation and (b) to spare as much of the normal critical anatomical structures of the head and neck (as possible) or to at least lower one's likelihood of exposure to radiation.

In spite of continuing improvements in the delivery and dosing of radiation therapies, the majority of head and neck cancer patients treated with radiation therapies experience significant treatment effects, both during and after treatment. When the dosage used during radiation therapy is 55 Gy or greater, long-term toxicities often occur (Marur & Forastiere, 2016). Effects of high dose radiation therapies may include skin blistering, skin dryness, nausea and vomiting, dysgeusia (taste alteration), dysphagia, trismus, oral fungal infections, fatigue, jaw and mouth stiffness and pain, mucositis, impaired function or destruction of the salivary glands resulting in xerostomia, and dental complications including tooth decay and osteonecrosis of the jaw (Dirix, Nuyts, & Van den Bogaert, 2006; Lalla, Brennan, & Shubert, 2011; Manikantan et al., 2009; NCI, 2016).

Chemotherapy

Chemotherapy drugs can be used for the treatment of oral cavity and oropharyngeal cancers. Chemotherapy drugs may include: (a) cisplatin, (b) cetuximab, (c) carboplatin, (d) 5-fluorouracil (5-FU), (e) paclitaxel, (f) docetaxel, or (g) a combination of chemotherapy drugs such as cisplatin and 5-FU or cisplatin, 5-FU, and docetaxel (National Cancer Institute, 2015). Each type of treatment may result in several short-term as well as long-term side effects. Short-term side effects from chemotherapy may include hair loss, nausea, diarrhea, mouth sores, vomiting, loss of appetite, and decreased red, white, and platelet blood cell counts that may result in decreased immunity, bleeding or bruising, and fatigue. Long-term side effects from chemotherapy may include neuropathy in the hands and feet, and ototoxicity including hearing loss and tinnitus.

Late-Effect Physiologic Symptoms in Head and Neck Cancer Survivors

In the TUS, physiologic symptoms are identified as normally functioning body systems but also include pathologies such as trauma and the person’s level of energy (Lenz et al., 1997). Physiologic factors often are reflected and diagnosed by the presence of unpleasant symptoms. The various aspects of physiologic factors often are interrelated with psychological and situational factors in relation to their symptoms (Lenz et al., 1997). Based on the review of the literature, physiologic late-effect symptoms that were explored in this study included but were not limited to dysphagia, xerostomia, mucositis, pain, and constipation. However, in this study, these symptoms were measured using the MDASI-HN Factors I and II. These are restricted to those measured by the MDASI-HN Factors I and II.

Dysphagia

The term *dysphagia* refers to difficulties in swallowing or eating. Swallowing difficulties commonly are seen in head and neck cancer patients undergoing multimodal treatments such as surgery, radiation, and chemotherapy (Murphy & Gilbert, 2009). In a study conducted by Garcia-Peris et al. (2007), dysphagia was present among 50.6% of head and neck cancer patients surveyed.

Surgical resection dependent upon the location, size, and extent of the tumor as well as the type of reconstruction may result in scar tissue, a loss of sensation, hypofunction of salivary glands, as well as problems with dentition (Murphy & Gilbert, 2009), and all together directly may affect the ability to chew and swallow. Neuropathy and muscle atrophy are potential causes of long-term dysphagia resulting from radiation treatment, and chemotherapy intensifies its effects both in the short and long term (Cartmill et al., 2016; Hutcheson, 2013).

Dysphagia has been shown to have a significant impact on distress and quality of life for head and neck cancer patients. While undergoing treatment, many head and neck cancer patients opt for a feeding tube to maintain adequate nutrition and hydration due to treatment-related effects such as mucositis, fibrosis, swallowing difficulties, xerostomia, aspiration, etc. (Manikantan et al., 2009; Murphy & Gilbert, 2009). Dysphagia also may develop years following treatment due to lymphedema and muscle atrophy (Murphy & Gilbert, 2009). In several studies, dysphagia has been shown to have a definite negative impact on head and neck cancer survivors' quality of life as well as health-related quality of life (Garcia-Peris et al., 2007; Hutcheson, 2013; Langendijk et al., 2008; Murphy & Gilbert, 2009; Nguyen et al., 2005; Payakachat et al., 2012). Fifty-one percent of head and neck cancer patients reported a decrease in overall quality of life, as related to dysphagia (Garcia-Peris et al., 2007). Furthermore, depression and anxiety are significantly worse among head and neck cancer survivors who have dysphagia (Garcia-Peris et al., 2007; Nguyen et al., 2005).

Xerostomia

Xerostomia refers to dry mouth, and for head and neck cancer patients, results from hypofunction of the salivary glands due to cumulative damage from radiation therapy (Cassolato & Turnbull, 2003). Xerostomia may also be caused by chemotherapy and certain medications as well as a side effect from other disease processes (Pinna et al., 2015). Xerostomia varies based on the location of the cancer with highest prevalence and severity in nasopharyngeal and oropharyngeal tumors (Huang et al., 2000; Jensen et al., 2010). Xerostomia is the most commonly reported side effect for head and neck cancer patients who undergo radiation treatment. Unfortunately, xerostomia may be permanent and constant throughout the remainder of the patient’s life. In a recent study, 90% of head and neck cancer patients received radiation therapy as a part of their treatment and 85% of those individuals developed xerostomia (Jensen et al., 2010; Sasportas et al., 2013; Vissink et al., 2010).

In a systematic review conducted by Jensen et al. (2010), prevalence rates of xerostomia during treatment ranged from 81.4% to 100% remaining as high as 90.9% more than two years after treatment. Dirix et al. (2006) reported that hypofunctioning with up to a 50% to 60% decrease of the salivary glands due to radiation therapy damage begins during the first week of radiation treatments. After seven weeks of radiation treatments, flow of saliva decreases to approximately 20%.

Xerostomia results in decreased saliva and dry mouth putting patients at increased risk of long-term oral complications including sore throat, alterations in voice quality, dysgeusia, difficulties with chewing and swallowing, and dental caries (Dirix et al., 2006; Pinna et al., 2015). Xerostomia has a significant impact on head and neck cancer patients' quality of life both during and post-treatment (Epstein et al., 2012; Jensen et al., 2010; Murphy et al., 2007; Pinna et al., 2015).

Mucositis

Mucositis refers to inflammation of the oral mucosa during chemotherapy and/or radiation therapy as well as after (Keefe et al., 2007; Peterson et al., 2015). Mucositis is a common side effect of head and neck cancer treatments. The prevalence of mucositis is approximately 85% among patients who are being treated with radiation (Peterson et al., 2015). Mucositis results in ulcerations, sores, erythema, and oral pain. Oral pain and difficulty to eat often requires head and neck cancer patients to received nutritional support with the use of a feeding tube or gastrostomy (Peterson et al., 2015).

Pain

Pain is physiologically defined as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage" (International Association of Pain, 1994, p. 210). Pasero and McCaffery (2011) provided a broader definition of pain in that it is a subjective experience. Essentially, whatever a person is experiencing or reporting pain to be is what pain is/means for that individual (Pasero & McCaffery, 2011).

Pain is an unfortunate yet common long-term aftereffect of cancer treatment experienced by many cancer survivors. Furthermore, pain often causes physical and emotional distress for the survivor and their families and loved ones (Glare et al., 2014). Pain affects multiple aspects of cancer survivors' quality of life including functional status, financial resources, family dynamics, spirituality and social support systems (Breitbart, Park, & Katz, 2010). Brown, Ramirez, and Farquhar-Smith (2014) noted that pain in cancer survivors is common with prevalence being between 30% and 60% along with its negative effects on quality of life.

In a meta-analysis of the international prevalence and severity of pain in cancer patients, van den Beuken-van Everdingen, Hochstenbach, Joosten, Tjan-Heijnen, and Janssen (2016) found that even after treatment for cancer, pain prevalence rates were 39.3%. Glare et al. (2014) related that the problem of pain in cancer survivors particularly is pronounced in the early years post-treatment. The researchers described that pain is also a significant problem in the longer term with debilitating chronic severe pain experienced in 5% to 10% of cancer survivors (Glare et al., 2014). Pain is related to the type and stage of the initial cancer treated, treatment regimens utilized, time from treatment, and efficacy of the initial treatment for pain (Paice et al., 2016).

Cancer treatments use a variety of interventions including surgery, radiation, and chemotherapy, as well as other drug-based treatments, all of which may result in painful symptoms immediately or sometimes appearing several years after treatment has been completed. Paice (2011) estimated that chronic pain after cancer surgery may be as high as 50% with multiple factors contributing. Lynch and Paice (2011) and Paice (2011) categorized the various cancer treatment related pain syndromes related to surgery, chemotherapy, radiation, stem cell transplantation, and hormonal therapy. Chemotherapy treatments may result in several types of chronic pain including chemotherapy induced peripheral neuropathy (CIPN) as well as pain from possible necrosis and osteoporotic fractures (Paice, 2011). The aftereffects of radiation therapy may be present anywhere from 6 months to the duration of life after treatment and may include pain syndromes such as skin pain, plexopathies, burns, chest pain, mucositis, oral pain, dysphagia, xerostomia, osteoporosis, osteoradionecrosis, and secondary malignancies (Lynch & Paice, 2011). Soft tissue injury known as radiation fibrosis syndrome is a significant occurrence in head and neck cancer patients receiving radiation therapy to the head and neck areas. Radiation fibrosis signs and symptoms may include restricted mouth opening known as trismus, neck tightness and pain, head and neck swelling known as lymphedema, and damage to swallowing muscles in the throat resulting in swallowing difficulties known as dysphagia may all be the result of radiation treatments. Signs and symptoms may worsen over time (American Head and Neck Society, 2016).

The prevalence of pain in head and neck cancer patients is significant, with approximately 50% to 70% reporting pain both during and after treatment (Epstein et al., 2001; Murphy et al., 2007; Shuman et al., 2012). Pain in head and neck cancer patients may occur from tissue damage caused by several possible sources including radiation treatment, tumor invasion, mucosal injury, and nerve damage or compression (Epstein et al., 2009). Surgical interventions including neck dissection may result in lymphedema, scar tissue, tissue, and nerve and muscle damage, all contributing to ongoing pain. In a prospective cohort study of head and neck cancer patients (*n* = 374) one year following diagnosis, the variables independently associated with pain included: neck dissection, feeding tube, xerostomia, depressive symptoms, presence of pretreatment pain, consumption of more pain medication, less physical activity, and poor sleep quality (Shuman et al., 2012).

Fatigue

Fatigue is defined as extreme tiredness and a lack of energy resulting in an inability to function and may be chronic or acute in nature (National Cancer Institute, 2017). Fatigue is a common side effect of radiation therapy and chemotherapy. Prevalence rates of fatigue in cancer patients range from 14% to 96% for patients in active treatment and from 19% to 82% for those post-treatment (Cella et al., 2002). generally resolving once treatment has been completed. Cancer-related fatigue is defined as persistent, distressing, subjective sense of exhaustion on the physical, emotional, and/or cognitive levels, which is related to cancer treatment (Berger, Whitmer, & Walker, 2001). Cancer-related fatigue eventually resolves but may persist well into survivorship (Baker et al., 2005).

Psychologic Symptoms in Head and Neck Cancer Survivors

In the TUS, psychologic symptoms are described as a person’s mood or mental state, emotional reaction to illness, and the uncertainty as well as knowledge about symptoms and their potential meaning (Lenz et al., 1997). Cancer patients have an increased incidence of psychologic comorbidities with approximately one-half exhibiting emotional difficulties such as depressed mood, anxiety, and loss of self-esteem (Krebber et al., 2014). In a German study, Mehnert et al. (2014) reported that nearly one-third of cancer patients experienced a clinically significant level of psychological distress meeting the diagnostic criteria for psychological disorders including depressive and adjustment disorders as well as anxiety. The prevalence varied by cancer type with the highest rates found among those with breast cancer (42%) and head and neck cancer (41%; Mehnert et al., 2014).

Substantial psychological distress is evidenced in cancer patients by their suicide rates being nearly two times greater than that of the general U.S. population (Misono et al., 2008). In addition, reported suicidal thoughts among cancer patients ranged between 7% to 40% (Watson & Grassi, 2017). Watson and Grassi (2017) related some of the risk factors for suicide in patients with cancer that included older age, male gender, pain, depression and anxiety, a sense of hopelessness, and cancer type. Suicide is more common in cancer patients with lung, prostate, pancreatic, esophageal, or stomach cancer, and in those with head and neck cancer, particularly pharyngeal and laryngeal malignancies (Anguiano et al., 2012).

Head and neck cancer patients report some of the highest rates of psychological distress of any cancer patients (Gilbert et al., 2012). The intensity and location of treatments for head and neck cancer may result in late-effect physical symptoms that may be associated with major lifelong psychological effects. Psychosocial effects of head and neck cancer survivors are varied and may become exacerbated over time (Rapoport et al., 1993). Demoralization, depression, and anxiety are important psychological symptoms affecting head and neck cancer patients. Demoralization will be the focus of examination in this study.

Demoralization

Engel (1967) described demoralization as the “given up-giving up” syndrome. Frank (1974) defined the term *demoralization* in the context of psychotherapeutic terms as a failure to cope with stressors either internally or externally induced, leading to a sense of the meaningless of life. Frank (1974) noted that anxiety and depression were direct expressions of demoralization and that the more demoralized a person was, the greater their symptoms were, both psychologically and physically. Frank (1974) went on to relate that improved patients showed a greater ability to cope as well as a sense of inner control, independence, and self-determination. Demoralization syndrome is a psychological response frequently observed in patients with serious illness (Kissane et al., 2001; Robinson et al., 2015). Demoralization is not currently classified as a psychological disorder in the DSM-V and therefore official diagnostic criteria are lacking. After studying cancer patients in the palliative care setting, Clarke and Kissane (2002) and Kissane et al. (2001) suggested that a diagnosis of demoralization could be made if the following symptoms were present: distress, hopelessness, helplessness, lack of drive and support, and a sense of personal failure. Clarke and Kissane (2002) described demoralization as feelings of hopelessness or helplessness, caused by a loss of meaning and purpose in life, and an inability to cope. In their systematic review of the literature, Robinson et al. (2015) found that demoralization was prevalent in patients with cancer or progressive diseases and clinically significant in 13% to 18% of patients. The researchers found several factors consistently associated with demoralization including poorly controlled physical symptoms, substance dependence, and inadequately treated anxiety and depression.

Kissane (2017) related that demoralization is of clinical concern when the prognosis is poor, the disease is progressing and unresponsive to treatments, and when there is poor symptom control, among other factors. Kissane (2017) further defined demoralization along a continuum from mild to severe beginning with disheartenment then moving into despondency, despair, and finally loss of purpose and giving up. Demoralization is closely related to depression and may overlap with major depression and adjustment disorders; however, both may exist independently of one another. The treatments are different, therefore obtaining accurate diagnoses is important.

Fang et al. (2014) found that for inpatients and outpatients with cancer, demoralization was more of an influence on suicidal ideation than depression. In their exploration of the variables mediating suicidal ideation, demoralization accounted for 25%, depression accounted for 18%, and demoralization combined with depression resulted in 31.8%. A cancer patient experiencing depression and demoralization results in an increased effect on suicidal ideation between 50% to 75.4% greater than the effect of depression alone (Fang et al., 2014; Kissane, 2017). Therefore, identification and treatment of demoralization is critical, particularly in the cancer patient/survivor population.

Depression

Depression rates are highly correlated with head and neck cancer patients and particularly among those who have oropharyngeal cancers (Lazure, Lydiatt, Denman, & Burke, 2009). Approximately 22% to 57% of individuals who have oropharyngeal cancers have depression (Archer et al., 2008; Massie, 2004). The concept of a major depressive disorder and the term depression are used interchangeably throughout literature. According to the National Institute of Mental Health (2019), “Depression (major depressive disorder or clinical depression) is a serious mood disorder which causes severe symptoms that affect how one feels, thinks, and handles day to day activities such as sleeping, eating, or working” (para. 1). Up to 40% of head and neck cancer patients have depression/major depressive disorder (Lazure, Lydiatt, Denman, & Burke, 2009). The high prevalence of depression is perhaps due to the multiple, life-altering, long-term effects that may result from head and neck cancer treatments. These effects may include visible permanent facial disfigurement, difficulties in communicating, and challenges in eating and swallowing, all of which may contribute to psychological sequelae not only during but also after treatment.

Barber et al. (2016) conducted a systematic review regarding depression and survival in head and neck cancer patients. The researchers determined that two out of three studies reviewed revealed a statistically significant difference in survival for head and neck cancer patients with depression. In a prospective cohort study by Ehlers (2002), a significant difference in mortality in those who scored greater than 7 on the Beck Depression Inventory (BDI) was demonstrated.

With every additional point scored on the BDI, the relative risk of mortality increased by 5% (Barber et al., 2016; Ehlers, 2002). In a prospective cohort study of 130 oropharyngeal cancer patients, who were followed for five years during treatment and beyond, Shinn et al. (2016) found that self-reported depression had a significant impact on the survival of head and neck cancer patients and was associated with decreased overall survival and disease recurrence. A decreased overall survival duration (hazard ratio = 3.6; 95% confidence interval = 1.2 to 10.8) and disease recurrence (hazard ratio = 3.8; 95% confidence interval = 1.2 to 12.2) were associated with self-reported depression in survivors of oropharyngeal cancer (Shinn et al., 2016).

Depression in cancer patients often is underdiagnosed with studies showing that only one-third of clinically depressed patients are being identified and treated (Katz et al., 2004; Sollner et al., 2001). Depression also has been associated with poorer quality of life for cancer patients in numerous studies (Aarstad et al., 2005; Brown et al., 2009; de Graeff et al., 2000; Duffy et al., 2007; Llewellyn et al., 2005). Head and neck cancer patient depression also is associated with increased levels of tobacco use and drinking alcohol (Duffy et al., 2007; Humphris & Rogers, 2004), both of which put patients at greater risk of recurrence.

Demoralization as Compared to Depression

Although demoralization and clinical depression may be associated, they are distinct conditions requiring different tools for identification and treatment (Clarke & Kissane, 2002; Robinson et al., 2015). Clinical depression includes loss of pleasure and interest in the present characterized by a general anhedonia (Kissane, Clarke, & Smith, 2001). Demoralization is characterized by feelings of subjective incompetence, despair, loss of hope, meaning, and purpose in life (Clarke & Kissane, 2002). De Figueiredo and Frank (1982) and De Figueiredo

(1993) further distinguished between demoralization and depression with demoralization comprising the feeling of subjective incompetence based upon external sources of distress such as their diagnosis and experiences with cancer (Table 1). While those experiencing major depression also experienced distress based upon internal perceptions with feelings of guilt and lack of perceived motivation. Hopelessness is a key identifier of demoralization and is associated with negative outcomes in physical and psychological illness. Demoralization may occur in those experiencing depression as well as those with personality disorders, psychosis, and those with chronic and terminal physical illnesses such as cancer (Clarke & Kissane, 2002). Perhaps most importantly, demoralization is also associated with suicidal ideation and a wish for death, making its identification and treatment a psychological concept of critical importance for clinicians and researchers alike (Clarke & Kissane, 2002).

Table 1

Comparison of Demoralization and Depression

Construct	**Context**	**Symptoms**	**Research**
Demoralization	Primary Source of Distress is External	Do Not Feel Guilty Perceptions of diminished competence and control over one's own functioning, i.e., subjective incompetence	Not a DSM-V disorder No established treatment
Depression	Primary Source of Distress is Internal	Feelings of Guilt Anhedonia	A DSM-V Disorder Evidenced-based treatment

To date, little research has been conducted regarding the prevalence and effects of demoralization among head and neck cancer survivors. In a study conducted by Lee et al. (2012), about cancer patients (*n* = 234) at an outpatient clinic in Taiwan, the study results confirmed a statistically significant ($p < 0.05$) demoralization phenomenon among cancer patients. Lee et al. (2012) also reported that head and neck cancer patients had higher demoralization scores and lower quality of life scores compared to other cancer types in the study.

Situational Factors in Head and Neck Cancer

Lenz et al. (1997) described situational factors as including aspects of the social and physical environments that may affect the individual's experience and reporting of symptoms. Lenz et al. (1997) state that social situational factors may include family and relationship status, employment, access to healthcare, social support, and lifestyle behaviors (e.g., exercise and diet). Two situational factors of particular importance to head and neck cancer survivors are tobacco and alcohol use. Tobacco use combined with excessive alcohol use has a major impact on incidence of head and neck cancer. Tobacco use is estimated to account for 85% of head and neck cancers (American Cancer Society, 2011; American Society of Clinical Oncology, 2011). In a study conducted by Hashibe et al. (2007), at least 75% of head and neck cancers resulted from a combination of cigarette smoking and drinking alcohol.

Tobacco Use

Tobacco use is the largest single risk factor for squamous cell carcinomas, accounting for 85% of all diagnoses (American Society of Clinical Oncology, 2016; Van Liew et al., 2014). In a study of tobacco and alcohol use in head and neck cancer survivors ($n = 264$) who were diagnosed and treated for early stage carcinomas, those who smoked increased their risk of dying with risks reaching 5.4 (95% confidence interval, 0.7 to 0.1; Mayne, Cartmel, Kirsh, & Goodwin, 2009). Although smoking is a well-known risk factor for head and neck cancer and recurrence, 20% to 61% of survivors continue to use tobacco after treatment for head and neck cancer (Allison, 2001; Duffy et al., 2007). In a study conducted by Mayne et al. (2009), 21% of the study cohort continued to smoke after their cancer diagnosis, despite clinical recommendations to quit smoking at the time of study randomization combined with referrals to tobacco cessation programs.

Alcohol Use

Excessive alcohol consumption increases one's likelihood of developing specific types of cancers. In fact, individuals who consume alcohol daily, in large quantities, are at an especially greater risk for developing various types of cancers, especially head and neck cancer in the larynx, pharynx, and/or oral cavity (Baan et al., 2007). Individuals who consume 50 grams or more of alcohol per day, which is approximately 3.5 or more alcoholic beverages per day, have at least a two to three times greater risk of developing head and neck cancer compared to non-drinkers.

Alcohol in combination with tobacco use substantially increases the risks of head and neck cancer (Baan et al., 2007; Hashibe et al., 2007; Hashibe et al., 2009). In Mayne et al.'s (2009) study, those head and neck cancer patients who drank alcohol prior to diagnosis also experienced poorer survival rates with mortality risks reaching 4.9 (95% confidence interval; 1.5 to 1.3). Head and neck cancer patients have an increased incidence of smoking and drinking and have experienced significant depressive symptoms and/or depression compared to the general population. Head and neck cancer patients who smoke tobacco and drink alcohol also are more likely to experience negative quality of life (de Graeff et al., 2000; Duffy et al., 2008; Jensen et al., 2007; van Liew et al., 2014).

Quality of Life in Head and Neck Cancer Survivors

Quality of life (QOL) is a complex concept including a broad range of definitions and domains. The World Health Organization (WHO; 1997) defined *QOL* as the "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (p. 1). The WHO (1997) further explained that QOL is affected by physical health, psychological state, independence level, relationships, beliefs, and individual's relationship to his/her environment. Quality of life is defined by its multidimensionality consisting of several domains including physiological, psychological, social, environmental, and spiritual factors as well as functionality (Cella, 1994). For cancer patients, QOL may be defined by patients' evaluation and satisfaction with their level of functioning compared to what is thought to be possible or ideal (Cella, 1994).

Health-related quality of life (HRQOL) relates to a person's perceptions of their physical and mental health over time. Specifically, HRQOL is related to an individual's disease and disease-related treatment impacts in terms of the physical, psychological, and social aspects of a person's life (Centers for Disease Control and Prevention [CDC], 2000). Chandu et al. (2006) further defined *HRQOL* as a subset of QOL, which considers psychological aspects and assesses symptoms and functionality.

Survival has and continues to be a key outcome measure in cancer treatment. However, with the development of QOL measures that place importance on patients' subjective reports of their wellbeing, as well as the identification of QOL as a clinical research outcome measure, QOL has significantly increased in importance (Murphy et al., 2007; Ringash, 2015; Timmerman, 2012). In addition, QOL increasingly has become recognized as an important factor not only in the treatment of cancer patients but also in cancer survivorship (Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; Rogers et al., 1999). In 2006, the Institute of Medicine (IOM) Committee on Cancer Survivorship released a report entitled "From Cancer Patient to Cancer Survivor: Lost in Transition." This report highlighted many important issues in cancer survivorship including recommendations to improve the health care and QOL for the growing numbers of cancer survivors in the United States (Institute of Medicine and National Research Council, 2006). The committee also indicated the need for research focused on improving the understanding of the prevalence of late-effects as well as interventions to improve the quality of life of cancer survivors (Institute of Medicine and National Research Council, 2006).

The American Society of Clinical Oncology (ASCO, 2017) released the “Head and Neck Survivorship Care Guideline,” which provided recommendations for adult head and neck cancer treatment, assessment, and management of late-effect symptoms from treatment. Guidelines place emphasis on the assessment and management of physical and psychosocial long-term and late-effects of head and neck cancer and its treatment, such as osteonecrosis, anxiety, and depressive symptoms. In addition, the panel emphasized health promotion including tobacco cessation and dental care (American Society of Clinical Oncology, 2017). All of these recommendations are aimed to improve head and neck cancer survivors’ outcomes as well as their quality of life (American Society of Clinical Oncology, 2017).

Head and neck cancer and its various treatments presents multiple challenges on many levels for survivors. Due to treatment toxicities and their sequelae, head and neck cancer survivors may have multiple physiological, psychological, and situational issues related to QOL. Post-treatment physiological issues and conditions including xerostomia, dysphagia, dysgeusia, trismus, lymphedema, mucositis, oral candidiasis, acid reflux, presence of a temporary or permanent feeding tube, hearing loss, carotid artery stenosis, secondary cancers, erythema, fatigue, pain, communication difficulties, acid reflux, neuropathy, and disfigurement are all potential impacts on survivors’ QOL (Howren et al., 2013; Murphy & Deng, 2015). Quality of life is negatively impacted in head and neck cancer survivors by a variety of symptoms resulting from treatment, many of which may continue throughout the remainder of life (Chandu et al., 2006; Howren et al., 2013; Humphris & Ozakinci, 2006). Due to the changes in daily physical functional, psychological, and situational factors, QOL for head and neck cancer survivors may never reach pre-treatment baselines. Presented with a host of physical limitations, many head and neck cancer patients struggle with continuance of unhealthy situational behaviors such as tobacco and alcohol use. Furthermore, the fear of recurrence presents challenges psychologically for many head and neck cancer survivors. This may result in feelings of anxiety, depression, and demoralization, particularly when contemplating the future along the survivorship trajectory.

Quality of life research in head and neck cancer is evolving in recognition of the complexity and need to identify and determine the multiple factors affecting survivors' QOL. This is critical for evolving existing treatment protocols as well as developing new ones in order to lessen or remove negative late-effect symptoms. There have been multiple studies conducted examining the relationship of various physical, psychological, and situational factors on QOL in head and neck cancer survivors. Quality of life studies in head and neck cancer survivors use a variety of measures to assess QOL resulting in a lack of consistency with no single agreed upon standard measure (Murphy, Ridner, Wells, & Dietrich, 2007). A lack of standardization of measures as well as research methodologies has offered conflicting results. In a review of head and neck cancer QOL research, Murphy et al. (2007) also emphasized the importance and need for QOL research that provides a holistic view of the patients' health experience, not just the singling out of individual variables.

Physiologic Symptoms and Impact on Quality of Life

Two resulting physiological late-effects of head and neck cancer treatments, dysphagia and xerostomia, impact QOL in head and neck cancer survivors significantly. Funk et al. (2012)

examined health-related QOL in five-year head and neck cancer survivors ($n = 337$). The study determined that eating problems and persistent pain were the most common problems faced by survivors. In the study, over 50% had difficulty eating and 28.5% reported depressive symptoms with 17.3% reporting substantial pain. In addition, 38.9% continued to use alcohol and 13.6% continued to smoke. Multivariate statistical analyses identified one-year pain and diet were the strongest predictors of five-year health-related QOL outcomes (Funk et al., 2012).

In a much smaller sample, Maurer et al. (2011) examined the relationship between dysphagia and QOL after radiation therapy in head and neck cancer survivors ($n = 35$). They found that dysphagia was reported by 86% and significantly affected QOL ($p = 0.033$). Nguyen et al. (2005) reported reduced QOL scores in head and neck cancer survivors according to their dysphagia severity ($n = 71$). Survivors experiencing mild or no dysphagia experienced greater quality of life compared with those reporting severe or moderate dysphagia ($p = 0.0005$). Less anxiety ($p = 0.005$) and depression ($p = 0.0001$) also were reported, respectively (Nguyen et al., 2005).

Xerostomia has been shown to have a major impact on QOL in head and neck cancer survivors. In a review of the literature, Dirix et al. (2010) observed that quality of life is strongly impacted by xerostomia related to difficulties in chewing and swallowing food as well as difficulties with altered taste and speech problems. However, Ringash et al. (2005) found conflicting results in their prospective clinical trial of head and neck cancer patients undergoing radiation therapy. Patients were randomized to either a treatment group ($n = 65$) for xerostomia versus a placebo group ($n = 65$). Although a clinically significant decline in the QOL measure was observed by week six of radiation therapy ($p < 0.0001$), scores returned to baseline by six months after treatment despite persistent xerostomia. In a systematic review, which was conducted by Jensen et al. (2010), that included 255 articles, the researchers found that xerostomia worsens overall QOL in multiple domains including physical, emotional, role, and social function. They found that xerostomia's effect on quality of life after radiation therapy was more pronounced in female and younger patients. Jensen et al. (2010) found several methodological issues in the studies reviewed, which included discrepancies in definitions of xerostomia as well as a lack of standardization of assessment scales including the use of invalidated scales.

Psychological Symptoms and Impact on Quality of Life

Depression was identified as having a significant impact on QOL in multiple studies. Barber et al. (2016) in a prospective cohort study (n = 71) identified reduced quality of life scores in those with moderate to severe depressive symptoms (p = 0.03). The risk ratio in the moderate to severe depressive symptoms group was 5.66. Barber et al. (2016) concluded that depressive symptoms in head and neck cancer patients treated with surgery were high (53.5%). In addition, patients with moderate to severe depressive symptoms had a significantly decreased postoperative functional performance score, increased narcotic use, decreased completion of adjuvant therapy, and a longer length of hospital stay (Barber et al., 2016). Brown, Kroenke, Theobald, and Tu (2010), in their secondary cross-sectional analysis of adult cancer patients with depression and/or pain (n = 397), noted that 135 participants had anxiety and depression. Depression effects multiple areas of a cancer patient's life, which impacts the individual's overall quality of life, general health perceptions, vitality, and perceived disability. In a study of head and neck cancer patients (n = 973), Duffy et al. (2007) found that 46% of patients screened positive for depressive symptoms, 30% of patients smoked, and 16% of patients screened positive for problem drinking. Duffy et al. (2007) also noted that depressive symptoms had a strong negative association with all eight quality of life scales on the SF-36 measure as well as the four quality of life scales on the HNQOL instrument. Smoking had a negative association with all but one of the QOL scales used.

Situational Factors (Smoking and Alcohol Use) and Impact on Patient Outcomes

A retrospective study of 1,871 head and neck cancer patients was conducted to evaluate the prevalence and influence of smoking and alcohol use on patient outcomes (Fortin, Wang, &Vigneault, 2009). Of the data analyzed, 40% were former smokers, 25% were former drinkers, 51% were active smokers and 55% were active drinkers (Fortin, Wang, & Vigneault, 2009). Current smokers had lower local control and slightly lower survival rates than former smokers. Mayne, Cartmel, Kirsh, and Goodwin (2009) examined head and neck cancer early stage survivors (*n* = 264) for an average of 4.2 years to determine if an association existed between alcohol and tobacco use and survival. They determined that smoking history before diagnosis increased the risk of dying with risks reaching 5.4 (95% confidence interval; 0.7 to 40.1). The researchers also determined that alcohol before diagnosis increased mortality with risks reaching 4.9 (95% confidence interval; 1.5 to 16.3). Continued drinking post-diagnosis significantly increased risk to 2.7 (95% confidence interval; 1.2 to 6.1). Contradictory results involved continued smoking, which was non-significantly associated with higher risk to 1.8 (95% confidence interval; 0.9 to 3.9). A possible study limitation included potential inaccuracies of self-reported smoking status, which was not verified biochemically leading to potential measurement error (Mayne et al., 2009).

Summary

The theory of unpleasant symptoms (TUS), which was created by Lenz et al. (1997), served as a guiding framework for this review of literature. The TUS research obtained was related to head and neck cancer survivors. The TUS lends itself particularly well to examining the relationships between the late-effect physical symptoms (i.e., xerostomia, mucositis, dysphagia, pain, and fatigue), tobacco and alcohol use, and demoralization among head and neck cancer survivors. Using the TUS, researchers explored the experiences and rating of patients regarding symptoms that impacted performance/daily functions. Unpleasant symptoms were described in regard to timing, intensity, quality, and distress caused. These symptoms were influenced by a variety of factors including physiological and psychological factors (Liehr, 2005).

Unpleasant symptoms are reported using scales measuring duration, quality, and intensity, as well as the experience of the symptom (Liehr, 2005). Unpleasant symptoms are operationalized by symptom assessment, management, and interventions designed to provide symptom relief (Liehr, 2005). The literature reviewed revealed an emphasis on studies examining late-effect physical symptoms focused on or including dysphagia and xerostomia. Studies that have examined depression and depressive symptoms were the majority regarding psychological symptoms. Studies focused on the situational symptoms of tobacco and alcohol use and their negative impact on head and neck cancer survivors' treatment outcomes, as well as their association and relationship to depressive symptoms and poorer treatment outcomes. Few studies examined situational factors that may affect the experiences of physiologic and psychologic symptoms on head and neck cancer survivors such as the effects of partnership, education levels, employment status, or treatment at a large academic medical center with a large catchment population in a poverty area. Furthermore, few if any studies examined late-effect symptoms, tobacco and alcohol use, and their association with demoralization in head and neck cancer survivors.

Chapter 3: Methods

Chapter 3 describes detailed information about the methods used in this study. Specifically, this chapter explains the study design, the setting, and details about the sample of head and neck cancer survivors who participated in this study. Additionally, information about why a power analysis was conducted is discussed, variables measured are overviewed, and the data analysis process is explained. Ethical considerations and study limitations also are described in this chapter.

Study Design

A descriptive, correlational research design was used to examine the relationship between late-effect physiologic factors, psychologic factors, and situational factors in regard to quality of life among post-treatment head and neck cancer survivors. The theory of unpleasant symptoms (TUS) served as the guiding framework for this study and the specific exploration of physiologic factors related to late-effect physical symptoms, which included but was not limited to dysphagia, xerostomia, mucositis, pain, and fatigue. The psychologic factor explored in this study was demoralization and the situational factors explored were tobacco and alcohol use (Appendix B).

Setting and Sample

Setting

This study took place at the following locations: (a) the University of Kansas Department of Otolaryngology-Head and Neck Surgery clinic, (b) the KU Cancer Center clinics, and (c) the University of Kansas Cancer Center Support for People with Oral Head and Neck Cancer (SPOHNC) local group. The University of Kansas Department of Otolaryngology – Head and Neck Surgery clinic, the KU Cancer Center Clinics, and the University of Kansas Cancer Center‘s Head and Neck Cancer Support Group for People with Oral Head and Neck Cancer

(SPOHNC) local group were selected as locations for this study because of the large potential pool of eligible participants.

The University of Kansas Cancer Center Head and Neck Cancer Support Group supports patients and families from diagnosis through treatment and into survivorship (Head and Neck Cancer Support Group, 2016). The University of Kansas Cancer Center's Head and Neck Cancer Support Group is affiliated with the Support for People with Oral and Head and Neck Cancer (SPOHNC) Association. SPOHNC is a national not-for-profit organization created to educate and support patients and families from diagnosis through treatment and into survivorship (About SPOHNC, 2017). Additionally, the SPOHNC provides awareness and education to the public about oral and head and neck cancer (About SPOHNC, 2017). The group meets twice per month, at the University of Kansas Health System, and maintains an electronic list of approximately 100 e-mail addresses of individuals and are actively in treatment or have completed treatment.

Currently, the SPOHNC sponsors over 125 chapters of head and neck cancer patient/survivor support groups, including chapters in Kansas, Missouri, Nebraska, and Iowa. Additionally, SPOHNC is recognized by the American Cancer Society (ACS) and the National Cancer Institute (NCI). For the purpose of this research, SPOHNC's local chapter at the University of Kansas Medical Center was used to recruit participants (Appendices F and G).

The KU Department of Otolaryngology – Head and Neck Surgery clinic is affiliated with the University of Kansas Health System, which is a large regional academic medical center located in the Kansas City metropolitan area. Annually, the KU Department of Otolaryngology sees approximately 12,797 patients and performs 3,577 surgeries. The KU Department of Otolaryngology clinic sees approximately 1,828 patients on an outpatient basis per year (Department News, 2016).

The Masonic Cancer Alliance (MCA) is the outreach network of the University of Kansas Cancer Center and is a network of 22 member-based organizations. MCA provides cancer care, research, and support across Kansas and Western Missouri. MCA consists of public, private, and educational organizations including hospitals and clinical research partners. The MCA partners with the University of Kansas Cancer Center to provide access to cancer clinical trials.

Sample

Participants for this study were recruited from the three organizations listed above. The sample included adult men and women, 18 years and older, who were diagnosed with head and neck cancer and were undergoing or had completed treatment during the time of their research participation. Participants were required to read, write, speak, and understand English in order to participate. Exclusion criteria included any current diagnoses of cancer and/or current treatment for any type of cancer other than head and neck cancer.

A Priori Power Analysis

Green's rule of thumb (1991) was used to calculate the minimum number of participants needed to achieve a power of 0.80 with an alpha = 0.05 and a medium effect size (f_2 of 0.25). A total sample size of 54 participants were required to achieve power of 0.80 with five independent variables. The five independent variables included: physical symptoms (1) Factor I: mouth sores, tasting food, constipation, teeth/gum problems & skin pain, (2) Factor II: voice problems, choking/coughing, swallowing/chewing & mucus, (3) Life interference items: general activity, mood, work (including work around the house), relations with other people, walking, and enjoyment of life, (4) Situational factors: tobacco and alcohol use, and (5) Control variable of age. The dependent variable was demoralization.

Procedures and Data Collection

All human subject cancer or cancer-related protocols (therapeutic/treatment, prevention, ancillary/companion and correlative), must be reviewed, approved, and monitored by the University of Kansas Cancer Center's (KUCC) Protocol Review and Monitoring Committee (PRMC), prior to applying for University of Kansas Medical Center (KUMC) Human Subjects Committee (HSC) approval. Thus, approval for this study was applied for and granted by the KUCC PRMC. Then, approval was applied for and granted by the KUMC HSC. Both approvals were obtained prior to the implementation of the study. No data were collected before properly obtaining the necessary authorizations.

Permission was obtained from the University of Kansas Health System Department of Otolaryngology clinic in order to recruit adult participants for the study (Appendix C [Letter to Healthcare Professionals] and Appendix D [Synopsis of the Study]). Permission was obtained from the Director of the Masonic Cancer Alliance (MCA) in order to recruit potential participants from member healthcare organizations of the MCA in Kansas and Missouri (Appendix E).

Study data were collected and managed using REDCap electronic data capture tools hosted at the KUMC (Harris et al., 2019). Research Electronic Data Capture (REDCap) is a secure, web-based software platform designed to support data capture for research studies, providing (a) an intuitive interface for validated data capture; (b) audit trails for tracking data manipulation and export procedures; (c) automated export procedures for seamless data downloads to common statistical packages; and (d) procedures for data integration and interoperability with external sources (Harris et al., 2019). REDCap, a web-based application for building and managing online surveys and databases, was used for survey creation and management. REDCap was selected due to its robust, secure platform and functionality including creation and management of online surveys and databases. The study survey instrument was created and digitized in REDCap. A paper copy of the study survey instrument was created. Participants were given the option of completing a paper copy of the survey or completing it electronically. To screen participants effectively, inclusion/exclusion criteria were denoted at the beginning of the survey in both formats. Specifically, individuals were required to answer three questions with either a “yes” or a “no” response (Appendix H). A total of 63 responses to the survey were received, though only 51 responses were analyzed since 12 individuals did not meet the inclusion criteria. If online participants did not meet the required inclusion criteria, they received a message that thanked them for their interest in the study. Even though they may not have been eligible to participate in the study, they were given the option to enter the drawing for a $50 Visa gift card that was held at the completion of the study. Upon receiving this message, the survey would have timed out. Participants answering the survey in paper copy also were required to answer the same three questions with either a “yes” or “no” response. Whether they were eligible or not to participate in the study they were given the option of entering the drawing for a $50 Visa gift card, held at the completion of the study. Participation in the study was voluntary. Therefore, at any point during the study, participants were able to withdraw from the study. Participant confidentiality was upheld and maintained, and all data collected were deidentified (Appendix I).

Participants answering the survey online who met the inclusion criteria that was demonstrated by a “yes” to the three inclusion criteria questions: (1) Are you 18 years of age or older?, (2) Are you currently being treated or have you previously been treated for any type of head and neck cancer?, and (3) Are you currently being treated for any other type of cancer?

Participants then were redirected to a secured link to complete informed consent. After being granted access to the secured link, participants were required to consent to participating in the survey. Consent was indicated by a “yes” and was expressed through the online informed consent document. When consent was obtained, participants were redirected to the electronic survey that was displayed for survey completion. Responses were electronically recorded. All de-identified data was stored on the KUMC’s encrypted, secure, password-protected server. Participants answering the paper copy of the survey who met the inclusion criteria then were required to review the consent to participate in the study, to verify that they were at least 18 years of age, that they had read and understood the consent form, and that they and to consent to participate in the study by selecting “yes” on the consent form.

It was anticipated that the survey would take 20 minutes or less to complete. After successfully completing and submitting the survey, participants completing the survey using both online and paper versions were offered the opportunity to submit their contact information for a prize drawing. Participants also were offered the opportunity to enter the gift card drawing even if their survey was not successfully completed or if they were ineligible to participate. If their name was randomly selected in a drawing held at the completion of the study, they received a $50 Visa gift card. Participants were offered the opportunity to win one of 15 $50 Visa gift cards if their name was randomly selected in a drawing after completion of the study. All 15 gift cards were distributed to participants.

Measures

Various measurements were used to collect survey data. The Demoralization Scale II, the M.D. Anderson Symptom Inventory – Head and Neck module (MDASI-HN), four items from the Cancer Patient Tobacco Use Questionnaire (C-TUQ), and one question from the

Recommended Alcohol Questions (National Institute on Alcohol Abuse and Alcoholism) were used in this study. Additionally, demographic data was collected.

Demoralization Scale II (DS-II)

The Demoralization Scale II (DS-II) instrument was selected to measure the dependent variable of demoralization (Appendix J). The DS-II is a 16-item, self-report measure using 3-point response options, that includes: 0 = Never, 1 = Sometimes, and 2 = Often. The DS-II measures symptoms over the previous two weeks. The instrument consists of a total score and two factor scores (i.e., Meaning and Purpose; Distress and Coping Ability). The DS-II has demonstrated an internal consistency with a Cronbach's alpha of 0.89 (Kissane, 2017). The Meaning and Purpose subscale of the DS-II demonstrated a Cronbach's alpha of 0.84, and an intraclass correlation (ICC) of 0.68. The Distress and Coping Ability subscale demonstrated a Cronbach's alpha of 0.82 and an ICC of 0.82 (Robinson et al., 2016). A score of 30 or higher is indicative of high demoralization. The total score provided by participants was used for this study. Permission was obtained from Dr. David Kissane, the developer of the DS-II, to use this instrument.

MD Anderson Symptom Inventory - Head and Neck Module

The MD Anderson Symptom Inventory- Head and Neck Module (MDASI-HN) was used to measure the late-term physical effects (symptoms) and life interferences (Appendix K). The MDASI-HN is a 28-item, two-part, self-report symptom burden measure that includes 11-point response options. Part I of the measure consists of two factors which ask how severe the symptoms of participants had been in the last 24 hours. A score of zero, on any of the options, represented that a symptom was "Not Present." A score of a ten, on any of the options, represented that a symptom was "As Bad As You Can Imagine." Part II of the measure asked if one’s symptoms had interfered with his/her life in the last 24 hours. A score of zero represented that symptoms did not interfere and a score of 10 indicated that symptoms had interfered completely. This part of the instrument assessed the symptom burden of multiple head and neck cancer-related symptoms and the impact of these symptoms on daily functioning (life interference) over the past 24 hours.

Part 1 (Symptoms)

Part I of the MD Anderson Symptom Inventory- Head and Neck Module explores 13 core symptoms. These 13 symptoms are represented through items 1 to 13 and include the following: pain, fatigue, nausea, disturbed sleep, emotional distress, shortness of breath, lack of appetite, drowsiness, dry mouth, sadness, vomiting, difficulty remembering, and numbness or tingling

In addition to the aforementioned 13 symptoms, which are general symptoms experienced by cancer survivors, there were an additional nine items that are specific to head and neck cancer that were assessed. These nine additional items constitute items 14 through 22 and include: mucus in the mouth and throat, difficulty swallowing/chewing, choking/coughing, difficulty with voice/speech, skin pain/burning/rash, constipation, problems with tasting food, mouth/throat sores, and problems with teeth or gums (Cleeland, 2016). The nine items comprise two factors that are specific to head and neck symptoms, that include: (1) a factor consisting of mouth sores, tasting food, constipation, teeth or gum problems, and skin pain (5 items), and (2) a factor consisting of problems with voice, choking/coughing, swallowing/chewing, and mucus (4 items; Cleeland, 2016). The two factor scores were used to test the study’s model.

Part 2 (Life Interference)

The Life Interference section of the MD Anderson Symptom Inventory- Head and Neck Module consists of six items. These six items measure how much have symptoms interfered with life including: general activity, mood, work (including work around the house), relations with others, walking, and life enjoyment. These six self-reported items were noted by participants through the use of 11-point response options (0 = Did Not Interfere to 10 = Interfered Completely).

Internal consistency reliability of the MDASI-HN was demonstrated by Cronbach alphas ranging from 0.72 to 0.92 for the 13 core symptom items, which included the nine items specific to head and neck symptoms and the six interference items. Permission to use the MDASI-HN was obtained from MD Anderson Department of Symptom Research.

Cancer Patient Tobacco Use Questionnaire (C-TUQ)

A self-report measure was used to examine tobacco use among study participants (Appendix L). The Cancer Patient Tobacco Use Questionnaire (C-TUQ) consists of a total of 22 items and was designed for use in adult cancer patients either receiving treatment or having completed treatment. All items of the C-TUQ were cognitively tested on cancer patients and survivors. Items were evaluated on ease of comprehension and revised accordingly so that content validity of the measure was established (Land et al., 2016). This study used four of the items from the C-TUQ including items 7, 8, 10a, and 13. These four items measured smoking frequency during time periods related to cancer diagnosis and treatment, types of tobacco products used since first being diagnosed with cancer, if cigarettes were smoked in the past 30 days, and if participants' cancer doctors had advised them to quit smoking cigarettes. Items were summarized, thereby creating one variable for tobacco use. The variable was coded so that a response of one denoted that the participant used tobacco and a score of zero denoted that the participant did not use tobacco. The C-TUQ is publicly available, therefore, no permission was needed to use this instrument.

Recommended Alcohol Questions (National Institute on Alcohol Abuse and Alcoholism)

The Recommended Alcohol Questions that were created by the National Institute on Alcohol Abuse and Alcoholism (NIAAA), is a self-report measure to examine alcohol use. The instrument is designed to capture information about one's level of consumption of alcohol and associated drinking patterns. One item, from the instrument, was used to identify the frequency of alcohol consumption among participants. This question was developed as part of a question set that examined overall alcohol use (Appendix M). The instrument provides researchers, of all fields, with alcohol-related questions to assess alcohol use. The Recommended Alcohol Questions measure is publicly available.

Demographic Questionnaire

A demographic questionnaire was developed and included as part of the survey (Appendix N). Specifically, 16 demographic items were collected from project participants. The information collected included details about the participant's (1) current age, (2) gender, (3) current relationship status, (4) race/ethnicity, (5) highest level of education, (6) employment status, (7) date of diagnosis, (8) age at diagnosis, (9) stage of disease at diagnosis, (10) location of originating head and neck cancer at diagnosis, (11) type(s) of treatment, (12) if treatment was completed, (13) symptoms experienced as a result of treatment, (14) diagnosis of or treatment for depression/anxiety, (15) current medication for depression/anxiety, and (16) any additional information regarding the participant's physical or emotional experiences with head and neck cancer.

Data Analysis

To analyze the data obtained, different statistical analyses were used. For research questions one and two, descriptive statistics were used. The purpose of using descriptive statistics was to describe the occurrence and intensity of late-effects symptoms, tobacco and alcohol use, and demoralization.

Research question three was explored through the use of a hierarchical multiple regression. The purpose of this regression was to explain the relationship between the independent variables (e.g., late-effect symptoms, life interference, and tobacco and alcohol use with demoralization), while controlling for age. To determine the amount of variation in demoralization, as explained by the independent variables, the following variables were entered in blocks to represent the various factors of the Theory of Unpleasant Symptoms. These four blocks were represented by: (a) Block One (the control variable, age), (b) Block Two (tobacco and alcohol use; situational factors), (c) Block Three (late-effect symptoms represented by the two factors of the MDASI-HN), and (d) Block Four (the life interference scale of the MDASI-HN). An evaluation of the assumptions for regression (i.e., normality, linearity, independence-Durbin-Watson, non-multicollinearity, homoscedasticity, and evaluation of outliers) was conducted. Furthermore, correlations for multicollinearity were examined for the independent variables (Gelman & Hill, 2007).

Ethical Considerations

Confidentiality

Confidentiality was maintained throughout this study. Participants submitted online data anonymously and all paper copies of the survey were de-identified. All electronic data was kept password protected and stored on secure servers at the KUMC. Completed paper copies of the survey were kept in a locked storage box offsite at a location only known to the doctoral student conducting the study.

Study Limitations

Physical symptom variables (e.g., trismus, lymphedema, neuropathy, neck and shoulder stiffness/pain/difficulty, physical disfigurement, sleep disturbances, and cognitive difficulties), all of which may potentially relate to quality of life, were not examined in this study. In addition, the medical records of participants were not reviewed. The possibility for error exists, as all measures depend upon participants' self-report. The potential for selection bias exists.

The exclusion criteria applied during this study may have limited the generalizability of the findings. Head and neck cancer-survivors who participated in the study may not represent the entire population of head and neck cancer survivors, thereby limiting any generalizations that may be made to the larger population.

Chapter 4: Results

The purpose of this study was twofold, first to identify the occurrence and intensity of late-effect symptoms (e.g., xerostomia, mucositis, dysphagia, pain, and fatigue), tobacco and alcohol use, and demoralization among head and neck cancer survivors. The second purpose of the study was to examine the relationships among late-effect symptoms, tobacco and alcohol use, and demoralization in head and neck cancer survivors. Chapter 4 presents the demographic characteristics of the sample of study participants as well as the results addressing the following three research questions:

1. What is the occurrence and intensity of late-effect symptoms (as measured by the M.D. Anderson Symptom Inventory – Head and Neck module (MDASI-HN)), and tobacco and alcohol use among head and neck cancer patients and survivors?
2. What is the occurrence and intensity of demoralization in head and neck cancer patients and survivors?
3. Controlling for age, do late-effect symptoms (Factor I: mouth sores, food tasting, constipation, teeth/gum problems, skin pain; and Factor II: voice, choking/coughing, dysphagia [swallowing/chewing], and mucus and Part II: life interference scale)) and tobacco and alcohol use in head and neck cancer patients and survivors explain the variance in demoralization?

The chapter begins with demographic and other background characteristics of the sample (Tables 2 to 8). These tables report data addressing Research Question 1. Specifically, they include information about the initial cancer diagnosis, treatments received, side effects experienced, and information about diagnosis and treatment of anxiety and/or depression. The descriptive statistics for all scales used in the study are presented to address Research Questions

1 and 2 (Tables 2 to 9 and Figure 1). Finally, the statistical tests conducted to explore Research Question 3 are presented (Tables 10 to 12).

Demographics of Sample

Fifty-one participants qualified for this study and completed all the questionnaires (Table 2). The average age of the participants was 62.88 years old (*SD* = 10.85) with respondents ranging in age from 34 to 91 years of age. Of the participants, 58.8% identified as male (*n* = 30) and 41.2% identified as female (*n* = 21). Almost all participants identified as White or Caucasian (90.2%). Over half of the respondents reported being married (*n* = 29; 56.9%). Much smaller numbers reported being single (*n* = 8, 15.7%), widowed (*n* = 6, 11.8%), divorced (*n* = 5, 9.8%), or in a relationship (*n* = 3, 5.9%). The sample was well-educated, with 88.3% having had at least some college, and almost half (47.1%) having earned a bachelor's or graduate degree. Half of the sample reported being retired, while almost a quarter were working full-time. Approximately 16% of respondents reported being disabled and less than 6% reported being employed part-time, being on medical leave, or unemployed.

Table 2

Participant Demographics

Question	Frequency	Percentage
With what gender do you most identify?		
Male	30	58.8
Female	21	41.2
What race or ethnicity do you identify with?		
American Indian/Alaska Native	1	2.0
Asian	2	3.9
Black or African American	2	3.9
White or Caucasian	46	90.2
What is your current relationship status?		
Single	8	15.7
Divorced	5	9.8
Married	29	56.9
Widowed	6	11.8
In a relationship	3	5.9
What is your highest level of education?		
No High School Degree	2	3.9
High School Diploma or GED	4	7.8
2 Years of College (Associates) or Trade Degree	7	13.7
Some College	14	27.5
Bachelor’s Degree	10	19.6
Graduate School or Graduate Degree	14	27.5
What is your employment status?		
Full time	12	23.5
Part time	2	3.9
Medical Leave	3	5.9
Disabled	8	15.7
Retired	25	49.0
Unemployed	1	2.0

Cancer Diagnosis, Treatments, and Side Effects

Approximately half (52.9%) of the sample received their cancer diagnosis within the last five years, with 21.6% reporting a diagnosis 6 to 10 years ago, and a quarter (25.5%) reporting a diagnosis over 11 years ago (see Table 3).

Table 3

Years Since Cancer Diagnosis

Years	***n***	**Percentage**
Less than 2	10	19.6
3 to 5	15	33.3
6 to 10	11	21.6
Over 11	13	25.5

Table 4 shows that over a quarter (27.5%) of the participants reported their initial diagnosis as Stage 4, the most severe level, with 21.6% reporting that they did not know/did not remember or were uncertain about the stage of their initial diagnosis of head and neck cancer.

Table 4

Stage of Cancer at Initial Diagnosis

Stage	***n***	**Percentage**
1	10	19.6
2	8	15.7
3	8	15.7
4	14	27.5
Did Not Know, Did Not Remember, or Uncertain	11	21.6

Most respondents reported knowing the location of their initial diagnosis (94.1%). The locations included but were not limited to the tongue, tonsils, throat, and jaw (see Table 5).

Table 5

Location of Initial Diagnosis of Head and Neck Cancer

Location	***n***
Tongue	11
Tonsils	5
Mouth	5
Sinus	5
Jaw	4
Throat	3
Larynx	3

Location	***n***
Thyroid	3
Neck	2
Salivary/Parotid Glands	2
Nasopharynx	1
Ear Canal	1
Unspecified	6

Radiation was the most common type of treatment received (86.3%), followed by surgery (70.6%), and chemotherapy (54.9%). Immunotherapy was rarely reported (3.9%), as well as other types of treatment (15.7%), which included supplements, occupational and physical therapy, etc. (see Table 6).

Table 6

Types of Treatment Received or Currently Receiving

Type of Treatment	***n***	**Percentage**
Radiation	44	86.3
Surgery	36	70.6
Chemotherapy	28	54.9
Immunotherapy	2	3.9
Other treatment	8	15.7

Most of the participants (82.4%) indicated that they had finished their treatment. Although for 27.5% treatment completion occurred within the previous 2 years, 52.8% indicated that it had been 3 years or greater since completion of their treatment (Table 7).

Table 7

Years Since Completion of Cancer Treatment

Years	***n***	**Percentage**
Less than 2	14	27.5
3 to 5	9	17.6
6 to 10	9	17.6
11 or more	9	17.6
Missing data	10	19.6

Table 8

Length of Time Since Diagnosis – Comparisons Between Variables

Demographics	**Total Sample** (*N* = 51)	**Less than or equal to 3 years** (*n* = 19)	**Over 3 years** (*n* = 22)	***t* statistics (*p* value)**
Age – Mean (SD) Range: year-year	62.88 (10.75) 34-91	61.68 (12.24) 36-91	64.64 (10.46) 34-83	*t* = 0.83 (0.410)
Duration of time since DX	6.78 (4.71) Range: 1-17	3.53 (2.20) Range: 2-10	10.45 (3.46) Range: 5-16	*t* = -7.51 (0.001)
Gender – n (%)				
Female	21 (41.2%)	5 (26.3%)	9 (40.9%)	N/A
Male	30 (58.8%)	14 (73.7%)	13 (59.1%)	N/A
Alcohol use in last 30 days – n (%)				
Yes	19 (37.3%)	8 (42.1%)	8 (36.4%)	N/A
No	32 (62.7%)	11 (57.9%)	14 (63.6%)	N/A
MDASI – Five Items				
Mean (SD) Range: year-year	1.76 (1.86) 0-7.40	1.94 (1.87) 0-6.20	1.64 (1.70) 0-7.20	*t* = 0.53 (0.596)
MDASI – Four Items				
Mean (SD) Range: year-year	3.49 (2.59) 0-9.00	3.80 (2.64) 0-9.00	3.53 (2.47) 0-8.00	*t* = 0.34 (-0.738)
Life Interference				
Mean (SD) Range: year-year	2.71 (2.53) 0-8.17	3.19 (2.84) 0-8.17	2.43 (1.96) 0-6.67	*t* = 1.01 (0.318)
Demoralization				
Mean (SD) Range: year-year	4.82 (6.03) 0-29.00	7.37 (8.27) 0-29.00	3.73 (3.83) 0-14.0	*t* = 1.85 (0.072)

When comparing selected variables between length of time since diagnosis of less than or equal to or greater than three years, no significant differences were found.

Independent Variables Measurement

The independent variables selected for this study included physical symptoms related to participants' cancer (e.g., communication difficulties, teeth/gum problems, dysphagia, etc.) and substance use (i.e., alcohol and tobacco). Table 9 outlines the various side effects of participants' cancer treatment. Communication difficulties, due to treatment, were the most common side effects reported, with nearly half of respondents noting this. Communication difficulties included voice problems, hearing loss, etc.

Other difficulties included loss of teeth and physical disfigurement, which were the next most common reports, with hearing loss reported by 21.8% of the participants (Table 9). Other side effects included but were not limited to dry mouth, cough, excessive mucus, lymphedema, neuropathy, muscle fibrosis, difficulty eating, memory loss, difficulty sleeping, neurological deficits, and chronic neck and shoulder pain.

Table 9

Side Effects of Cancer Treatment(s)

Side Effects	***n***	**Percentage**
Communication Difficulties	25	49.0
Loss of Teeth	22	43.1
Physical Disfigurement	19	37.3
Hearing Loss	11	21.6
Permanent Throat Opening	4	7.8
Permanent Feeding Tube	3	5.9
Other	31	60.8

Anxiety, Depression, Alcohol, and Tobacco Use

About a third (33.3%) of respondents reported that they had been diagnosed with and/or treated for depression/anxiety, yet only 31.4% indicated that they were currently taking medication for depression/anxiety.

The question posed was, “In the last 30 days, have you smoked any cigarettes, even one or two puffs?” While none of the participants indicated that they had smoked, almost 20% of respondents did not answer this question.

In addition to determining tobacco use, information about alcohol consumption was collected. A question about how often individuals, since their diagnosis, drank alcohol found that 10% of respondents reported daily use of alcohol. Twenty percent of respondents reported that they drank on a weekly basis. Forty-one percent of respondents reported that while they did drink, in the past, they had not had any alcohol during the last year. Only 2% of respondents indicated they had never consumed alcohol.

Descriptive Statistics for Scales Used in Study

Table 10 details descriptive statistics for the scale variables used in this study: (1) the MD Anderson Symptom Inventory-Head and Neck (MDASI-HN) module includes two scales. One scale is comprised of two factors that measure the intensity of various side effects of head/neck cancers and side effects from treatment. Factor I include 5 items: mouth sores, food tasting, constipation, teeth/gum problems, and skin pain and Factor II includes 4 items: voice, choking/coughing, dysphagia [swallowing/chewing], and mucus. 2) The other, the Life Interference Scale, explores six interference items including general activity, mood, work (including work around the house), relations with other people, walking, and enjoyment of life. Participants responded on a 10-point scale with 0 indicating the symptom “Did not interfere” to 10 indicating that it had “Interfered completely.” 3) The Demoralization Scale II (DS-II) is a 16-item, 2 factor (Meaning and Purpose and Distress and Coping Ability) measuring demoralization. All of the measures reveal positively skewed distributions, which indicates low scores on all the variables of interest.

Table 10

Central Tendency Statistics for Independent and Dependent Variables

Data Responses	Minimum	Maximum	Mean	SD	Variance
MDASI-HN (5)	0	7.40	1.77	1.87	3.50
MDASI-HN (4)	0	9.00	3.49	2.60	6.75
Life Interference Scale	0	8.17	2.71	2.53	8.38
Demoralization Scale II (DS-II)	0	29.00	2.82	6.03	36.39

Independent Variable Measurement

Research Question 1

“What is the occurrence and intensity of late-effect symptoms (as measured by the M.D. Anderson Symptom Inventory – Head and Neck Module (MDASI-HN)), and tobacco and alcohol use among head and neck cancer patients and survivors?” (See Figures 1 and 2). Due to there being no variability on tobacco use, that variable was eliminated from the analysis. Alcohol use was minimal with

The MDASI-HN measures symptom intensity and the scores range from 0 (Not Present) to 10 (As Bad as You Can Imagine). The five items for Factor I of the MDASI-HN include: mouth sores, food tasting, constipation, teeth/gum problems, and skin pain. Factor I had a mean score of 1.78, with a standard deviation of 1.87. This indicates, and Figure 1 illustrates, a positive skew for this factor, with only a few people reporting relatively high scores (over 6) of symptom intensity.

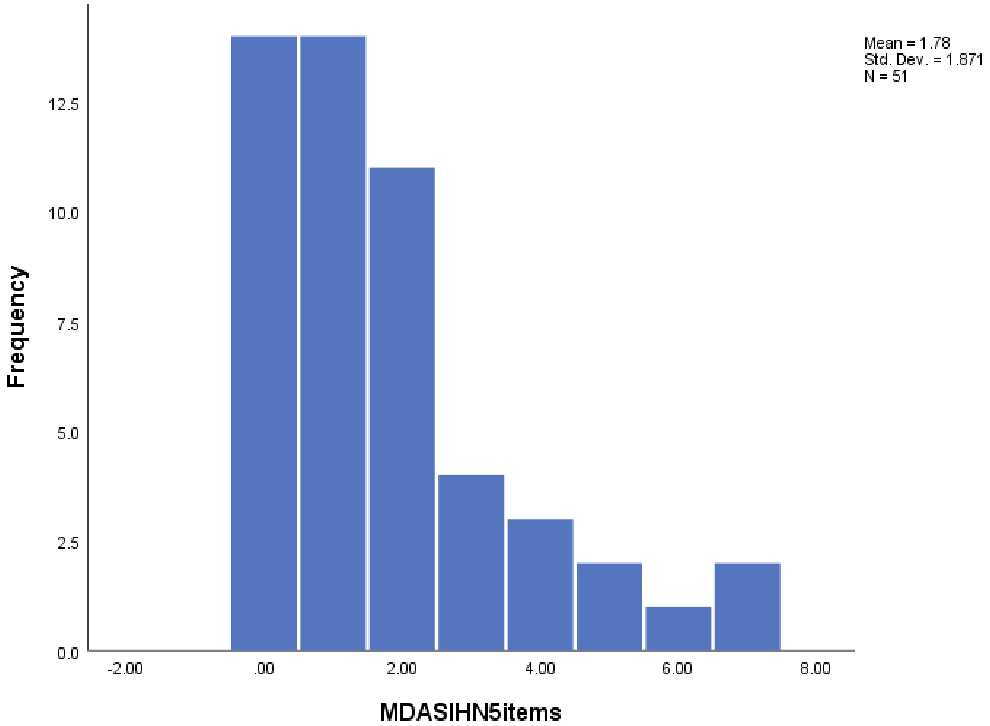

Figure 1. Histogram of MDASI-HN Factor I total scores.

Factor II of the MDASI-HN includes four items: voice, choking/coughing, dysphagia [swallowing/chewing], and mucus with a possible range of scores between 1 to 10. The Factor II sample mean was 3.49 with a standard deviation of 2.59. Figure 2 illustrates a slightly positive skew of the distribution, with mostly low scores, yet some relatively high scores (8 and 9). Thus, Factors I and II reveal a sample of mostly low scores for the symptom scale.

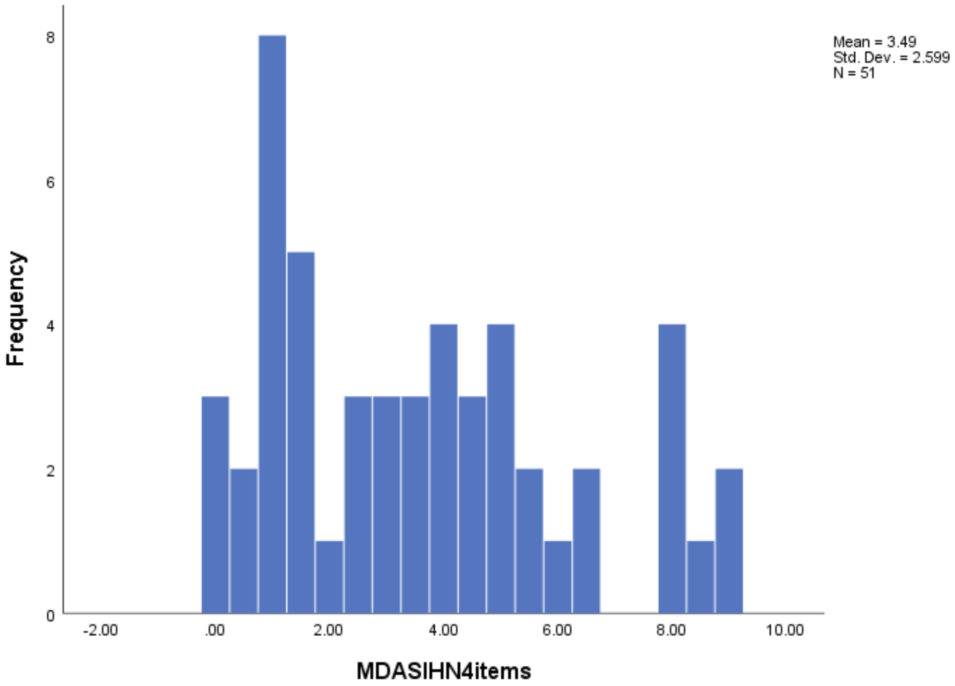

Figure 2. Histogram of MDASI-HN Factor II total scores.

The Life Interference Scale of the MDASI-HN consists of six questions, explores how much symptoms have interfered with the following items in the last 24 hours: general activity, mood, work (including work around the house), relations with other people, walking, and enjoyment of life. The sample had a mean score of 2.71 with a standard deviation of 2.52. As with the other two symptom factors (Factor I and Factor II), Figure 3 reveals a positively skewed distribution, which indicates low symptom intensity among this sample.

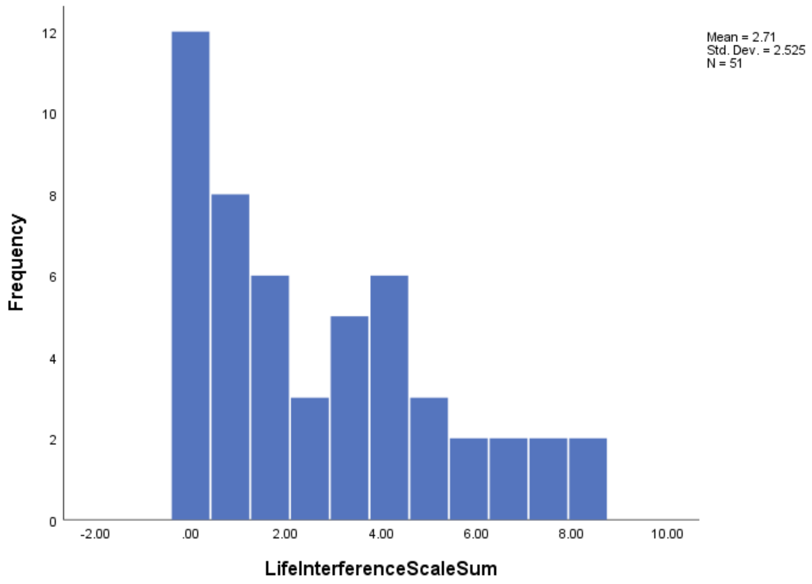

Figure 3. Histogram of Life Interference Scale total scores.

Dependent Variable Measurement

The Demoralization Scale II (DS-II) contains 16 items. Permission to use the Demoralization Scale II was obtained from the scale's original author, David Kissane, MD (Appendix J). The DS-II has two subscales: (1) Meaning & Purpose and (2) Distress & Coping Ability. Each subscale is comprised of eight questions. The items for both subscales are measured using a 3-point scale, with 0 representing Never, 1 representing Sometimes, and 2 representing Often. The DS-II uses a sum of both subscales for a total score that encompasses all 16 items. The DS-II asks participants a series of questions, indicating how much (or how strongly) they have felt a certain way over the past two weeks. For example, item 1 of the DS-II states "There is little value in what I can offer others." The total possible score for this scale ranges from a low of 0 to a high of 32. A score of 30 or greater indicates high demoralization.

Research Question 2

Research question two explored, “What is the occurrence and intensity of demoralization in head and neck cancer patients and survivors?” In this sample, the mean DS-II score was 4.82 and the standard deviation was 6.032. The histogram in Figure 4 illustrates the positive skew of the distribution for this sample, indicating that, overall, this sample has low demoralization scores.

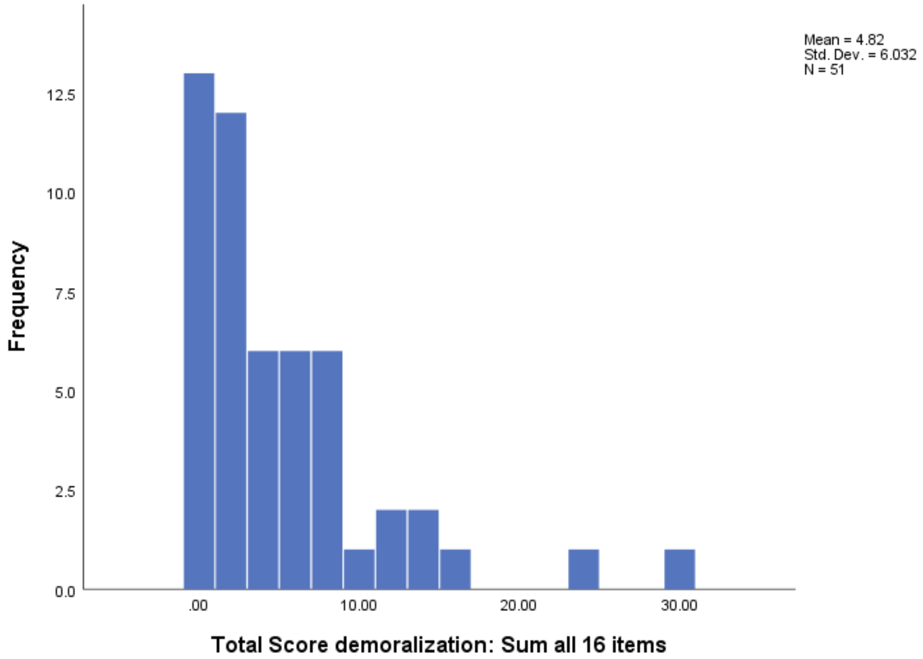

Figure 4. Histogram of demoralization total scores.

Statistical Analyses

Research Question 3

“Controlling for age, do late-effect symptoms (Factor I: mouth sores, food tasting, constipation, teeth/gum problems, skin pain; and Factor II: voice, choking/coughing, dysphagia [swallowing/chewing], and mucus and Part II: life interference scale) and alcohol use in head and neck cancer patients and survivors explain the variance in demoralization?” To answer this question, a hierarchical regression analysis was conducted. Before regression analyses were conducted, a series of tests were performed to address questions of linearity, collinearity among variables, and collinearity among residuals, homoscedasticity, and outliers. There was linearity as assessed by partial regression plots and a plot of studentized residuals against the predicted values. There was independence of residuals, which was assessed using a Durbin-Watson statistic of 1.962. There was homoscedasticity, which was assessed using a visual inspection of a plot of studentized residuals versus unstandardized predicted values. There was no evidence of multicollinearity, as assessed by tolerance values no greater than 0.7 and no values less than 0.1. There were no studentized deleted residuals greater than ±3 standard deviations, no leverage values greater than 0.2, and values for Cook's Distance were above 1. The assumption of normality was met, as assessed by visual inspection using a P-P Plot and a histogram. Therefore, there were no considerations to be taken into account before pursuing regression analyses.

A hierarchical multiple regression was conducted using SPSS Version 26 statistical software. Age was controlled for and the statistical analysis was run to determine if late- effect symptoms and tobacco and alcohol use among head and neck cancer survivors explained variance in demoralization. Table 9 provides full details for the regression stage. Stages are numbered based on the order (Stages 1, 2, 3, and 4).

Stage 1 consisted of the control variable age and was not statistically significant, $R_2 = 0.060$, $F(_{1,\,49}) = 2.742$, $p = 0.104$, adjusted $R_2 = 0.034$. With the addition of Stage 2, alcohol and tobacco use in the last 30 days, no statistical significance was demonstrated, $R_2 = 0.060$, $F(_{2,\,48}) = 1.545$, $p = 0.224$, adjusted $R_2 = 0.021$. The addition of Stage 3 that included the two factors of the MDASI-HN (Factor I: mouth sores, food tasting, constipation, teeth/gum problems, skin pain; and Factor II: voice, choking/coughing, dysphagia [swallowing/chewing], and mucus, contributed significantly to the explanation of demoralization with an $R_2 = 0.188$, $F(4, 46) = 2.656$, $p = 0.045$, adjusted $R_2 = 0.117$.

Stage 4 (consisting of age, alcohol use in the last 30 days, tobacco use in the last 30 days, and two factors consisting of late-effect symptoms: Factor I: mouth sores, food tasting, constipation, teeth/gum problems, skin pain; and Factor II: voice, choking/coughing, dysphagia [swallowing/chewing], and mucus and the Life Interference Scale from the MDASI-HN measure) also was statistically significant and contributed the most to the explanation of variance for demoralization with an $R_2 = 0.279$, $F(5, 45) = 3.488$, $p < 0.009$; adjusted $R_2 = 0.199$.

Table 11

Results of Multiple Regression Analysis of Independent Variables on Demoralization

Stage	**R**	**R_2**	**Adjusted R_2**	**Std. Error**	**R_2 Change**	***F* Change**	**df1**	**df2**	**Sig *F* Change**
1 Age	0.230	0.053	0.034	5.93	0.053	2.74	1	49	0.104
2 Alcohol Use in last 30 days	0.246	0.060	0.021	5.97	0.007	0.38	1	48	0.539
3 MDASI-HN Factors I and II	0.433	0.188	0.117	5.67	0.127	3.60	2	46	0.035
4 Life Interference	0.529	0.279	0.199	5.40	0.092	5.73	1	45	0.021

To determine which of the particular independent variables were significant, regression coefficients are presented in Table 11 that presents the regression coefficients for the four stages of the model tested. It indicates that age becomes a significant contributor to the explanation of demoralization in Stage 3 ($p = 0.04$). In the fourth stage tested, age remains significant ($p = 0.05$), while Factor I of the MDASI-HN becomes insignificant, and the Life Interference score is a significant contributor to the explanation of variation in demoralization in this sample (*p* = 0.02) in this sample.

Table 12

Regression Coefficients for Explaining Demoralization

Stage		Unstandardized Coefficients		Standardized Coefficient	*t*	Level of Significance	Zero Order	Partial Correlations	Part
		B	Std. Error	Beta					
1	Constant	12.950	4.977		2.602	0.012			
	How old are you (in years)?	-0.129	0.078	-0.230	-1.656	0.104	-0.230	-0.230	-0.230
2	Constant	12.763	5.018		2.543	0.014			
	How old are you (in years)?	-0.133	0.079	-0.236	-1.684	0.099	-0.230	-0.236	-0.236
	AlcoholUsedinLast30Days	1.071	1.733	0.087	0.618	0.539	0.070	0.089	0.087
3	Constant	11.881	4.802		2.474	0.017			
	How old are you (in years)?	-0.157	0.075	-0.280	-2.087	0.042	-0.230	-0.294	-0.277
	AlcoholUsedinLast30Days	1.393	1.653	0.113	0.843	0.404	0.070	0.123	0.112
	MDASHIHN5items	1.025	0.550	0.318	1.862	0.069	0.319	0.265	0.247
	MDASHIHN4items	0.144	0.397	0.062	0.363	0.718	0.220	0.053	0.048
4	Constant	10.103	4.633		2.181	0.034			
	How old are you (in years)?	-0.148	0.072	-0.263	-2.054	0.046	-0.230	-0.293	-0.260
	AlcoholUsedinLast30Days	2.022	1.596	0.164	1.267	0.212	0.070	0.186	0.160
	MDASHIHN5items	0.513	0.566	0.159	0.906	0.370	0.319	0.134	0.115
	MDASHIHN4items	-0.022	0.385	-0.009	-0.056	0.956	0.220	-0.008	-0.007
	LifeInterferenceScaleSum	0.893	0.373	0.374	2.393	0.021	0.424	0.336	0.303

*Zero order – correlation for age was -0.230, partial correlations for age was -0.236; these numbers indicate the possibility of suppression, to be explored in future larger studies.

Chapter 5: Discussion

This descriptive, correlational study was conducted to evaluate the occurrence and intensity of late-effect symptoms, tobacco and alcohol use, and their relationships to the level of demoralization among head and neck cancer survivors. Late-effect symptoms were measured by the two factors of the M.D. Anderson Symptom Inventory – Head and Neck Module (MDASI-HN). Factor I of the MDASI-HN includes 5 items: mouth sores, food tasting, constipation, teeth/gum problems, and skin pain; and Factor II includes 4 items: voice, choking/coughing, dysphagia [swallowing/chewing], and mucus. Part II of the MDASI-HN was the life interference scale which measured participants' life interference from their symptoms. The frequency of tobacco and alcohol use among participants was recorded. Those variables were then examined in relation to demoralization as measured by the Demoralization Scale II (DS-II). The variables analyzed in this study were selected on the basis of the literature review and the theory of unpleasant symptoms. This final chapter includes a summary of research findings, strengths and limitations, implications of and recommendations for future research.

Research Findings

Using the theory of unpleasant symptoms as the guiding theoretical framework, this study was designed to address two specific aims: (a) identify the occurrence and intensity of late-effect symptoms, tobacco and alcohol use, and demoralization in head and neck cancer survivors, and (b) examine the relationships among late-effect symptoms, tobacco and alcohol use, and demoralization in head and neck cancer survivors. The purpose of the study was achieved by recruiting adult participants who had been treated for head and neck cancer and were not being treated for any other type of cancer. Participants answered a questionnaire consisting of a series of questions addressing demographics, such as alcohol and tobacco use, and late-effect symptoms including life interference, and psychological issues being experienced. Participant responses were de-identified.

The research questions explored in this study include:

1. What is the occurrence and intensity of late-effect symptoms, as measured by the M.D. Anderson Symptom Inventory – Head and Neck Module (MDASI-HN), and tobacco and alcohol use among head and neck cancer patients and survivors?
2. What is the occurrence and intensity of demoralization in head and neck cancer patients and survivors?
3. Controlling for age, do late-effect symptoms (Factor I: mouth sores, food tasting, constipation, teeth/gum problems, skin pain; Factor II: voice, choking/coughing, dysphagia [swallowing/chewing], and mucus and Part II: life interference scale) and tobacco and alcohol use in head and neck cancer patients and survivors explain the variance in demoralization?

Occurrence and Intensity of Late-Effect Symptoms

The purpose of research question one was to determine the occurrence and intensity of a specified set of late-effect symptoms, which was measured by the M.D. Anderson Symptom Inventory – Head and Neck (MDASI-HN) scale. Part I of the MDASI-HN consists of two factors (Factor I: mouth sores, food tasting, constipation, teeth/gum problems, skin pain; Factor II: voice, choking/coughing, dysphagia [swallowing/chewing], and mucus). Part II of the MDASI-HN is a Life Interference Scale, which consists of six items. The majority of respondents stated that they did not use alcohol or tobacco at all. Only one participant reported daily use of alcohol.

The purpose of research question two was to determine the intensity and occurrence of demoralization over the past two weeks. Demoralization was measured using the Demoralization

Scale II (DS-II), which is comprised of 16 items. The mean score for demoralization for this sample was relatively low at 4.82. Although the overall mean score for the Demoralization Scale II was low, it is important to note that there were items on the measure that were noteworthy, due to the responses provided by participants. For example, number 7, on the measure, stated "I feel hopeless." This measure had 19.6% of respondents indicating that they sometimes felt hopeless. Number 8, on the measure, stated "I feel irritable," which had 56.9% of respondents indicating that they "Sometimes" felt irritable, and 7.8% of respondents noting that they "Often" felt irritable. Forty-seven percent of participants who responded to item number 12 indicated that they "Sometimes" or "Often" felt distressed about what was happening to them. Furthermore, nearly 30% of respondents indicated that they "Sometimes" or "Often" did not cope well with life. These results may provide hints regarding further areas of exploration that are clinically significant, which may warrant additional research.

To examine research question three, a hierarchical multiple regression was conducted. This analysis examined whether, when controlling for age, late-effect symptoms (Factor I: mouth sores, food tasting, constipation, teeth/gum problems, skin pain and Factor II: voice, choking/coughing, dysphagia [swallowing/chewing], and mucus and Part II: life interference scale), and alcohol use, among head and neck cancer patients and survivors, explained demoralization among the sample. The first stage in the hierarchical multiple regression was the control variable age. Age was controlled for due to findings in the literature search that older adults with cancer tend to experience less distress than younger cancer survivors. Therefore, age was controlled for in regression to make certain it was not a confounding variable possibly affecting demoralization scores in the sample. Stage 2 included alcohol and tobacco use in the last 30 days. Stage 3 consisted of the two factors of MDASI-HN, and Stage 4 consisted of age, alcohol use, in the last 30 days, with Part 1 of the MDASI-HN (i.e., the two factors of the MDASI-HN consisting of late-effect symptoms) and Part 2 of the MDASI-HN (i.e., consisting of the six questions of the Life Interference Scale). The addition of Stage 4 entered the life interference variable and resulted in statistically significant increases in the explanation of variance in demoralization among head and neck cancer patients.

Across the four regression stages, two variables within the study framework, age and life interference, explained variation in the sample's demoralization scores. Yet, the measures of the situational factors of tobacco and alcohol use and late-effect symptoms (Factor I and Factor II) were not significant in explaining the variance of demoralization in this sample. This result was unexpected because undergirding the study model was the theory of unpleasant symptoms. Thus, it was expected that the broad range of symptoms specific to head and neck cancers would impact demoralization. However, age was a controlled factor, which was thought to explain the variance in demoralization, as noted in the literature. One explanation for the lack of symptom explanation was that the majority of sample participants were two years or more out from their original treatment. Another possible explanation is that the majority of symptoms may have been adapted to over time. In addition, over 50% of the sample participants were either married or partnered. Marriage/partnership has been shown to be a social protective factor, which may assist cancer survivors with proper management and adaptation to late-effect symptoms. An interesting finding to be explored in future studies with larger samples was possible suppression involving the control variable of age (Cohen & Cohen, 1975).

Theoretical Relevance

The theoretical framework that guided this study was the theory of unpleasant symptoms. The theory of unpleasant symptoms states that there are situational, physiologic, and psychologic factors that explain relationships and can lead to symptom treatment (Lenz et al., 1997). Symptoms are the main focus of the theory as they are indicators of changes in normal functioning. The primary focus of this study was to determine relationships of late-effect symptoms experienced by head and neck cancer survivors and the potential effects of these symptoms on patient demoralization.

Specifically, these study results indicated, found, when controlling for age, a relationship between a psychologic factor of symptom-related life interference (general activity, mood, work including work around the house, relations with other people, walking, and enjoyment of life) and demoralization. Variables representing situational factors (alcohol and tobacco use), were not significant in the model, nor were the physiological factors of late-effect physical symptoms. The shared variance between the two physiologic factors may have decreased their unique variance with the dependent variable of demoralization based on their zero-order correlations. Also, due to the lack of variability on the smoking factor it was dropped from the analysis. Thus, findings of this study partially supported the use of variables, which represent the various factors of the theory of unpleasant symptoms, by explaining the variance of demoralization among head and neck cancer survivors.

Meaning of Results

Symptom occurrences and intensities were relatively low in this sample. Several potential reasons for the low scores on these measures need to be denoted. First, many of the respondents, over 52.8%, were three years or greater more out from their completion of treatment and perhaps symptom severity had subsided by the point that they completed the survey or patients had learned to live with their symptoms. Second, although symptoms may have persisted, the intensity or the perception of the symptom might have decreased, overtime, due to the chronic nature of the late-effect symptoms measured. Finally, the study instruments captured a narrow timeframe for symptom intensity and occurrence. The MDASI-HN measures symptom intensity over the past 24-hours and the Demoralization Scale II measures demoralization over the past two weeks. These timeframes may not have adequately captured participants' experiences of late-effect symptoms. The mean score for the Life Interference Scale also was low at 2.71 with a standard deviation of 2.52.

Perhaps the strongest explanation regarding why the scores on the MDASI-HN and the Demoralization Scale II were low may lie in the sample's demographic data. Over half of participants were male (58.8%) and reported being married (56.9%) or in a relationship (5.9%). Social support is a major protective factor for cancer patients. A study of Surveillance, Epidemiology, and End Results (SEER) data, that included patients who were diagnosed with a variety of cancers (including head/neck cancers), revealed that those who were diagnosed and were married were at a significantly lower risk for metastatic cancer, undertreatment, and death due to cancer (Aizer et al., 2013). In the study conducted by Aizer et al. (2013), head and neck cancer patients who were married received a greater survival benefit than that of receiving chemotherapy treatment. Specifically, head and neck cancer patients who were married had the largest relative reduction in cancer-related deaths (33%; Aizer et al., 2013). In another study conducted with newly diagnosed head and neck cancer patients in the 65 and older age group, 56% of unmarried patients reported clinically elevated distress compared with 44% of married patients (Lominska, Hamilton, Murray, Neupane, Shnayder, Kakarala, & Chen, 2017). In this study, 33.3% of participants responded "yes" to the question if they had ever been diagnosed with or treated for anxiety/depression. Furthermore, 31.4% of respondents indicated that they were currently taking medication for depression/anxiety, which may have been a mitigating factor in the lower scores reported across the measures. Additional demographic factors, that may have resulted in lower scores, among participants, on both the MDASI-HN and the Demoralization Scale II measures, may have been related to education levels and employment status. Participants reported their highest level of education being some college, bachelor's degree, or graduate school or degree with almost half reporting their employment status as retired. The majority of participants in this study were not recruited from the support group.

Strengths and Limitations

A key strength of this study is the information provided about late-effect symptoms, life interference, demoralization, and the sparse alcohol and tobacco use among this sample of head and neck cancer survivors. A purposive sample of 51 head and neck cancer survivors participated in this study. Participants answered a survey consisting of demographic questions, that included information about their age and education level, questions about their physical symptoms (i.e., occurrence and intensity), how physical symptoms may have interfered with the individual's daily life in the previous 24 hours, questions about their alcohol and tobacco use, and questions about their experiences with psychological issues (i.e., particularly focusing on demoralization over the past two weeks). Another strength of this study is that there are few studies that have addressed demoralization in cancer survivors and particularly in head and neck cancer survivors.

This study is clinically significant because suicide rates are higher among cancer survivors, as compared to survivors of other chronic diseases. In a study of the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) data, Osazuwa-Peters et al. (2018) reported that head and neck cancer survivors were nearly twice as likely to die from suicide as compared to survivors of other types of cancer. These suicide rates represent a significant risk for head and neck cancer survivors. More specific and sensitive measures need to be developed that target the unique issues of this group of cancer survivors. These measures should be easy to administer and exhibit excellent reliability and validity, that ideally will aid in the early identification of individuals who are distressed, thereby facilitating referrals to more appropriate and effective care resources. Recommendations would include increased use of the MDASI life interference scale and testing a version of the MDASI-HN that asks about symptoms further out than 24 hours without recall bias in this population. These measures may not have adequately captured the issues experienced by longer term survivors, as there were so many that were not assessed by the MDASI-HN. Although, no significant differences were noted in those participants at three years or less versus those greater than three years out since diagnosis. Anxiety and distress levels should be examined in future studies as well.

Nursing professionals working with multidisciplinary clinicians are well-positioned to identify distress as well as additional unidentified issues among head and neck cancer survivors. Working with multidisciplinary clinicians in various areas allows for these survivors to gain needed support from their team. For example, over time many patients develop or continue to have swallowing difficulties. Team members such as social workers and speech pathologists may inform the support team that this is an issue, causing difficulty for the patient and family, not only physically but psychologically, possibly requiring additional ongoing support, imaging, assessment, interventions, other referrals, etc. Healthcare professionals treating head and neck cancer survivors need information and education about treating demoralization and its potential relationship with suicidal ideation. Also needed are the training and support to utilize tools to identify demoralization and suicidal ideation as well as distress in the head and neck cancer survivor population. Based on literature (Pirl et al., 2014; Cartmill et al., 2016) that indicates that distress may be higher that what is being captured by measures that capture symptoms beyond the last 24 hours and the last two weeks, new measures are needed that may result in the early identification of cancer survivors who are in distress, thereby offering providers the opportunity to make necessary referrals sooner. Hopefully early identification of distress will result in greatly lessening or eliminating the risk for suicide in this cancer survivor population.

This study sample was limited in number due to only 3% of all cancers diagnosed being head and neck cancers (American Society of Clinical Oncology, 2016; Stenson, 2020; World Health Organization [WHO], 2014). This study provided a very limited snapshot of a small sample of head and neck cancer survivors. Further research is needed to explore demoralization in larger and more diverse samples of this population of head and neck cancer survivors. The small sample size prohibits making any pronouncements regarding trends, generalizations, or potential interventions. However, given some of the higher percentages of response to instrument items referenced above, these would suggest the need for further research to delve into areas of demoralization and distress for head and neck cancer survivors. Another limitation of this study was the timing cited in the measures used that may not have adequately identified symptoms occurring for head and neck cancer survivors after treatment and through survivorship. Opportunities exist for future measures to be developed which pose symptom questions asking for ratings initially 3 months after completion of treatment and then 1 year after treatment as an adjunct to clinical follow-ups throughout survivorship.

Considering the detailed questions related to life interference and extensive symptoms measured, healthcare clinicians may need more specific training to understand and be sensitized to the psychological risks associated with head and neck cancers. Nursing, occupational and physical therapy, rehabilitation medicine, psycho-oncology, speech pathology, nutrition, and social work, are a few of the disciplines which could partner to offer a team approach. A coordinated, multidisciplinary approach is critical in identifying, referring, treating and following up with these patients post-treatment as they may need a variety of interventions and support along the survivorship continuum.

The MDASI-HN asks participants to rate their symptoms and to select psychological and life interference experiences over the past 24 hours. The Demoralization Scale II asks participants to rate their psychological experiences over the last two weeks with the scale having been developed and tested with palliative care oncology patients. The time periods specified in these instruments may not have adequately reflected the distress occurring in this sample post-treatment. Furthermore, it is possible that the instrument measures did not capture the feeling of “something missing after treatment,” that was described by a head and neck cancer survivor as being present six months following initial treatment. More specific and sensitive measures are needed to identify psychological impacts of head and neck cancer, what is being experienced and when across the treatment and recovery phases. That data will allow specific referrals to be made earlier. Measures to assess and identify potential suicidal ideation in this population need to be included in any and all measures as well. Further rigorous qualitative research may offer additional information about this patient population in order to identify themes repeated by patients so that nursing interventions may be developed to address and understand and support the lived experiences of head and neck cancer survivors. Caregiver research in this population is also currently quite limited and is also needed.

Summary and Conclusion

This study was quite limited in its sample and needs further testing with larger samples to verify regression findings. However, the occurrence and intensity of late-effect symptoms and life interference, alcohol use, and demoralization scores among head and neck cancer survivors were measured herein. The findings of this study can add to limited literature about this population of cancer survivors. This study also indicates the need for further rigorous research on the experiences of head and neck cancer survivors, and especially appropriate psychological assessment and support in order to identify the risk of demoralization among this population.

Hopelessness is a key component of demoralization. Demoralization is a significant factor in suicidal ideation (Robinson, Kissane, Brooker, & Burney, 2016). Screening for demoralization among head and neck cancer survivors is important, so appropriate referrals can be made. If demoralization can be aligned with a sense of hopelessness and hopelessness is a strong indicator for suicidal ideation, then this may be quite important in regard to future research. Although the number of measures with statistical significance in this study were somewhat low, the clinical significance of the findings may be very important regarding risks for head and neck cancer survivors, as this population has some of the highest suicide rates among cancer patients (Osuzawa-Peters, 2018).

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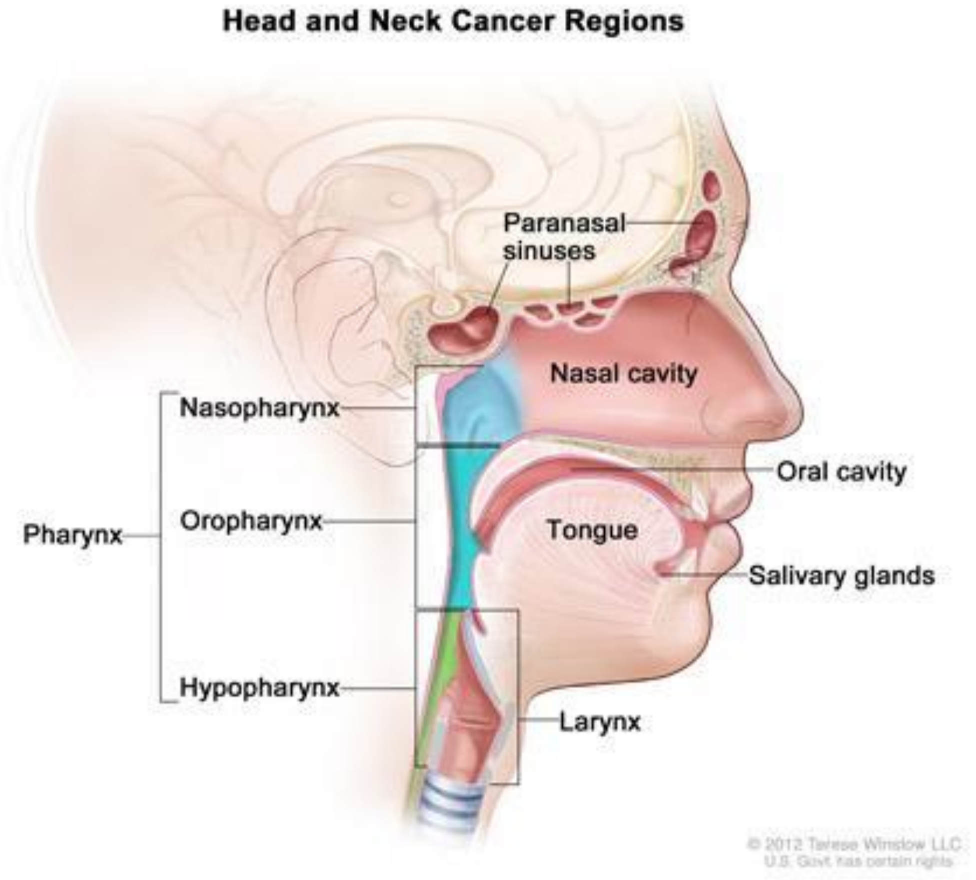
Appendix A

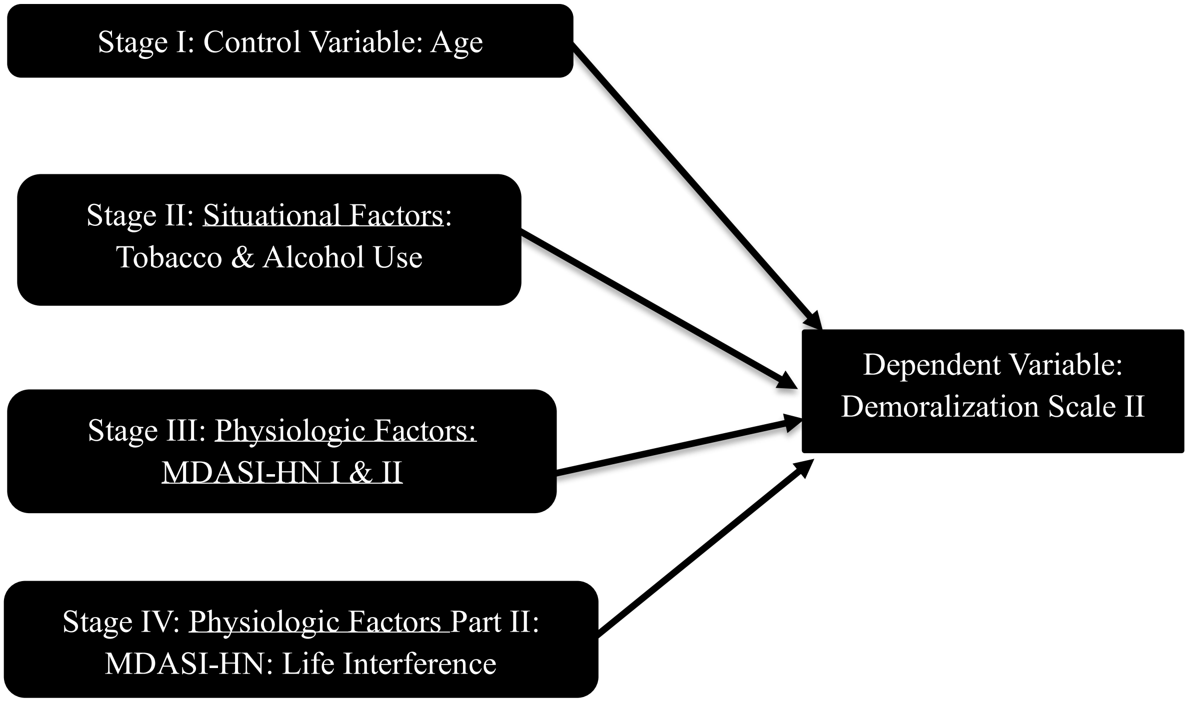
Head and Neck Cancer Regions



Head and neck cancer regions, illustrating location of paranasal sinuses, nasal cavity, oral cavity, tongue, salivary glands, larynx, and pharynx (including the nasopharynx, oropharynx, and hypopharynx).
From “Anatomy of the Oral Cavity,” by T. Winslow, 2012, National Cancer Institute. Copyright 2012 by the National Cancer Institute. Reprinted with permission.

Appendix B

Hierarchical Multiple Regression – Stages & Relationship to Demoralization



Key: MDASI-HN – MD Anderson Symptom Inventory – Head and Neck Module.

Bold arrows depict significant relationships found in this study regression.

Underlines are factors in the theory of unpleasant symptoms.

Appendix C

Letter to Healthcare Professionals (Description of the Study)

Dear Healthcare Professional,

I am a doctoral student in the KU School of Nursing seeking your assistance in recruiting adult head and neck cancer survivors to participate in a research study. As part of my doctoral dissertation research, I am conducting a quantitative research study designed to provide more information about the possible relationship between late-effect symptoms, tobacco and alcohol use, and demoralization among adult head and neck cancer patients. Enclosed is a synopsis of my study as well as a flyer describing the study and providing my contact information.

After reviewing the enclosed synopsis and flyer, if you have patients in your practice or support group that may be eligible to participate, please inform them about the study and determine if they might be interested. Please provide interested adult head and neck cancer survivors with the flyer/link to the study questionnaire online and my contact information. I would be happy to talk with you by phone or in person if you have questions or would like more information.

The aims of this study are to examine the occurrence and intensity of late-effect symptoms such as but not limited to xerostomia, mucositis, dysphagia, pain, and fatigue, tobacco and alcohol use, and demoralization. Better understanding and early identification of these factors will help guide identification of and interventions designed to reduce cancer survivor distress as well as inform and educate healthcare professionals who care for these patient populations.

Kind regards,

Andreanna (Andi) Steinhoff, MLS, BSN, RN
913-283-4240
asteinhoff@kumc.edu

Appendix D

Synopsis of the Study

Specific aims of the study are to:

- Identify the occurrence and intensity of late-effect symptoms, tobacco and alcohol use, and demoralization in head and neck cancer survivors.
- Examine the relationships among late-effect symptoms, tobacco and alcohol use, and demoralization in head and neck cancer survivors.

Inclusion criteria:

- Adults ages 18 and over.
- Diagnosed with any stage of head and neck cancer.
- Undergoing or have completed treatment for head and neck cancer, including surgery, chemotherapy, or radiation therapy.
- Able to read, write, speak, and understand English (preferably at a sixth-grade reading level or above).

Exclusion criteria:

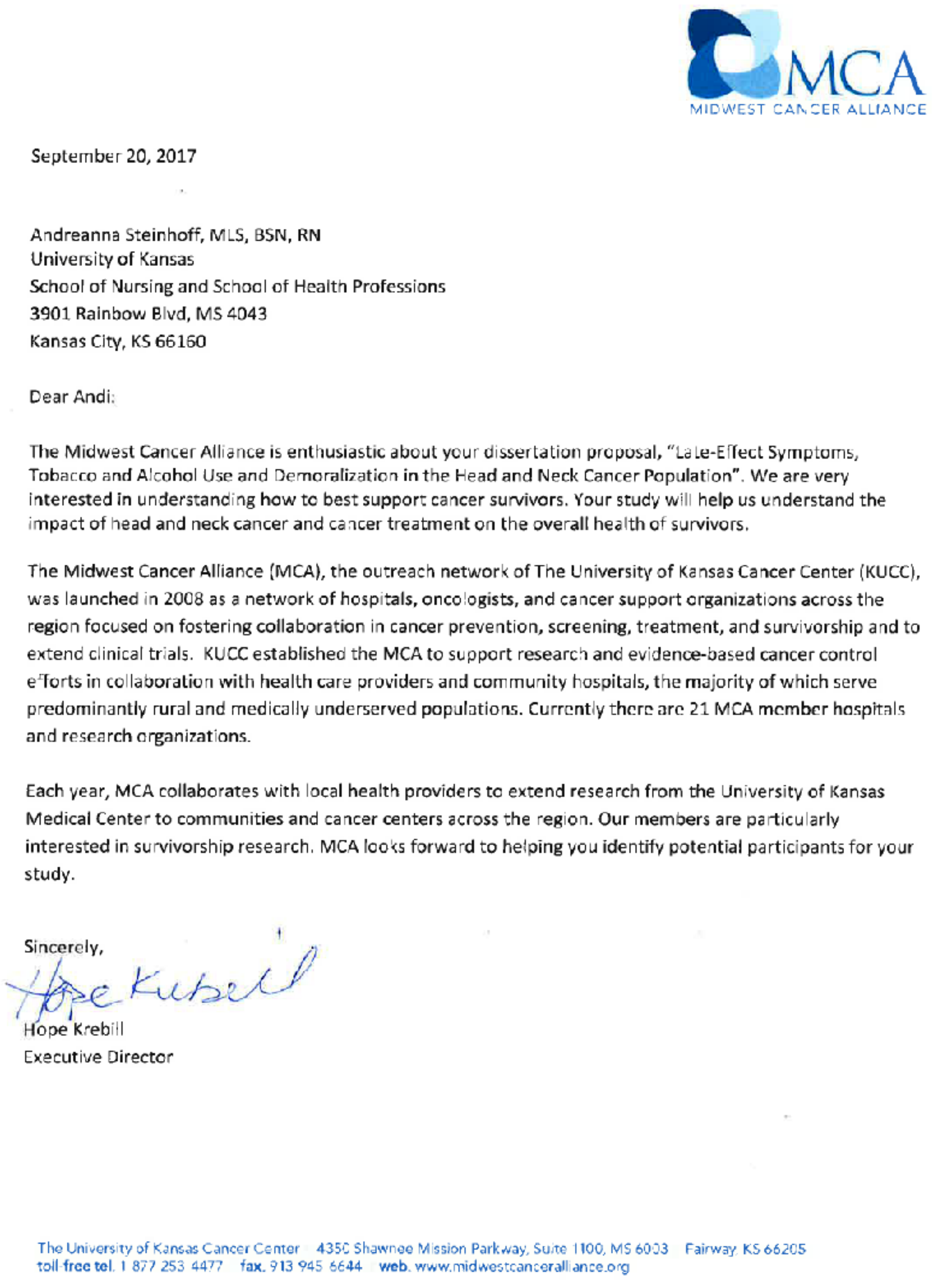
- Current active treatment for any other type of cancer not including head and neck cancer, including surgery, chemotherapy, radiation, or immunotherapy.

The desired sample size is 54 participants. All participants will be asked to complete the following instruments:

- A demographic questionnaire, including information about age at diagnosis, stage and location of disease, type(s) and duration of treatment, etc. – 16 questions.
- The Demoralization Scale–II. – 16 questions.
- The M.D. Anderson Symptom Inventory–Head & Neck (MDASI-HN) – 28 questions.
- Cancer Patient Tobacco Use Questionnaire (C-TUQ) – 4 questions.
- Recommended Alcohol Question (National Institute on Alcohol Abuse and Alcoholism) – one question.

Appendix E

Midwest Cancer Alliance Letter of Support



MCA
MIDWEST CANCER ALLIANCE

September 20, 2017

Andreanna Steinhoff, MLS, BSN, RN
University of Kansas
School of Nursing and School of Health Professions
3901 Rainbow Blvd, MS 4043
Kansas City, KS 66160

Dear Andi:

The Midwest Cancer Alliance is enthusiastic about your dissertation proposal, "Late-Effect Symptoms, Tobacco and Alcohol Use and Demoralization in the Head and Neck Cancer Population". We are very interested in understanding how to best support cancer survivors. Your study will help us understand the impact of head and neck cancer and cancer treatment on the overall health of survivors.

The Midwest Cancer Alliance (MCA), the outreach network of The University of Kansas Cancer Center (KUCC), was launched in 2008 as a network of hospitals, oncologists, and cancer support organizations across the region focused on fostering collaboration in cancer prevention, screening, treatment, and survivorship and to extend clinical trials. KUCC established the MCA to support research and evidence-based cancer control efforts in collaboration with health care providers and community hospitals, the majority of which serve predominantly rural and medically underserved populations. Currently there are 21 MCA member hospitals and research organizations.

Each year, MCA collaborates with local health providers to extend research from the University of Kansas Medical Center to communities and cancer centers across the region. Our members are particularly interested in survivorship research. MCA looks forward to helping you identify potential participants for your study.

Sincerely,

Hope Krebill
Executive Director

The University of Kansas Cancer Center 4350 Shawnee Mission Parkway, Suite 1100, MS 6003 Fairway KS 66205
toll-free tel. 1 877 253 4477 fax. 913 945 6644 web. www.midwestcanceralliance.org

Appendix F

Email for Subject Recruitment

Have you been diagnosed with head and neck cancer?

You are invited to participate in a brief online research study by clicking on the following link (insert web address of survey here). I am a nurse and a doctoral student at the University of Kansas School of Nursing. I am interested in learning more about your symptoms, tobacco and alcohol use, and demoralization during or after your treatment. The purpose of this study is to learn more about these symptoms, tobacco and alcohol use, and demoralization among head and neck cancer patients/survivors. I hope to help healthcare professionals better understand what head and neck cancer survivors are experiencing as a result of their head and neck cancer treatment.

Are you:

- An adult head and neck cancer patient aged 18 or over
- Undergoing or finished with your treatment (chemotherapy, radiation, surgery, etc.)

What you will do:

- Either complete a paper copy of the survey or access the survey online via a confidential survey link
- Answer survey questions about your head and neck cancer, alcohol and tobacco use, and experience of demoralization (20-25 minutes)

What are the benefits?

- Help researchers better understand treatment related symptoms, alcohol and tobacco use, and demoralization in head and neck cancer patients and survivors
- Enter a drawing for a $50 Visa gift card after you complete and submit your survey either in person or online

Questions? Please contact Andreanna Steinhoff at 913-283-4240 asteinhoff@kumc.edu for more information!

Appendix G

Study Flyer

Are you a Head and Neck Cancer Patient who is undergoing or completed treatment?

You are invited to participate in a brief research study to understand better your experiences as a head and neck cancer patient/survivor. I am a nurse and a doctoral student at the University of Kansas School of Nursing. I am interested in learning more about your symptoms, alcohol and tobacco use, and experience of demoralization. The purpose of this study is to learn more about some of the commonly experienced late-effect symptoms and behaviors of head and neck cancer patients, and how they may affect demoralization. In doing so I hope to help healthcare professionals understand what head and neck cancer survivors may experience. With better understanding, we can then create better solutions to identify and address the problems head and neck cancer survivors face during and after treatment.

Participation in this study would involve:

- Completing a questionnaire (20 minutes) either online or a paper copy
- Submitting the questionnaire online or by mail
- Being entered into a drawing for a $50 Visa gift card when your completed questionnaire is successfully submitted

To be eligible for this study you must be:

- An adult head and neck cancer survivor aged 18 or over
- Undergoing or finished with your treatment (chemotherapy, radiation, surgery, etc.)
- Able to read, write, speak, and understand English

If you would be interested in participating or learning more about this research study, please contact me:

Andreanna (Andi) Steinhoff, MLS, BSN, RN
913-283-4240
asteinhoff@kumc.edu

Appendix H

Screening Questions for Eligibility

1. Are you 18 years of age or older?

   ____Yes

   ____No

2. Are you currently being treated or have you previously been treated for any type of head and neck cancer?

   ____Yes

   ____No

3. Are you currently being treated for any other type of cancer?

   ____Yes

   ____No

Appendix I

Consent to Participate in Late-Effect Symptoms, Tobacco and Alcohol Use, and Demoralization in Head and Neck Cancer Survivors Study

Thank you for agreeing to participate in our study. We are conducting this study to learn more about head and neck cancer survivors' physical, behavioral, and psychological experiences during and after cancer treatment. We believe this study will help build awareness and ultimately knowledge, particularly regarding demoralization. Information from this study may lead to improved awareness and education regarding demoralization in cancer patients and survivors. This is an important psychological factor for multidisciplinary healthcare providers caring for head and neck cancer patients to be aware of in order to identify and refer for treatment where needed.

There are four brief surveys that should take no more than 20 minutes to complete. The first survey asks about your emotional experiences, and how you are feeling about things in your life. The second survey asks about some physical symptoms you may be experiencing. The third survey asks you about your tobacco use and the fourth survey about your alcohol use. There are no personal benefits or risks to participating in this study. Participation is voluntary, and you can stop taking the survey at any time.

After you complete and submit the survey, if you would like to be entered into a drawing for a $50 Visa gift card, please complete the section at the end with your contact information. Winners will be randomly selected in a drawing held at the completion of the study. If you have any questions, please contact Andreanna Steinhoff (asteinhoff@kumc.edu). For questions about the rights of research participants, you may contact the University of Kansas Medical Center Institutional Review Board (IRB) at (913) 588-1240.

Thank you for your help with our project!

Yes ○

Sincerely,

No ○

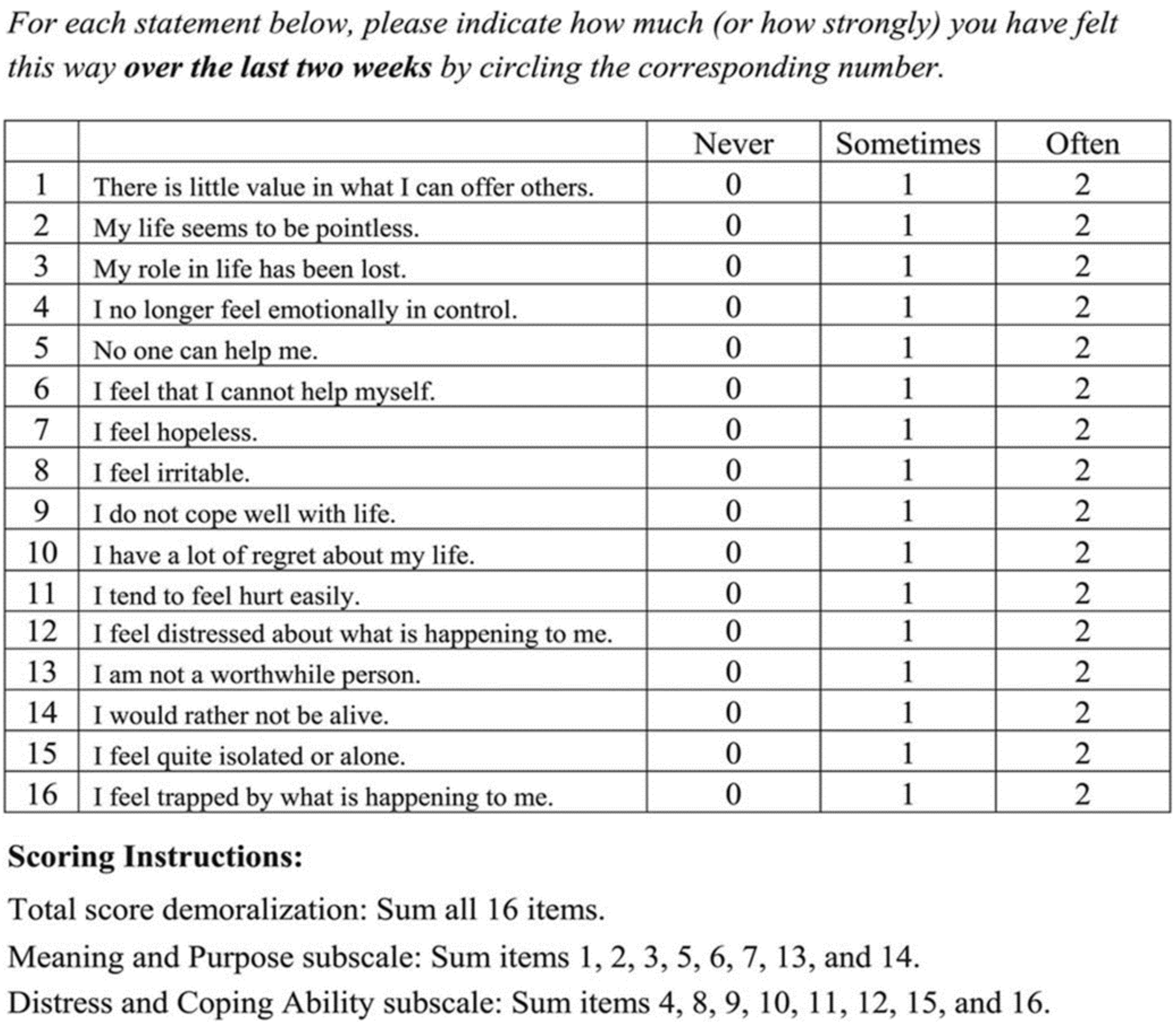
Marge Bott, PhD, RN

Andreanna Steinhoff, MLS, RN

(Please choose "yes" to verify that you are least 18 years old and agree to participate in the survey.)

Appendix J

Demoralization Scale II



For each statement below, please indicate how much (or how strongly) you have felt this way ***over the last two weeks*** *by circling the corresponding number.*

		Never	Sometimes	Often
1	There is little value in what I can offer others.	0	1	2
2	My life seems to be pointless.	0	1	2
3	My role in life has been lost.	0	1	2
4	I no longer feel emotionally in control.	0	1	2
5	No one can help me.	0	1	2
6	I feel that I cannot help myself.	0	1	2
7	I feel hopeless.	0	1	2
8	I feel irritable.	0	1	2
9	I do not cope well with life.	0	1	2
10	I have a lot of regret about my life.	0	1	2
11	I tend to feel hurt easily.	0	1	2
12	I feel distressed about what is happening to me.	0	1	2
13	I am not a worthwhile person.	0	1	2
14	I would rather not be alive.	0	1	2
15	I feel quite isolated or alone.	0	1	2
16	I feel trapped by what is happening to me.	0	1	2

Scoring Instructions:

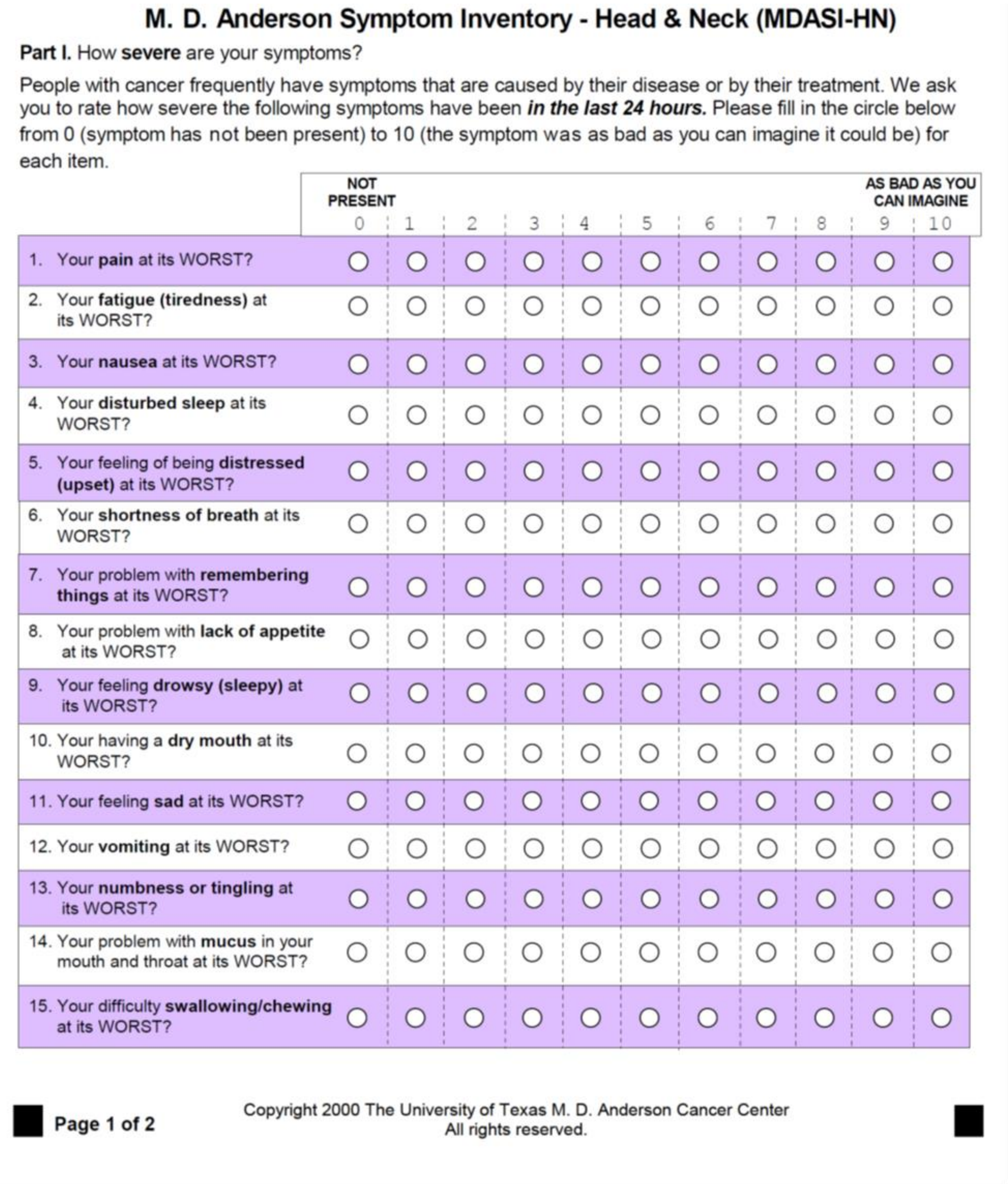
Total score demoralization: Sum all 16 items.

Meaning and Purpose subscale: Sum items 1, 2, 3, 5, 6, 7, 13, and 14.

Distress and Coping Ability subscale: Sum items 4, 8, 9, 10, 11, 12, 15, and 16.

Appendix K

M.D. Anderson Symptom Inventory – Head & Neck (MDASI-HN)



M. D. Anderson Symptom Inventory - Head & Neck (MDASI-HN)

Part I. How **severe** are your symptoms?

People with cancer frequently have symptoms that are caused by their disease or by their treatment. We ask you to rate how severe the following symptoms have been ***in the last 24 hours.*** Please fill in the circle below from 0 (symptom has not been present) to 10 (the symptom was as bad as you can imagine it could be) for each item.

	NOT PRESENT										AS BAD AS YOU CAN IMAGINE
	0	1	2	3	4	5	6	7	8	9	10
1. Your **pain** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
2. Your **fatigue (tiredness)** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
3. Your **nausea** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
4. Your **disturbed sleep** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
5. Your feeling of being **distressed (upset)** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
6. Your **shortness of breath** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
7. Your problem with **remembering things** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
8. Your problem with **lack of appetite** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
9. Your feeling **drowsy (sleepy)** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
10. Your having a **dry mouth** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
11. Your feeling **sad** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
12. Your **vomiting** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
13. Your **numbness or tingling** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
14. Your problem with **mucus** in your mouth and throat at its WORST?	○	○	○	○	○	○	○	○	○	○	○
15. Your difficulty **swallowing/chewing** at its WORST?	○	○	○	○	○	○	○	○	○	○	○

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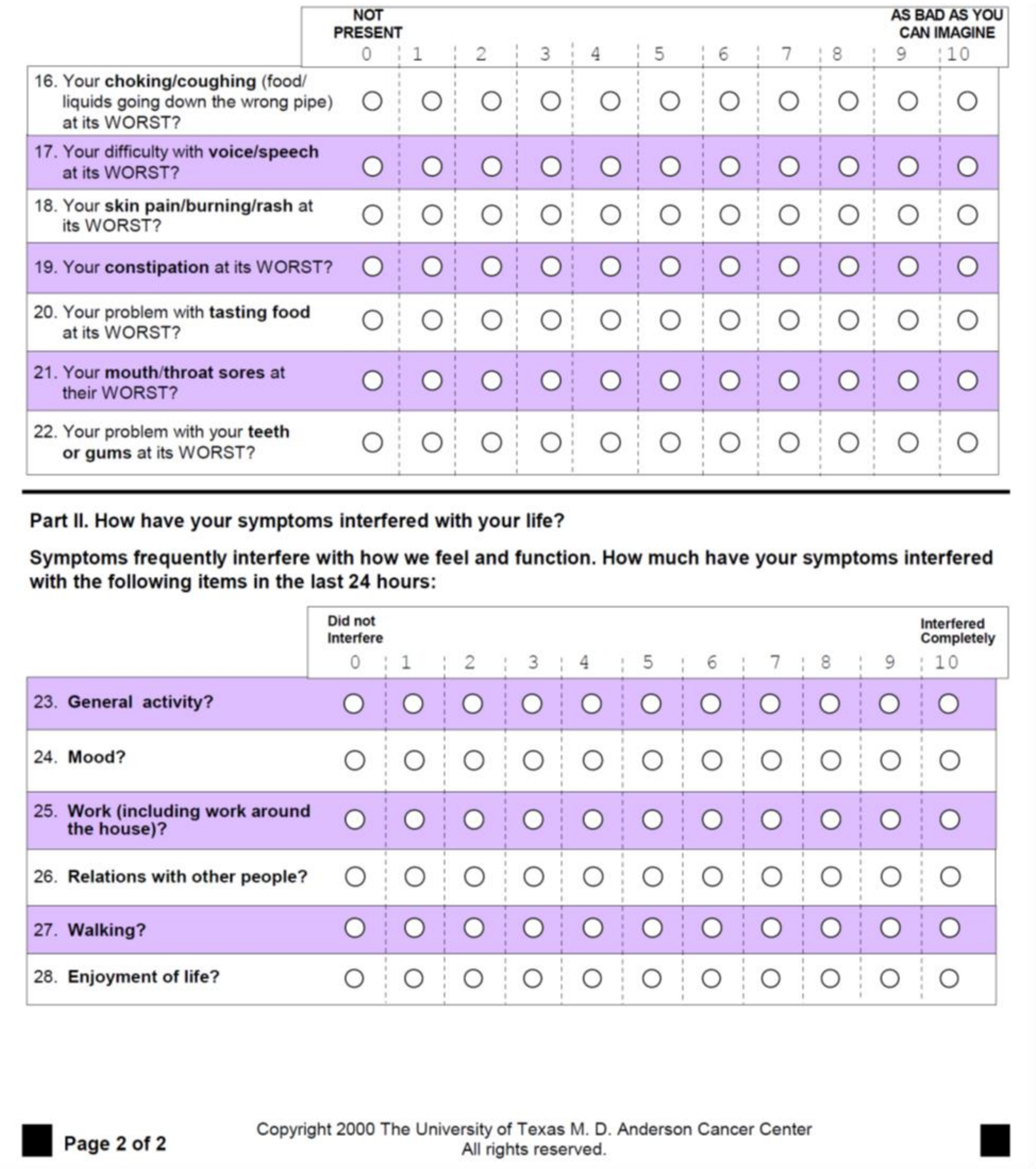

	NOT PRESENT 0	1	2	3	4	5	6	7	8	9	AS BAD AS YOU CAN IMAGINE 10
16. Your **choking/coughing** (food/ liquids going down the wrong pipe) at its WORST?	○	○	○	○	○	○	○	○	○	○	○
17. Your difficulty with **voice/speech** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
18. Your **skin pain/burning/rash** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
19. Your **constipation** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
20. Your problem with **tasting food** at its WORST?	○	○	○	○	○	○	○	○	○	○	○
21. Your **mouth/throat sores** at their WORST?	○	○	○	○	○	○	○	○	○	○	○
22. Your problem with your **teeth or gums** at its WORST?	○	○	○	○	○	○	○	○	○	○	○

Part II. How have your symptoms interfered with your life?

Symptoms frequently interfere with how we feel and function. How much have your symptoms interfered with the following items in the last 24 hours:

	Did not Interfere 0	1	2	3	4	5	6	7	8	9	Interfered Completely 10
23. **General activity?**	○	○	○	○	○	○	○	○	○	○	○
24. **Mood?**	○	○	○	○	○	○	○	○	○	○	○
25. **Work (including work around the house)?**	○	○	○	○	○	○	○	○	○	○	○
26. **Relations with other people?**	○	○	○	○	○	○	○	○	○	○	○
27. **Walking?**	○	○	○	○	○	○	○	○	○	○	○
28. **Enjoyment of life?**	○	○	○	○	○	○	○	○	○	○	○

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Appendix L

Tobacco Use in Relation to Cancer Diagnosis and Treatment

1. During each of the following time frames, please indicate whether you smoked cigarettes every day, some days, or not at all.

	Smoked every day	**Smoked some days**	**Didn't smoke at all**	**Don't know/ Not sure**	**Not applicable**
The year before you were first told you had cancer					(I have not been diagnosed.)
After diagnosis, and before treatment started					(I have not been diagnosed.)
From 2 days before your last cancer surgery to 2 days after					(I have not had cancer surgery.)
During the course of treatment					(I have not received treatment.)
After treatment ended					(I have not completed treatment.)
Since your last visit to this clinic					(This is my first visit to this clinic.)
Since your last visit to this clinic					(This is my first visit to this clinic.)

2. Since you were first told you had cancer, which of the following products have you used regularly? *Check all that apply*.

   __ Cigarettes

   __ E-cigarettes or other electronic nicotine delivery system

   __ Traditional cigars, cigarillos or filtered cigars

   __ Pipes

   __ Hookah

   __ Clove cigarettes or kreteks

   __ Bidis

   __ Smokeless tobacco, like dip, chew, or snuff

   __ Snus

   __ Paan with tobacco, gutka, zarda, khaini

   __ None

   __ Other. *Please specify*: __________________

3. In the past 30 days, have you smoked any cigarettes, even one or two puffs?

   __ Yes

   __ No

4. Have your cancer doctors advised you to quit smoking cigarettes?

   __ Yes

   __ No

   __ Not applicable

   __ I have not smoked cigarettes since my diagnosis.

Appendix M

Alcohol Use in Relation to Cancer Diagnosis and Treatment

1. Since you were diagnosed with head and neck cancer, how often have you had any drink containing alcohol? (By a drink, we mean half an ounce of absolute alcohol (e.g. a 12-ounce can or glass of beer or cooler, a 5-ounce glass of wine, or a drink containing 1 shot of liquor). Please <u>check only one answer</u>.

   __ Every day
   __ 5 to 6 times a week
   __ 3 to 4 times a week
   __ Twice a week
   __ Once a week
   __ 2 to 3 times a month
   __ Once a month
   __ 3 to 11 times in the past year
   __ 1 or 2 times in the past year
   __ I did not drink any alcohol in the past year, but I did drink in the past
   __ I never drank any alcohol in my life

Appendix N

Demographic Questionnaire

Date: _______________

Participant ID: _____________

1. How old are you (in years)? _________________________

2. To what gender do you most identify?

__Female __Male __Other __Do not care to respond

3. What is your current relationship status?

__ Single

__ Married

__ Separated

__ Divorced

__ Widowed

__ In a relationship

4. What race or ethnicity do you identify with?

___ American Indian or Alaskan Native

___ Asian

___ Black or African American

___ Hispanic or Latino

___ Native Hawaiian or Pacific Islander

___ White or Caucasian

___ Multi-racial (please describe) ____

___Other____

5. What is the highest level of education you have obtained?

___ No High School Degree

___ High School or GED

___ 2 years of College (Associates) or Trade Degree

___ College's Bachelor’s Degree

___ Graduate School or Degree

6. What is your employment status?

___ Full time

___ Part time

___ Medical leave

___ Disabled

___ Retired

___ Unemployed

___ Student

7. When were you first diagnosed with head and neck cancer? (month/year) _______________

8. How old were you in years when you were diagnosed with head and neck cancer? ______

9. What was the stage of your initial diagnosis of head and neck cancer?

___ Stage 1

___ Stage 2

___ Stage 3

___ Stage 4

___ Do not know/Do not remember/Uncertain

10. Where was the location of your head and neck cancer?

____

____ Do not know/Do not remember/Uncertain

11. What type of treatment are you having/did you have? Please check all that apply:

___ Chemotherapy

___ Radiation

___ Surgery

___ Other (please describe) ____

12. Have you finished your treatment?

____ Yes

___ No

If yes, when did you finish your last treatment? (month/year)___________________

13. Have you experienced any of the following because of your treatment? Please check all that apply:

___ Loss of teeth

___ Physical disfigurement

___ Difficulty in communication (due to loss of teeth, voice quality, surgery/facial reconstruction, etc.)

___ Permanent opening in throat

___ Permanent feeding tube

___ Hearing loss

___ Other (please describe) ____

14. Have you ever been diagnosed with and/or treated for depression/anxiety?

___ Yes

___ No

___ Do not know/Do not remember/Uncertain

15. Are you currently taking any medication for depression/anxiety?

___ Yes

___ No

___ Do not know/Do not remember/Uncertain

16. Is there anything you would like to tell us about your physical and/or emotional experiences with head and neck cancer?
____

Appendix O

Contact Information – Gift Card Drawing

After you have completed the entire survey and submitted it, please complete the information below to be entered into a random drawing for a $50 Visa Gift Card.

Thank you for your participation!

First Name ________________________________

Last Name ________________________________

Street, City, State, ZIP ________________________________

____

Phone number ________________________________

E-mail ________________________________

Appendix P

Location of Initial Diagnosis of Head and Neck Cancer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		5	9.8	9.8	9.8
	Back of tongue	1	2.0	2.0	11.8
	Base of tongue	1	2.0	2.0	13.7
	Base of tongue/tonsils	1	2.0	2.0	15.7
	Bottom gum, tongue, and floor of mouth	1	2.0	2.0	17.6
	Ear	1	2.0	2.0	19.6
	Ex-wife says it is where they had to cut my skull open at forehead because of traumatic brain injury good job of no scare	1	2.0	2.0	21.6
	Floor of mouth	1	2.0	2.0	23.5
	Front, near vocal cords	1	2.0	2.0	25.5
	In the mouth	1	2.0	2.0	27.5
	Jaw	1	2.0	2.0	29.4
	Left cheek and jawbone	1	2.0	2.0	31.4
	Left jaw, tongue	1	2.0	2.0	33.3
	Left maxillary sinus	1	2.0	2.0	35.3
	Left parotid gland	1	2.0	2.0	37.3

	Left side of neck swollen lymph node	1	2.0	2.0	39.2
	Left sinus	1	2.0	2.0	41.2
	Left tonsil	1	2.0	2.0	43.1
	Left tonsil/lymph nodes	1	2.0	2.0	45.1
	Lower left side of tongue	1	2.0	2.0	47.1
	Maxillary left pallet	1	2.0	2.0	49.0
	Maxillary sinus	1	2.0	2.0	51.0
	Mouth	1	2.0	2.0	52.9
	Mouth/throat	1	2.0	2.0	54.9
	Nasopharynx	1	2.0	2.0	56.9
	Neck in a lymph node	1	2.0	2.0	58.8
	Paraforma sinus	1	2.0	2.0	60.8
	Paranormal sinus	1	2.0	2.0	62.7
	Right tonsil	1	2.0	2.0	64.7
	Salivary gland base of tongue	1	2.0	2.0	66.7
	Subraglottic esophageal squamous cell	1	2.0	2.0	68.6
	Throat	1	2.0	2.0	70.6
	Throat cancer	1	2.0	2.0	72.5
	Throat, left side	1	2.0	2.0	74.5
	Thyroid	2	3.9	3.9	78.4
	Thyroid	1	2.0	2.0	80.4
	Tongue	2	3.9	3.9	84.3

	Tongue	1	2.0	2.0	86.3
	Tongue, right side	2	3.9	3.9	90.2
	Tonsil tongue soft palate mets to lymph	1	2.0	2.0	92.2
	Tonsils	1	2.0	2.0	94.1
	Top of the voice box	1	2.0	2.0	96.1
	Trigone area	1	2.0	2.0	98.0
	Under tongue, on tonsil	1	2.0	2.0	100.0
	Total	51	100.0	100.0	

Appendix Q

Other Physical Symptoms Due to Treatment

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		20	39.2	39.2	39.2
	1. Lack of saliva (dry mouth); 2. Jaw pain from 2a. broken plate (internal fixation) on mandible reconstruction; 3. Left arm/hand neurologic deficits from vascularized graft site (radius and associated tissue); 4. another important area postop was weight management (calorie intake). This is quite a challenge. Liquid diets become 'old' very quickly!	1	2.0	2.0	41.2
	All of my teeth were pulled before treatment, and given dentures. Muscle fibrosis due to radiation, hoarse voice, trouble swallowing, eating, cough	1	2.0	2.0	43.1
	Difficult swallowing, decrease voice, neck pain, lymphedema, neuropathy, tissue hardening, decrease and change taste, memory loss, sleep difficulty, thick phlegm.	1	2.0	2.0	45.1

	Difficulty eating: Liquid diet for past 7 years (2 years on feeding tube eat with syringe & extension).	1	2.0	2.0	47.1
	Difficulty swallowing, esophageal stricture vision floaters memory loss balance issues chronic neck and shoulder pain neuropathy acid reflex dry mouth chronic hoarseness vocal chord paralysis cervical dysphagia fatigue sleep problems	1	2.0	2.0	49.0
	Difficulty swallowing, extremely dry mouth, light headedness, memory issues.	1	2.0	2.0	51.0
	Difficulty swallowing, lack of stamina, tongue fatigue, memory problems, limited movement of neck, balance problems.	1	2.0	2.0	52.9
	Discomfort in my neck. My hearing is low on the right side, a terrible hinch in the neck, stiffness.	1	2.0	2.0	54.9
	Dry mouth, loss of taste, Ihermett's sign (numbness bottom of feet).	1	2.0	2.0	56.9
	Dry mouth, phlegm after eating anything, lymphedema, hard to swallow anything dry.	1	2.0	2.0	58.8
	Dry mouth, trouble talking, eating, tired, pain sometimes.	1	2.0	2.0	60.8
	Dysphagia, speech problems.	1	2.0	2.0	62.7

	Healing from surgery, tongue reconstruction/transplant.	1	2.0	2.0	64.7
	Lethargy, radiation burns, nausea and vomiting, swelling and congestion, cough.	1	2.0	2.0	66.7
	Lymphedema	1	2.0	2.0	68.6
	Lymphedema, numbness/pain, difficulty chewing/eating, stiff neck muscles & tendons, numbness & pain left wrist & arm. Loss of dexterity in left hand & fingers.	1	2.0	2.0	70.6
	Mouth ulcers, gastric feeding tube until after completion of radiation, slow healing of left leg (site of 'harvest' to rebuild cheek bone, jawbone, palate).	1	2.0	2.0	72.5
	My voice is much lower, it strains my throat to sing, my face and neck well up from fluid that doesn't drain because of scarring. It makes my face and throat very bloated and I have difficulty swallowing.	1	2.0	2.0	74.5
	No major disfigurement but did have major weight loss (70 lbs).	1	2.0	2.0	76.5
	Numbness - tingling sensations.	1	2.0	2.0	78.4

	Ringing in the ears, mouth, tongue, throat pain, fatigue, dry mouth, mucus, vomiting, numbness.	1	2.0	2.0	80.4
	Seem tired not getting as much work done.	1	2.0	2.0	82.4
	Slight dry mouth. Some trouble swallowing.	1	2.0	2.0	84.3
	Sore muscles (neck & shoulders) most of the time, esp. when eating and working. neck spasms. difficulty chewing & swallowing.	1	2.0	2.0	86.3
	Speech impairment, eating impairment, tasting loss, pain treatment, lack of energy.	1	2.0	2.0	88.2
	Taking (sic) care of my teeth/neck cramps/jaw cramps, eating dry meats such as roast or steak.	1	2.0	2.0	90.2
	Tired	1	2.0	2.0	92.2
	Trismus, pelvic floor issues, menopause symptoms associated with low estrogen, hypothyroidism, high blood pressure, tinnitus (ringing in ears).	1	2.0	2.0	94.1
	Trouble swallowing, trouble breathing.	1	2.0	2.0	96.1
	Trouble with chewing food & shaving chin.	1	2.0	2.0	98.0

	Wax build up due to 3 surgeries. Canal is deviated. Have had fungal infections & wired (sic) growths in ear. Had growth removed from back of throat. Told it will come back. Experience minor pain.	1	2.0	2.0	100.0
	Total	51	100.0	100.0	