2008

DIFFERENTIAL ASSESSMENT OF QUALITY OF LIFE IN INDIVIDUALS WITH ORAL AND LARYNGEAL CANCER: A PRELIMINARY INVESTIGATION

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Recommended Citation
Peleg-Brandt, Naomi, "DIFFERENTIAL ASSESSMENT OF QUALITY OF LIFE IN INDIVIDUALS WITH ORAL AND LARYNGEAL CANCER: A PRELIMINARY INVESTIGATION" (2008). *Digitized Theses*. 4151.
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DIFFERENTIAL ASSESSMENT OF QUALITY OF LIFE IN INDIVIDUALS WITH ORAL AND LARYNGEAL CANCER: A PRELIMINARY INVESTIGATION

(Spine Title: Quality of Life in Oral and Laryngeal Cancer)

(Thesis format: Monograph)

by

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Graduate Program in Communication Sciences and Disorders

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A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Science

School of Graduate and Postdoctoral Studies
The University of Western Ontario
London, Ontario, Canada

THE UNIVERSITY OF WESTERN ONTARIO
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The thesis by

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entitled:

Differential Assessment of Quality of Life in Individuals with Oral and Laryngeal Cancer: A Preliminary Investigation

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Date: ____________________

Chair of the Thesis Examination Board

Abstract

The purpose of this investigation was to gather information on whether there are differences in the areas of concern affecting quality of life for individuals treated for oral cancer versus laryngeal cancer. The investigation also sought to assess whether current questionnaires are able to detect differences between these two groups. Thirteen adults who had been treated for oral cancer and 6 adults who had been treated for laryngeal cancer served as participants. Participants completed three validated and widely used questionnaires. A method of assessing relative differences in areas of concern was explored. Results indicated variable findings, with some subscales approaching significance. Overall, both groups reported concern with talking/speech, eating, and swallowing. Commonalities were found in the areas of concern for both groups, although the impact of these areas may vary. The data suggest that further explorations are warranted and raise continuing clinical questions relative to the assessment of these populations.

Keywords: oral cancer, laryngeal cancer, head and neck cancer, quality of life

Acknowledgements

There are many individuals who have contributed to this project. Firstly, I would like to express my deepest thanks to Dr. Philip C. Doyle, my thesis supervisor. Your encouragement, support, and expertise were invaluable to the completion of my thesis.

I would also like to thank Dr. J.B. Orange and Dr. Marilyn Kertoy for their thoughtful contributions to this project, and to Dr. Kevin Fung for his support and continued pursuit of clinical research. I would like to recognize Francie Si for her help in organizing the list of patients for the study. Also, I would like to gratefully acknowledge the individuals who participated in this study.

To Adam Day, thank you for showing me how to compress hours into minutes. To Julie Theurer, thank you for your advice and support. To Tania Kalwani, one of the kindest and most caring people I know – thank you for your insights and more importantly, your friendship. To Mima, Anny and Pipa, Saba and Safta, your encouragement and love have made me believe anything is possible. To Mom and Dad, thank you for your endless love, confidence in me, and motivation to realize my potential. To Raffi, your friendship has been the greatest gift anyone could give. To Mike, thank you for being a constant source of inspiration, encouragement, and motivation. Together I know we will realize our dreams.

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Overview

Carcinoma of the head and neck represents less than 4% of all newly diagnosed cancers each year (Canadian Cancer Society [CCS], 2007) and is comprised of "all lesions of the mucosal surfaces from the internal nose and nasopharynx to the thoracic inlet level of the trachea and esophagus" (Davies & Welch, 2006, p. 451). According to Davies and Welch, separation across the inclusion criteria for cancers of the head and neck are a consequence of the development of medical understanding and practices in treatment options for given structures. Within the classification of head and neck cancer are several subgroups, two of which are *oral cancer* and *laryngeal cancer*. These two subgroups are often merged together because they can affect similar functions such as speech, digestion, and the functions of the upper airway (Hassan & Weymuller, 1993). While these two subgroups are currently viewed together, oral cancer and laryngeal cancer should be categorized as separate and distinct types of carcinoma. This separation is based on the facts that these cancers affect distinct anatomical structures, and have divergent treatment considerations. More importantly, the site of the cancer, subsequent treatments, and side-effects of the treatments impact differently on the individual's quality of life (QOL).

The 5-year survival rates for oral and laryngeal cancer are 62% and 66%, respectively (CCS, 2007). Though the survival rates for oral and laryngeal cancer are promising, it is important to note that survival rates and QOL are distinct and frequently divergent properties. More specifically, QOL is a multidimensional global construct that reflects a person's general feeling of well-being (Murphy, Ridner, Wells, & Dietrich, 2007). Central to the concept of QOL is the notion that QOL embodies several broad areas of an individual's life, and is defined by the individual him/herself.

The World Health Organization defines QOL as:

> "...an individual's perceptions of their position in life in the context of the culture and value system where they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept incorporating in a complex way a person's physical health, psychological state, level of independence, social relationships, personal beliefs and relationship to salient features of the environment" (WHO health promotion glossary, p. 27)

Due to the multidimensional nature of QOL, the components that contribute to its global construct evolve minimally from physical, psychological, and social influences, as well as many others, upon one's perceived well-being. Thus, the manifestation of perceived levels of QOL can be directly and explicitly determined by the unique nature and/or site of a particular disease. In the present context, there is reason to consider differential patterns of QOL secondary to whether one is diagnosed and treated for an oral malignancy or for a malignancy that involves the larynx. By classifying the two types of head and neck cancer diagnoses under one heading, there is potential for researchers and clinicians to overlook significant factors that affect an individual's QOL that may be unique to one diagnosis or to the other. However, to date there have been no formal attempts to consider such differences within the context of subgroups of disease sites for those diagnosed and treated for head and neck cancer.

QOL among individuals with head and neck cancer has become an increasingly important area to study, especially when considering treatment outcomes. Many successful and widely employed questionnaires have been developed to assess QOL in the unique population of those diagnosed with head and neck cancer. The most widely employed instruments include the: (1) University of Washington Quality of Life Questionnaire (UW-QOL) (Hassan & Weymuller, 1993), (2) European Organization for Research and Treatment of Cancer Quality of Life Questionnaire, Head and Neck Module (EORTC-QLQ-HN) (Bjordal, Ahlner-Elmqvist, Tollesson, Jensen, Razavi, Maher, & Kaasa, 1994; Bjordal, de Graeff, Fayers, Hammerlid, van Pottelsberghe, Curran, et al., 2000), and (3) the University of Michigan Head and Neck Quality of Life questionnaire (HNQOL) (Terrell, Nanavati, Esclamado, Bishop, Bradford, & Wolf, 1997) (Please see Appendix A for copies of each instrument).

Components of these questionnaires include questions about pain, appearance, activity, recreation, swallowing, chewing, speech, shoulder mobility, taste, and saliva (Weymuller, Alsarraf, Yueh, Deleyiannis, & Colterera, 2001). Clearly, these areas have significant importance and application to those with head and neck cancer. However, these measures have not addressed a fundamental concern in the evaluation of the overall QOL outcomes: the relevance and appropriateness of the questionnaire(s) *to an individual* affected by a *particular type* of head and neck cancer affecting *a specific anatomic region.* In other words, there remain unanswered questions about the questionnaires' ability to detect different sites of head and neck cancer. More directly, concerns are raised relative to the appropriateness of these tools in those diagnosed and treated for oral vs. laryngeal cancer. Based on these concerns, the emerging natural question is whether any given QOL instrument exhibits characteristics that are more applicable, or, more or less specific to one cancer site over the other? Additionally, could the supplement of several additional questions reveal issues that are central to each specific type of head and neck cancer?

A Brief Review of QOL Associated with Head and Neck Cancer

Several studies have addressed QOL in oral cancer (Hassanein, Musgrove, & Bradbury, 2005; Kademani, 2007; Rogers, Miller, Ali, Minhas, Williams, & Lowe, 2006) and laryngeal cancer (Deleyiannis, Weymuller, Coltrera, & Futran, 1999; Lotempio, Wang, Sadeghi, Delacure, Julliard, & Wang, 2005; Terrell, Fisher, & Wolf, 1998; Vilaseca, Chen, & Backscheider, 2006). However, the QOL tools used in these studies have not been studied to determine whether they are specific or are able to identify particular head and neck cancer subsites. Since oral and laryngeal cancers affect different anatomical structures and are treated differently, we must carefully examine the tools used to measure QOL in the hope of seeking to more accurately reflect actual outcomes as perceived by the individual. Such concerns are raised in an effort to improve our understanding of whether specific questionnaires more aptly target "functional" capacity in one group over another. The fact that existing QOL questionnaires are generic head and neck tools and, hence, do not differentiate between oral and laryngeal cancer leads one to assume that these subtypes of head and neck cancer have similar effects on QOL. Anecdotal information in the literature clearly indicates that the outcomes in terms of QOL of these head and neck cancer subtypes are not affected in uniform fashion. When evaluated collectively, these reports suggest that the influence of one's site of head and neck cancer upon QOL measures are, in fact, quite different in a global sense. Specifically, the differences in voice and speech (Doyle, 1994; Eadie & Doyle, 2005; Hassanein et al., 2001; Lotempio et al., 2005; Shepherd & Fisher, 2004; Vilaseca et al., 2006; Zeller, 2006), as well as varying levels of impact of treatment on eating (Shepherd & Fisher, 2004; Terrell et al., 1998) and social contact (Shepherd & Fisher, 2004) are clearly identified in the contemporary literature. With that, however, the ability to quantify such differential assessments offers a considerable challenge. In fact, no guidelines for how to approach such a concern currently exist.

Nevertheless, studies directed toward assessing differential performance for domains of functioning when comparing QOL between individuals affected by these two specific cancers have not yet been conducted. Due to these concerns, as well as the absence of empirical evidence to support either position, the following question must be posed. Since the oral cavity and the larynx are vastly different structures with different native functions, different cancer related morbidity, and are subject to divergent treatments, do the effects of treatments have similar effects on the individual's perceived QOL such that they should be grouped together? If the clinical process is to be directed toward facilitating the best possible rehabilitation outcome, it is obvious that outcome measures employed must be valid indices of such performance. With empirical confirmation related to this concern, critical information concerning outcomes may be missed or disregarded with potentially negative consequences.

Differential Considerations Relative to QOL

Many investigations have evaluated the effects of cancer treatment on QOL in those with head and neck cancer (Deleyiannis et al. 1999; Lotempio et al., 2005; Terrell, Fisher, & Wolf, 1998; Vilaseca et al. 2006; Weymuller, Yueh, Deleyiannis, Kuntz, Alsarraf, & Coltrera, 2000a; Weymuller, Yueh, Deleyiannis, Kuntz, Alsarraf, & Coltrera, 2000b). It has been shown that QOL outcomes differ depending on several factors such as tumor stage, lesion site, and treatment modality (Lotempio et al., 2005). Anatomically, the oral cavity and the larynx are independent structures with divergent biological and communicative functions. Also, the primary treatment modalities differ between the two forms of cancer. Functionally, however, different aspects of a one's life are affected based on both the site of the malignancy and the treatment modalities utilized; thus, at minimum the consequences of these factors will directly influence post-treatment QOL.

The purpose of the present project seeks to identify the relative and individually perceived weighting (ranking) of domains that are important to patients given their type of head and neck cancer. The project also seeks to evaluate the three QOL tools that are currently being used in terms of their relevance to oral versus laryngeal cancer, as well as to determine if there are domains, important to QOL from a individual's perspective, that are missing or insufficiently represented within the current tools.

One of the most significant areas of distinction between oral and laryngeal cancer is the effect that both the tumor site and the means of treatment have on post-treatment QOL. Negative outcomes on those who have undergone treatment for oral cancer include problems with swallowing (Hassanein, Musgrove, & Bradbury, 2001; Shepherd & Fisher, 2004; Zeller, 2006), shoulder dysfunction (Hassanein et al., 2001), disfigurement (Hassanein et al., 2001), fatigue (Shepherd & Fisher, 2004; Zeller, 2006), pain (Hassanein et al., 2001; Shepherd & Fisher, 2004), quality of speech (Eadie & Doyle, 2005; Hassanein et al., 2001; Shepherd & Fisher, 2004; Zeller, 2006), social eating (Shepherd & Fisher, 2004) and social contact (Shepherd & Fisher, 2004). Individuals who have undergone treatment for laryngeal cancer clearly suffer from problems with voice and speech associated with quality and loudness (Doyle, 1994; Eadie & Doyle, 2005; Lotempio et al., 2005; Vilaseca et al., 2006), appearance (Vilaseca et al., 2006), activity (Vilaseca et al., 2006), "bother" experienced by physical consequences of having a stoma (Terrell et al., 1998), depression (Terrell et al., 1998), pain (Lotempio et al., 2005; Terrell et al., 1998), eating (including problems associated with taste and swallowing) (Terrell et al., 1998), swallowing (Lotempio et al., 2005), and chewing (Lotempio et al., 2005).

While both the oral cavity and the larynx are utilized in verbal communication, their respective roles for communication are quite different. Individuals with oral cancer encounter problems with the articulatory and resonance aspects of speech production, whereas individuals with laryngeal cancer experience insult to the phonatory source of communication (i.e., loss of the primary mechanism for voice production). Both groups also experience an array of common problems such as those associated with eating and swallowing (Hassanein, Musgrove, & Bradbury, 2001; Lotempio et al., 2005; Shepherd & Fisher, 2004; Terrell et al., 1998; Zeller, 2006), although the specific nature of the problems are often not identified. These findings suggests that QOL instruments may not be uniformly appropriate to all who are diagnosed and treated for "head and neck cancer", because the outcomes of the two distinct cancer subtypes impact different aspects of the person's overall functioning and life in general. Consequently, there exists the potential that some relevant and functionally important information will not be addressed adequately or considered within the larger construct of QOL. In such circumstances, this may then lead to inefficient identification of problems and their relevant bearing and impact on the individual being assessed. Clearly, the longer term influence of such limitations in assessment hold tremendous weight and impact in determining the ultimate success and outcome for any given individual.

It must be acknowledged that oral cancer and laryngeal cancer do have areas of overlap in terms of surgical intervention. For example, procedures, such as neck dissections, are done for both types of cancer to reduce the occurrence of occult disease. Occult disease refers to a tumor for which the primary site cannot be found. A study by Weymuller et al. (2000a) studied the impact of neck dissections (both radical and selective) on QOL. They found that there were significant differences in the patient's assessment of "shoulder function" as well as some differences in "pain", wherein those with radical neck dissections reported worse scores for these two domains (Weymuller et al., 2000a). Thus, while commonalities between groups do exist, differences that may directly influence QOL outcomes must not be ignored.

Oral Cancer

Structures affected in oral cancer include the alveolus, hard palate, soft palate, tongue, mandible, and maxilla. Approximately 3,200 new cases of oral cancer will be diagnosed in Canada in 2007 (Canadian Cancer Encyclopedia – Canadian Cancer Society, 2007). This is almost three times the incidence of laryngeal cancers diagnosed. The prevelance of oral cancer is higher in men, with a ratio of approximately 2:1. In Canada, mortality is estimated at approximately 1,100 in the year 2007. In the United States, oral cancer is the sixth leading cause of cancer-related death (Kademani, 2007).

The primary form of treatment for oral cancer is surgical resection (Kademani, 2007). Small and moderately sized cancers often can be resected transorally with no facial incisions (Matthews & Lampe, 2005; Leeper, Gratton, Lapointe, & Armstrong, 2005). Larger, posterior or deeply invasive cancers often require facial or transcervical incisions (Matthews & Lampe, 2005). Generally, surgery can be the sole treatment for early stage oral cancers (Matthews & Lampe, 2005) or used together with post-operative radiotherapy for more advanced tumors (Matthews & Lampe, 2005).

Staging of tumors is described by the TNM clinical staging system. T reflects size of the tumor from T1 being small to T4 representing a more diffuse larger tumor. N reflects involvement of lymph nodes from N0, representing no nodal involvement, to N2 typically reflecting diffuse nodal involvement. Finally, M reflects the absence (M0) or presence (M1) of metastatic disease. This clinical staging system is widely used, and provides information on the size, staging, and prognosis of the disease.

Laryngeal Cancer

The anatomical structures affected by laryngeal cancer are vastly different than the structures affected by oral cancer. Structural regions affected in laryngeal cancer are divided into three subsites including the supraglottis (tissue between epiglottis and vocal folds), glottis (including the vocal folds), and subglottis (tissue between trachea and vocal folds). Presently, approximately 1,150 new cases of laryngeal cancer were expected to be diagnosed in Canada in 2007 (Canadian Cancer Encyclopedia – Canadian Cancer Society, 2007). This number represents 1.5% of all newly diagnosed cancers for the year. Again, the prevelance of this form of cancer is higher in men, with a ratio of approximately 4:1. In Canada, mortality from laryngeal cancer was estimated at approximately 510 in the year 2007 (Canadian Cancer Encyclopedia – Canadian Cancer Society, 2007).

In the last decade, treatment options for advanced laryngeal cancer have changed to include both organ preservation and total laryngectomy (Lotempio et al., 2005). Organ preservation therapies involve treatments that retain the anatomic structure and function of the larynx and thus preserve voice. These options include both chemoradiotherapy (Kademani, 2007) and endoscopic treatments for smaller, non-invasive lesions of the glottis (Doyle & Keith, 2005). More aggressive tumors and tumors failing initial organ preserving therapies typically require more invasive procedures including vertical partial laryngectomy (hemilaryngectomy) for T2 stage lesions (Zeitels, 2005), cricohyoidoepiglotticopexy (Zeitels, 2005), or total laryngectomy. Vertical partial laryngectomies involve removal of structures on one side of the larynx, including one vocal fold, thus preserving voice. For supraglottic cancers, the surgical management typically involves a transcervical horizontal supraglottic laryngectomy, similar to hemilaryngectomy, but above the level of the vocal folds (Doyle & Keith, 2005). Partial laryngectomy, while aiming to retain voicing abilities, does have implications for swallowing including compromise of one or more levels of airway protection, with one vocal fold, partial or total removal of false vocal folds, and partial or total removal of epiglottis.

Treatment Options

Treatment options for head and neck cancer include surgery (as described earlier), radiation therapy, chemotherapy, or a combination of modalities. Additional details concerning radiation and chemotherapeutic modalities are provided briefly below.

Radiation therapy. Radiotherapy is a conventional treatment for head and neck cancers (Orlikoff, 2005). This form of treatment involves daily administration of high-energy electromagnetic emissions applied to a given area of tissue at a pre-determined dose and duration. Each daily administration of radiotherapy is termed a "cycle" and conventional therapy for head and neck cancers typically involve 30 cycles administered over 6 weeks. Each administration of radiotherapy causes damage to all cells within the focused beam of radiation (Doyle & Keith, 2005; Orlikoff, 2005). The ability to adjust the radiation beam and the dosing interval regime allows for the efficacy of treatment with reduced impact to normal tissue surrounding the tumor (Doyle & Keith, 2005). Radiation therapy does, however, have limitations including the fact that some cancer cells may be unaffected by radiation (Doyle & Keith, 2005). As a result the limitations of therapy and the potential for tumors to be unresponsive to treatment may sufficiently impact one's perception of their QOL.

Chemotherapy. Cytotoxic (anticancer) drugs are directed towards rapidly growing and dividing cells and hinder the cell's ability to reproduce, thus leading to death of the cell (Doyle & Keith, 2005; Orlikoff, 2005). Though cancer cells are targeted, other healthy cells are affected in the process (Doyle & Keith, 2005; Orlikoff, 2005). Chemotherapy is often used in combination with other forms of treatment, typically radiotherapy, or reserved for very advanced tumors, because it is not considered a solely curative treatment modality (Doyle & Keith, 2005). While the aim of any treatment modality is to rid the individual of the disease process, these therapies often have secondary effects including structural alterations and tissue changes. These consequences can have a real and significant impact on the individual's QOL.

Treatment Issues

Treatments of oral and laryngeal cancers vary in both the intensity and extent of treatment, as well as by the site and stage of the malignancy (Fung & Terrell, 2004). For that reason, considerable variability exists in the post-treatment period, which holds significant potential to influence assessments of QOL. Treatments may result in differing effects on the physical functioning and QOL (Fung & Terrell, 2004; Hassanein et al., 2005; Myers, 2005) with substantial need to determine individual differences in efforts to better define QOL as well as to determine the influence of treatment on associated domains of functioning consistent with the concept of QOL.

Surgical treatment of oral cancer often includes reconstruction of the resected area, with the goal of minimizing disfigurement and restoring function. In laryngeal cancer, surgical intervention often includes removal of the voice source as well as adjacent tissues associated with lymphatics (Doyle & Keith, 2005). Functionally, those with laryngeal cancer can regain the ability to communicate verbally through several modalities of alaryngeal speech (tracheoesophageal, electrolaryngeal, or esophageal speech). These methods of verbal communication significantly compromise vocal capacity and overall communicative efficiency, as well as voice quality, which can certainly impact QOL. In contrast, those with oral cancer who are treated surgically do not lose their voice source but may be impacted by a variety of other articulatory problems with speech, resulting in individual specific degrees of speech impairment; that is, speech clarity, intelligibility, and resonance issues.

The surgical impact on the swallowing and mastication abilities in these two subgroups also differs. More directly, changes exist in that the nature of the treatment has different implications for one's ability to eat. Patients treated with total laryngectomies no longer retain the connection between the trachea, and the pharynx and oral cavity; thus, these patients are not at risk of aspiration and choking when taking food orally. The type of swallowing problems (dysphagia) these patients may experience occurs during the pharyngeal stage of swallowing, and is influenced by stenosis, or narrowing, of the esophagus secondary to scarring from surgery and/or fibrosis and tissue changes resulting from radiotherapy. Masticated material (bolus), therefore, might get stuck in the esophagus or be slow to travel through the upper digestive pathway. In those treated for oral cancer, for example, resection of part of the tongue, would have a different type of dysphagia in that the oral phase of swallowing would be impacted most significantly. These individuals also have difficulty manipulating the bolus in the oral cavity, and may have reduced tongue propulsion leading to residue and possible aspiration secondary to decreased intrabolus pressure. Thus, both groups – those receiving treatment for laryngeal cancer and those receiving treatment for oral malignancies – may experience dysphagia, but such abnormalities will be characterized by different symptoms and presentations.

Treatment of head and neck cancer through radiation can cause numerous side effects that impact functional capacity and collective evaluations of QOL. The most significant side effect of radiation treatment influences epithelial structures such as salivary glands, mucosa, and skin (Matthews & Lampe, 2005). Salivary glands are frequently included in the field of the radiation beam when treating an oral cancer and, therefore, are often damaged (Matthews & Lampe, 2005). This radiation induced damage causes decreased production of saliva (xerostomia) and production of thick (mucous) saliva (Doyle & Keith, 2005). Functionally, xerostomia can directly impact mastication and swallowing, with further effects on an individual's dentition resulting in additional deleterious effects on these vital functions. Additionally, the direct effect of radiation on teeth and bone (i.e., mandible and maxilla) can cause dental caries and osteoradionecrosis (i.e., bone death secondary to radiation exposure/treatment) (Leeper, et al., 2005), causing pain and increasing the potential for fractures, which in turn, can lead to further dental, medical, or surgical management (Leeper, et al., 2005). The need for management also may include the removal of teeth. Tooth extractions and removal of mandibular bone sections can have significant implications on one's ability to masticate, and thus, manipulate food orally.

Radiation therapy also can cause scarring and atrophy of muscles and mucosa, necrosis, fibrosis, and ossification of the cartilaginous framework of the larynx (Doyle & Keith, 2005). Further, these side effects can impact muscle strength and elasticity (Doyle & Keith, 2005), impinging on the dynamic function of the oral cavity and the larynx. Thus, the consequences of radiation therapy can be significant and cannot be discounted relative to the larger impact on individuals' functional status post-treatment. While the disease itself may be cured, the effects of treatment can create real levels of functional disability unique to the treatment sites with resultant individual reductions in perceived QOL.

Chemotherapy is a systemic treatment with side-effects such as hair loss, nausea, diarrhea, xerostomia, laryngoxerosis (i.e., dryness in the larynx), stomatitis (i.e., sores in the mouth), mucositis (i.e., the lining of oral cavity and pharynx becomes exceedingly sensitive), and a reduction in white blood cells (Doyle & Keith, 2005; Lazarus, 2005; Leeper et al., 2005). While often combined with other treatment modalities, chemotherapy-specific side effects can have significant negative consequences on functional aspects of a person's life. These include problems with swallowing and mastication due to xerostomia, pain due to stomatitis and sensitivity of oral cavity, the risk of life-threatening infections due to low white blood counts, life-threatening dehydration and weight loss due to nausea and vomiting, and finally, the significant impact to one's physical appearance due to poor nutrition and hair loss.

In summary, treatment of oral and laryngeal cancers, while designed to eliminate disease, can leave individuals with considerable residual trauma that cross multiple domains of functioning (e.g., physical, psychological, and social). The sequelae of such treatments can include pain, changes in appearance, mastication, swallowing, and deficits in speech and verbal communication. While the malignancy is treated medically, the treatments themselves can have significant negative implications on QOL.

Self-Administered Measurement Tools of Disease-Specific QOL

There are several disease-specific instruments that are frequently used to measure QOL in those diagnosed with head and neck cancer (Fung & Terrell, 2004). Each of these tools addresses a variety of functions specific to adults with head and neck cancer. They do not, however, currently consider oral cancer and laryngeal cancer as different forms of carcinoma, but rather, group them together as "head and neck" cancer. The following are QOL questionnaires that are frequently used: (1) University of Washington Quality of Life scale (UW-QOL) (Hassan & Weymuller, 1993), (2) European Organization for Research and Treatment of Cancer – Quality of Life Questionnaire (EORTC-QLQ-C30) and the Head and Neck Module (EORTC-QLQ-HN35) (Bjordal, Ahlner-Elmqvist, Tollesson, Jensen, Razavi, Maher, & Kaasa, 1994; Bjordal, de Graeff, Fayers, Hammerlid, van Pottelsberghe, Curran, et al., 2000), and (3) University of Michigan

Head and Neck Quality of Life (HNQOL) (Terrell, Nanavati, Esclamado, Bishop, Bradford, & Wolf, 1997).[1]

Among these three tools, the following is a list of items (domains) that appear on some or all of the questionnaires listed above: pain (1,2,3), eating/swallowing (1,2,3), senses (1[taste],2,3 [taste]), speech/communication (1,2,3), social eating (2), social contact (2), sexuality (2), emotion/mood (1,2,3), appearance (1,3), saliva (1), chewing (1), shoulder problems (1,3). (Please see Appendix B for a summary of the items appearing on the tools). All of the tools include the domains of pain, eating/swallowing, and speech. The manner in which the questions are posed, however, differs between each questionnaire, for example, wording of the questions is different. Additionally, differences between oral cancer and laryngeal cancer exist not only in the treatment approaches, but with varied levels of impact affecting each group. For example, while a range of communication changes can occur for those with oral cancer, all individuals with laryngectomies will suffer communication changes.

Several researchers (Deleyiannis et al, 1999; Weymuller et al., 2000a) mention the potential benefit of applying an importance-weighting scheme to head and neck cancer QOL instruments to give more accurate and representative scores as assessed by the individual. As is explained by Deleyiannis (1999) "...investigators acknowledge that the adjustment of individuals' QOL domains by their relative importance may provide a more accurate assessment of overall QOL. However, standard guidelines on how to weight severity scores by importance are not published..." (p. 321). A ranking/weighting system involves the individual placing the domains/areas of concern in

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[1] The numbers in the paragraph below represent the numerically identified questionnaires.

order of most to least impact on his/her QOL. A weighting system could then be applied to this ranking in order to give the *relative* impact score to each domain.

The addition of a ranking/weighting system to existing, validated disease-specific QOL instruments may prove to be a superior and ideally a more accurate indication of any given individual's QOL within the larger population of those with head and neck cancer. These data have the potential to provide for more precise understanding of the areas that are impacted by the diseases per se and by treatments of head and neck cancer. Furthermore, with the separation of oral cancer and laryngeal cancer into two distinct diagnostic groups, the scores from the QOL instruments would give an overall picture of the relative importance placed on given domains for each group.

Statement of the Problem

While validated tools that measure QOL in those diagnosed and treated for head and neck cancer currently exist, no tool specifically addresses issues that affect QOL in those with oral cancer separate from those with laryngeal cancer. The proposed study seeks to identify the need to distinguish specific elements of QOL instruments in the context of clear differences between those treated for oral cancer and those treated for laryngeal cancer. Thus, the direct emphasis of this preliminary project to focuses on the unique symptoms and deficits associated with treatment of different anatomical sites of head and neck cancer. The objective of the present investigation centers directly on the need to investigate potential differences and seeks to qualify, at least at the preliminary level, such observations via use of a ranking/weighting of domains on validated QOL instruments. These rankings/weightings will be provided directly by participants who are exposed to all instruments under study across these two clinical groups.

Significance of the Proposed Project

Oral cancer and laryngeal cancer affect different anatomical structures, they are treated medically using different methods, and functionally different domains/areas of functioning are often affected in a unique manner. Therefore, it is necessary to account for such differences in these two forms of head and neck cancer in an effort to identify and quantify QOL outcomes more clearly in both populations. More specifically, by segmenting those with head and neck cancer into more logical anatomical site groupings, we may be able to study independent factors in greater depth and, more directly, each population in terms of post-treatment QOL. By studying these two groups separately, health care providers may be able to gain further insight into the specific limitations and deficits associated with each population. This information holds the potential to provide an enriched view of factors that influence QOL. In doing so, we believe that these data can provide information that facilitates a better understanding of the specific issues experienced by each individual group secondary to his/her particular diagnosis.

Currently, the UWQOL uses a scoring system where respondents indicate the functional domains assessed (e.g., pain, appearance, chewing etc.); this identification represents the specific impact/importance of a given domain to one's QOL. However, all domains are ultimately weighted equally in this measure (Weymuller, Alsarraf, Yueh, Deleyiannis, & Coltrera, 2001). The issue arises where the person is asked to identify domains of importance, yet the scoring system has no method to account for relative weightings of the domains when calculating the final score. If the respondent rates each domain in order of what he/she feels to be the most to the least important, then there should be a weighting system that factors in level of "importance" or "impact" of each into the final score. For example, if issues of pain create the greatest obstacle to perceived quality of life, the ability to account differently for that impact via some form of weighting relative to other areas assessed could be of great value. While the importance of ranking has been acknowledged, there are no guidelines as to how the scores should (or could) be weighted (Deleyiannis et al., 1999). Despite the opportunity to provide a ranking, the overall score that is calculated weighs each domain equally regardless of the degree of importance given by the individual.

Objectives of the Project

This proposed project seeks to develop an empirically derived weighting system that is comprised of a three-part ranking and weighting procedure. In this process, the participant will identify and rank the six most relevant domains/areas of concern that significantly impact on his/her quality of life. The participant will also mark off the relative amount of importance or impact that each domain has on his/her QOL on a pie scale. (Please see Appendix C for weighting system example). The scale will function as an indicator of the degree of impact each domain, relative to the other domains, has on participants' overall QOL. With the introduction of an individualized weighting system, the true impact of factors affecting QOL may be more fully appreciated and empirically studied. Although the present work is indeed preliminary in nature, it is the first such attempt to explore a method of determining relative perceived values of particular features inherent to any given QOL measure.

Experimental Questions

The specific questions addressed in this project were:

1. Are there differences in areas of concern for individuals who have been treated for oral cancer versus laryngeal cancer?
2. Are the current questionnaires able to detect these differences?
3. Can a weighting system be developed that will provide an accurate assessment of the areas of concern that are affecting quality of life for each individual?

Method

Participants

Nineteen adults who had undergone treatment for oral cancer (n = 13) or laryngeal cancer (n = 6) at the Regional Cancer Program in Ontario were solicited to participate in this project. Participants were between 8 and 23 months post-treatment. Similarly, no participants were included if they were six months or less post-treatment, because the treatments may still have had a variable but significant effect on the patient's QOL due to the acute effects of treatment. The target timeframe post-treatment (12 to 18 months post) was chosen because investigators have found that the QOL in patients treated for head and neck cancer declines immediately following initiation of treatment, and then is observed to return towards baseline approaching 12 months post treatment onset (Murphy et al., 2007).

Age of the participants ranged from 45 to 71. The ages of participants in the oral cancer group ranged from 45 to 64, and participants in the laryngeal group ranged from 56 to 71. Participants had no medically documented evidence of cancer recurrence at the time of their most recent surveillance prior to mailing out of the packages. Demographic data as well as data on any concurrent health problems that the participants have was gathered in an effort to identify potential confounding factors to their assessment of particular areas of QOL (e.g., chronic obstructive pulmonary disease, cardiovascular disease, current medications etc.). A demographic assessment of age, sex, type and stage of tumor, and treatment history can be found in Appendix D.

Measurement Instruments

Tools utilized included the: (1) University of Washington Quality of Life Questionnaire (UW-QOL), (2) The European Organization for Research and Treatment of Cancer – Quality of Life Questionnaire C-30 combined with the Head and Neck Module (EORTC-QLQ-HN35), and (3) the University of Michigan Head and Neck Quality of Life Instrument (HN-QOL). (Please see appendix E for a summary of each questionnaire). These tools were chosen for several reasons including the fact that they are widely employed in post-treatment head and neck cancer assessment of QOL. All three instruments demonstrate acceptable psychometric properties specific to validity and reliability (Please see Appendix F for psychometric property information). The questionnaires also share additional features that make them attractive for use in the present project. This includes the fact that all are short in length and easy to complete by the participant. The general structure of the tools reflects a reading level of grade 5-6, though the complexity of wording may be more difficult. This complexity, however, may be further influenced by the individual's general cognitive statues, how he/she is feeling at the time, among other factors. In terms of time-span covered by the questionnaires, both the UW-QOL and the EORTC specify the time period in consideration to be "the past 7 days/during the past week", whereas the HN-QOL specifies that the period covered is "over the past four weeks".

Procedure

Each participant was contacted by the investigators via telephone contact and asked if he/she would like to participate in this study. Several subjects who had undergone a total laryngectomy were contacted via mail initially. The investigators attempted to make telephone contact with them with no response. Due to the nature of their surgery (i.e., removal of their voice source), it was decided that phone contact for approval may be more difficult for a variety of reasons. Therefore, in an effort not to exclude the individuals based on this fact, the investigators contacted four participants via mail. If they agreed to participate in the study the participants were then required to complete the package containing an information letter describing the purpose of the study, as well as information regarding the completion of the questionnaires and rating scales (each pie scale had the same instructions for each tool with different domains to rank based on each specific questionnaire being utilized). The package also contained the given questionnaires in sealed envelopes each marked with a number 1, 2, or 3, additional information sheet, a pencil, an eraser, return envelopes with numbers 1, 2, an 3, and an addressed return envelope with paid postage for the participant to send the questionnaire in return.

Participants in each category were assigned the three tools randomly, sequenced in random order. Each group completed the three previously identified head and neck QOL questionnaires in random, but sequential fashion. Tool number 1 was to be completed on day 1, tool number 2 was to be completed on day 2, and tool number 3 was to be completed on day 3. At the end of each tool, the participants were asked to rate the questionnaires in terms of how relevant and representative the tools were to his/her situation. They were asked to identify the degree to which the tool was reflective of his/her overall QOL by answering a forced choice question with several options (i.e., reflects all issues that affect my QOL, reflects most, reflects some, reflects only a few, reflects none). In addition to completion of the questionnaires, the participants were also given the opportunity to comment openly on domains that may be missing from the tool and/or other comments he/she may want to share on an additional information sheet.

The participants were also required to complete a ranking/weighting system after filling out the questionnaire. The ranking/weighting system consisted of a three-part procedure. An example of how to complete the system was provided. In the first step, the participant was instructed to check off the six most significant domains/areas of concern from a list provided. The list was relevant to the questionnaire the participant had just completed. In the second step, the participant was required to rank order the six domains he/she identified. The final step instructed the participant to plot (i.e., segment) the ranked domains on a pie-type chart to signify the relative impact each domain has on his/her overall quality of life. A pencil and eraser were provided in the package as to allow for modification of the scale so that the best representation could be achieved. Upon return of the package, measurements were taken of the pie chart with a single standard protractor to establish the individual weightings of the top six domains/areas of concern.

The requirements for completion of the three measures in a consecutive three day period was accomplished by instructing the participant to complete set 1 on day one, place all forms in the empty envelope marked with a one (1), seal, date, and sign the envelope. This procedure was described as such to ensure that the participant was following the timeline requirements of the study. The same procedure was to be followed for each of the other two questionnaire sets. At the end of the third day, or at the participant's earliest convenience, he/she was asked to place all three sealed envelopes in the large envelope. This envelope was to be mailed back to the investigators.

Data Analysis

Standard scoring procedures as described by the authors of each QOL instrument was employed for the three tools used in this study. T-tests were used to analyze data collected. The data were summarized and presented descriptively.

Questionnaires

The EORTC QLQ C-30 and EORTC QLQ – H&N35, UW-QOL v4, and HN-QOL were utilized in this study. The questionnaires were sent by mail to the patient's home with instructions on completion of the questionnaire. Additionally, open-ended text was made available for participants to share information that they feel is important to add. Support for open text has been found in several studies (Weymuller et al., 2000a; Weymuller et al., 2000b), and provides meaningful information from individual patients that may be missed with the current tools.

Results

The data collected in this project were analyzed through statistical measures (i.e., t-tests for independent samples), as well as descriptively. As the sample size collected was relatively small (total n = 19) and the two study groups were ultimately dissimilar (oral, n = 13, laryngeal, n = 6), use of t-tests was deemed the most appropriate method of analysis. In the following section, results from the statistical evaluation, as well as the findings from the analysis of the data through descriptive means are provided.

Statistical Analyses: Comparison between measurement instruments

A t-test for independent samples was performed to compare the mean total score values of the two groups (oral cancer and laryngeal cancer) between each tool. A p value of .05 was set as the a priori level of significance. As Levene's test for equality of variances revealed no significance for any of the overall scores for all three tools, it was assumed that the variances between the two cancer site groups were equal. However, it should be noted that the possibility that the variances may not be equal certainly may exist as the group sizes are both small and uneven.

Based on these statistical evaluations, it was determined that cancer site did not have a significant effect on the total QOL score for any of the three measurement tools: HNQOL total score $t(17) = (.459), p = .652$, UWQOL total score $t(17) = (-.143), p = .888$, EORTC C30 total score $t(16) = (-.315), p = .817$, EORTC HN35 total score $t(16) = (.579), p = .571$, EORTC total score $t(16) = (.440), p = .701$.

When analyzing specific subscores of the QOL instrument, Levene's test revealed significance for the EORTC H&N35 "Senses" ($p<0.002$), EORTC H&N35 "Weight Loss" ($p<0.000$), and HNQOL "Pain" subscores ($p<0.002$), thus, indicating variances between the two group are assumed to be unequal. The significance levels of the subscores for the HNQOL "Pain" and EORTC H&N35 "Weight Loss" with variances assumed to be unequal are as follows: HNQOL "Pain" $t(1, 17) = -1.993, p = 0.012$, and EORTC H&N35 "Weight Loss" $t(1, 16) = -1.952, p = 0.017$. With the t-test, the EORTC H&N35 "Senses" received a score on Levene's test of $p=0.002$, and thus assuming unequal variances, $p< 0.297$, was no longer considered as approaching significance. Other subscores (i.e., EORTC C30 "Appetite Loss", EORTC H&N35 "Less Sexuality, "Social Eating", and HNQOL "Speech") did not show significance on Levene's test, again indicating variances were assumed to be equal.

Findings of Subscores Assumed to be Equal

The findings of subscores where equality of variances was assumed to be equal were also assessed. This approach revealed the inclusion of the: a) EORTC C30 "Appetite Loss" $t(1, 16) = -1.584, p = 0.133$; b) EORTC H&N35 "Less Sexuality" $t(1, 16) = -1.774, p = 0.095$, "Social Eating" $t(1, 16)=-1.417, p = 0.176$; c) HNQOL "Speech" $t(1, 17)= 1.702, p = 0.107$. These significance levels were found to be at either the pre-established probability level ($p <0.05$) or approaching significance. Had the sample size been larger for at least the laryngeal cancer group, changes in determination of significance may have been observed more clearly.

Scores for subscales on all three QOL measurement tools

EORTC C30. The EORTC C30 was scored for each individual as per instrument instructions. Possible scores range from 0.00-100.00, with 0.00 being the lowest possible score, and 100.00 being the highest possible score. Mean values were similar across groups for most domains (Table 1). The range of mean scores for the oral cancer group

Table 1

EORTC C30 scores for select subscales

Domain/Scale	Mean	Standard Deviation	Standard Error	Confidence Interval (95%)	Range
		Oral Group			
Global Scale					
Global Health Status	62.50	27.64	7.98	46.86-78.14	0.00-100.00
Functional Scales					
Emotional	65.97	29.40	8.49	49.34-82.61	0.00-100.00
Social	68.06	35.15	10.15	48.17-87.94	0.00-100.00
Symptom Scales					
Appetite Loss	66.67	31.78	9.17	48.68-84.65	0.00-100.00
		Laryngeal Group			
Global Scale					
Global Health Status	65.28	19.31	7.88	49.83-80.73	33.33-83.33
Functional Scales					
Emotional	79.17	13.69	5.59	68.21-90.12	66.67-100.00
Social	72.22	17.21	7.03	58.45-86.00	33.33-100.00
Symptom Scales					
Appetite Loss	88.89	17.21	7.03	75.12-102.66	66.67-100.00

varied by approximately 6% (62.50-68.06), and the range of mean scores for the laryngeal cancer group varied by approximately 23% (65.28-88.89). There was an interesting finding of greater variation of mean value for the symptom scale of "Appetite Loss". The scores for this domain differed by approximately 22 points between the groups, with the oral group's mean score of 66.67, and the laryngeal group's mean score of 88.89. These scores indicate that the oral group rated this domain as more disabling to their QOL. A broader standard deviation for the oral group (31.78) compared to the laryngeal group (17.21) indicates a greater amount of variance for the oral group.

EORTC H&N35. The EORTC H&N35 was scored for each individual as per instrument instructions. Possible scores range from 0.00-100.00, with 0.00 being the lowest possible score to obtain, and 100.00 being the highest possible score to obtain. Mean values were similar across groups for some domains (Table 2). The range of mean scores for the oral cancer group varied by approximately 28% (58.33-86.11), and the range of mean scores for the laryngeal cancer group varied by approximately 37% (63.89-100.00). A large variability was noted especially between the groups on the "Less Sexuality" domain, where the mean score for the oral group was 58.33, and for the laryngeal group the mean score was 88.89, indicating a more negative impact of this domain on the oral group's QOL. The standard deviation on this domain was also variable between the oral group (39.25) and the laryngeal group (20.18). It should be noted, however, that the influence of highly discrepant single scores are expected to influence these smaller

Table 2

EORTC H&N35 Scores for select subscales

Domain/Scale	Mean	Standard Deviation	Standard Error	Confidence Interval (95%)	Range
		Oral Group			
Senses	84.72	18.06	5.21	74.50-94.94	50.00-100.00
Speech	81.48	19.15	5.53	70.65-92.32	44.44-100.00
Social Eating	70.14	27.86	8.04	54.38-85.90	16.67-100.00
Less Sexuality	58.33	39.25	11.33	36.13-80.54	0.00-100.00
Weight Loss	86.11	17.16	4.95	76.40-95.82	66.67-100.00
		Laryngeal Group			
Senses	63.89	42.71	17.44	29.71-98.06	0.00-100.00
Speech	66.67	21.08	8.61	49.80-83.54	33.33-88.89
Social Eating	87.50	14.67	5.99	75.76-99.24	66.67-100.00
Less Sexuality	88.89	20.18	8.24	72.74-105.04	50.00-100.00
Weight Loss	100.00	0.00	0.00	100.00-100.00	100.00-100.00

samples means and standard deviations; thus, this variability needs to be considered carefully.

HNQOL. The HNQOL was scored for each individual as per instrument instructions. Possible scores range from 0.00-100.00, with 0.00 being the lowest possible score to obtain, and 100.00 being the highest possible score to obtain. Mean values were variable between groups for the domains (Table 3). The range of mean scores for the oral cancer group varied by approximately 3% (71.15-74.52), and the range of mean scores for the laryngeal cancer group varied by approximately 37% (53.13-90.63). This variability was especially noted on the "pain" domain, where the oral group's mean score (71.15) was nearly 20 points lower than the laryngeal cancer group's mean score (90.63), indicating greater impact of "pain" on the oral group's QOL. The variability of the standard deviation for this domain also is large, as the standard deviation for the oral group (23.32) is approximately four times that of the laryngeal group (5.23).

UWQOL. The UWQOL was scored for each individual as per instrument instructions. Possible scores range from 0.00-100.00, with 0.00 being the lowest possible score to obtain, and 100.00 being the highest possible score to obtain. Mean values were similar across groups for the overall score (Table 4). The variability between the two groups was less than one point, indicating very similar overall performance on the tool as a whole.

Table 3

HNQOL Scores for select subscales

Domain/Scale	Mean	Standard Deviation	Standard Error	Confidence Interval (95%)	Range
			Oral Group		
Speech	74.52	20.96	5.81	63.13-85.91	37.50-100.00
Pain	71.15	23.32	6.47	58.48-83.83	31.25-100.00
			Laryngeal Group		
Speech	53.13	33.95	13.86	25.96-80.29	0.00-87.50
Pain	90.63	5.23	2.13	86.44-94.81	87.50-100.00

Table 4

UWQOL Scores

Overall score	Mean	Standard Deviation	Standard Error	Confidence Interval (95%)	Range
			Oral Group		
Overall score	71.83	12.51	3.47	65.02-78.63	53.75-88.75
			Laryngeal Group		
Overall score	72.78	15.39	6.28	60.46-85.90	54.17-95.83

Composite Ranking of Overall Scores

In an effort to investigate if one questionnaire provided for a more comprehensive view of the deficits or levels of disability experienced by both groups, each participant's overall scores for each questionnaire were ranked from highest score to lowest score (Table 5 and Figure 1). Results indicated no obvious patterns of scoring with the relative ranks being evenly distributed across tests. When comparing individual participant's ranking of scores, 38.9% (n=7) of the total number of participants' highest scores (indicating lowest level of impairment/best QOL) were found to occur on the H&N35 module. However, of those who indicated the lowest level of impairment/best level of QOL on the H&N35 module, 42.9% (n=3) indicated a worst level of functioning/lowest level of QOL for the general cancer module (i.e., the EORTC-C30). Further, 72.2% (n=13) of participants indicated a higher score on the H&N35 module compared to the C30 module (Please see Figure 2 for a graphic representation of all scores for each participant). No other such pattern emerged from performance on the other tool.

Ranking of Most Important Domains for Each of the Three Questionnaires

On the EORTC ranking sheet, participants identified several domains including talking, eating, teeth + jaw, swallowing, emotion, and appearance on their top three areas of concern. Specifically, the oral cancer group identified eating (24.2%), talking (18.2%), teeth + jaw (12.1%), swallowing (12.1%), and appearance (6.1%) as some of the domains having the most significant impact on their QOL. The laryngeal cancer group identified similar domains as talking (20%), eating (26.6%), and swallowing (26.6%) as being of greatest importance.

Table 5

Ranking of overall level of QOL by questionnaire and participant

Participant	EORTC C30+H&N35	HNQOL	UWQOL
O1	2	1	3
O2	1	3	2
O3	2	3	1
O4	3	1	2
O5	3	2	1
O6	2	1	3
O7	1	3	2
O8	1	2	3
O9	n/a	2	1
O10	2	3	1
O11	1	3	2
O12	2	1	3
O13	3	1	2
L1	2	1	3
L2	1	3	2
L3	1	3	2
L4	3	2	1
L5	2	1	3
L6	3	1	2

Figure 1
Total scores for each tool by participant: EORTC (C30 + H&N35), HNQOL, and UWQOL

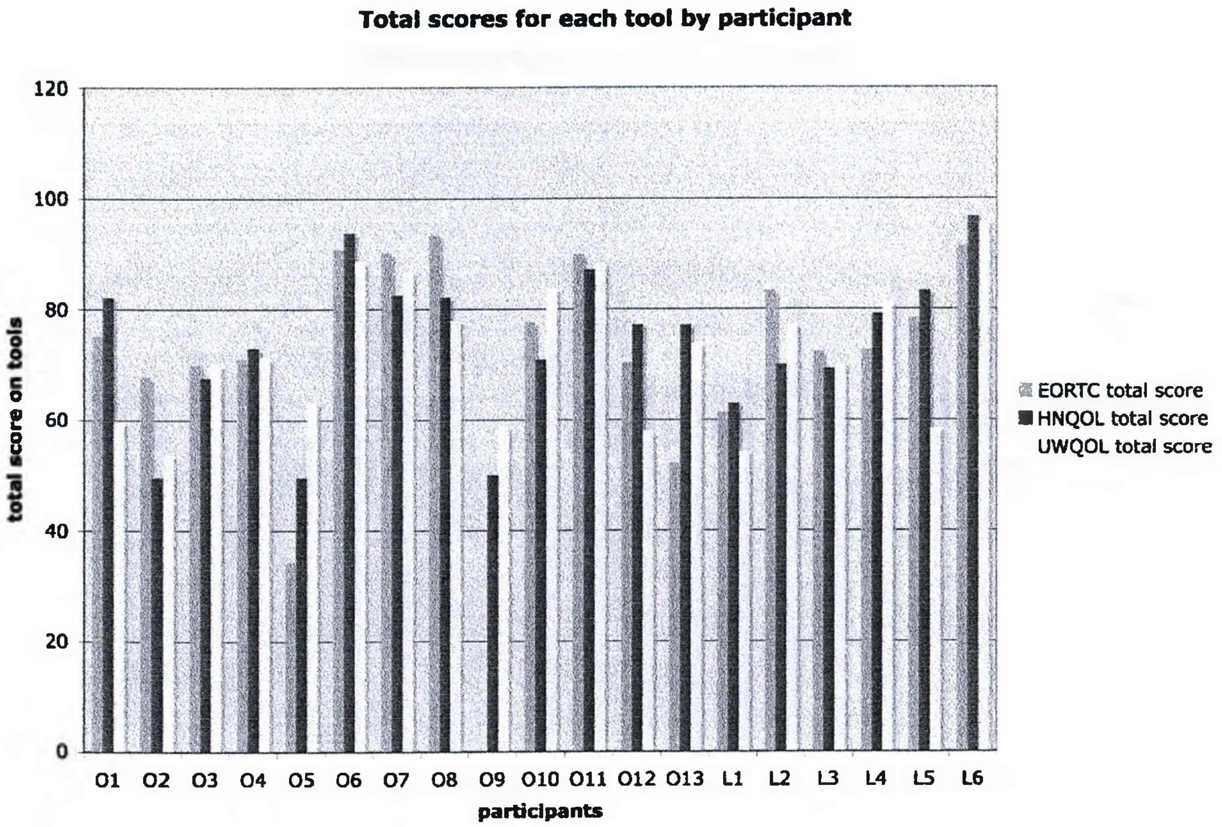
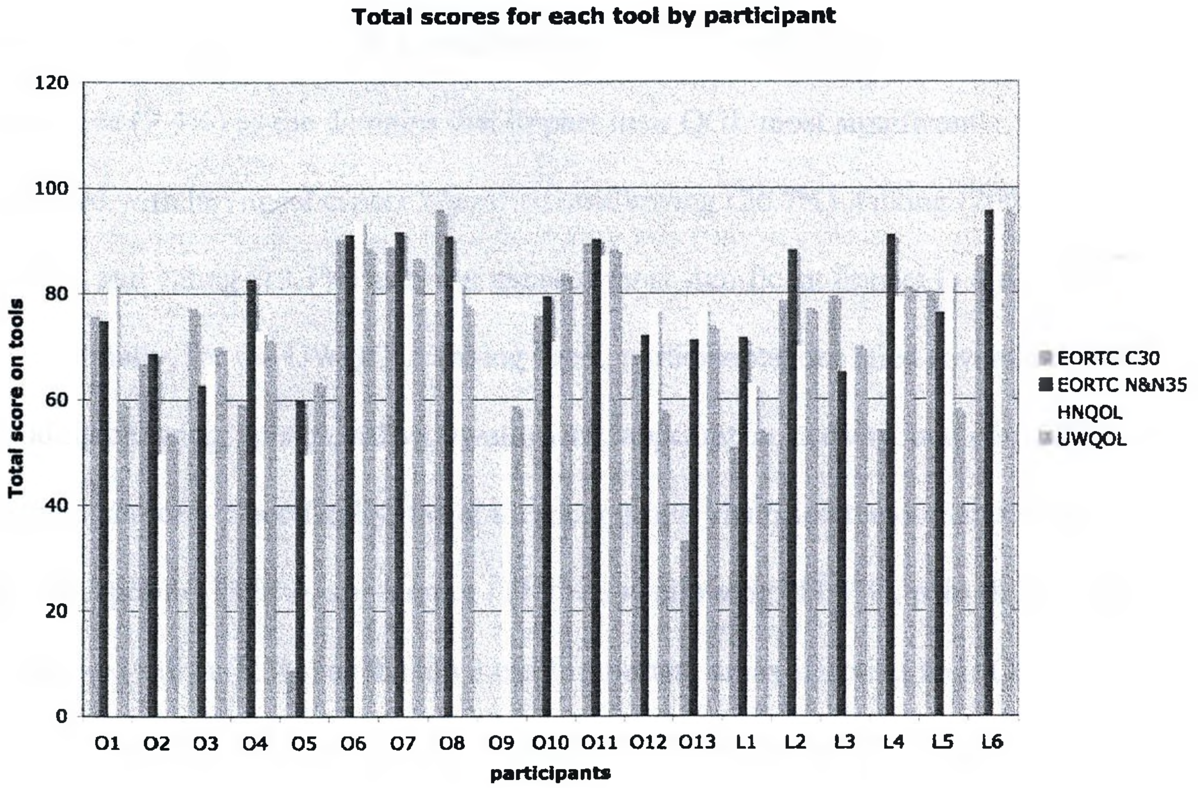


Figure 2

Total scores for each tool by participant – EORTC C30, EORTC H&N35, HNQOL, and UWQOL



Participants also identified several domains on the HNQOL ranking sheet, including talking, chewing, eating, swallowing, work/finances, appearance, and emotion within the top three choices. Specifically, the oral group identified chewing (25%), eating (18.6%), talking (15.6%), swallowing (12.5%), work/finances (9.4%), and appearance (9.4%) as the domains that impact their QOL most significantly. Those diagnosed with laryngeal cancer identified swallowing (26.7%), talking (20%), chewing (13.3%), and eating (13.3%) as being areas of most significant impact to their QOL.

Finally, for the UWQOL ranking sheet, participants identified several domains including chewing, speech, saliva, swallowing, appearance, activity, and pain within the top three choices. Specifically, the oral cancer group identified the domains of chewing (19.4%), speech (13.9%), appearance (11.1%), swallowing (11.1%), pain (8.3%), activity (8.3%), and saliva (8.3%) as the top 3 most important areas affecting their QOL. The laryngeal cancer group identified swallowing (26.7%), speech (20%), chewing (20%), and saliva (13.3%) as their three most important concerns.

Summary of Results

The results of this study indicate little variability between the oral group and the laryngeal group for overall scores of all three QOL measurement tools used in this study. There are, however, several subscales of the tools that indicate some distinct differences between groups. These differences remain relatively consistent across tools, leading to the assumption that they provide insight into specific domains of functioning and potential differential disability between these two groups. These findings will be discussed in greater detail within Chapter 4.

Discussion

The purpose of the present study was to investigate potential differences between two subgroups of individuals with head and neck cancer, those with oral cancer and those with laryngeal cancer. The focus of these potential differences was contextualized in terms of areas of concern that are perceived to influence one's QOL. In any discussion of QOL it is important to understand that the impact of the areas of concern typically addressed in QOL instruments is actually directed at the level of disability associated with a given domain, and to what extent the impairment impacts an individual's life. In exploring this broad topic, this study also sought to determine if there are differences in domains/areas of concern given the participants' type of head and neck cancer. As such, a complementary aim of the project was directed toward comparative evaluation of three specific QOL tools that are currently being utilized to evaluate those with head and neck cancers.

This collective interest was approached in terms of relevance to oral versus laryngeal cancer, and to determine if there are domains that are missing or insufficiently represented within the current tools. Recalling the suggestion by Weymuller et al. (2000b), it is important to consider a variety of issues central to evaluations of QOL in the context of the site of malignancy. Thus, any given head and neck cancer quality of life measurement tool may carry a potential for some inability to detect differences that exist for those with differing types of head and neck cancer such as oral cancer and laryngeal cancer.

The discussion to follow will address the findings of the present study in relation to three experimental questions. The discussion will first address differences in perceived areas of concern for the two groups. This includes description of the ranked domains, as well as the individual subscales of the given questionnaires. Next, the issue of a comprehensive assessment of the tools in terms of their ability to detect any differences within or across the participant groups will be discussed. Specifically, each tool will be addressed individually, as well as compared to the other questionnaires in terms of their general ability to detect levels of disability affecting QOL and functioning. This will be followed by a brief discussion regarding one of the questions posed at the outset of this project, that which centered on an interest in determining if some type of weighting system could be developed and employed in an effort to understand more fully the tools and the content areas they represent. Next, clinical implications of the research, as well as limitations of the project, will be addressed. Finally, directions for future research based on findings from the current data will be offered.

Research Question 1: Are there differences in areas of concern for individuals who have been treated for oral cancer versus laryngeal cancer?

Ranked domains for each of the three questionnaires

For each questionnaire completed, participants had the opportunity to choose and torank in order of importance six domains that they felt had the most significant impact on their QOL. Overall, and not unexpectedly, there were several areas of concern that were highlighted across groups, as well as between the groups under study.

EORTC. On the EORTC ranking sheet, participants identified several domains including talking, eating, teeth + jaw, swallowing, emotion, and appearance within the top three areas of concern. Specifically, the oral cancer group identified eating, talking, teeth + jaw, swallowing, and appearance as some of the domains having the most significant impact on their QOL. The laryngeal cancer group identified similar domains as talking, eating, and swallowing as being of greatest importance. It should be noted, however, that the swallowing domain was identified more than twice as frequently for the laryngeal group than for the oral cancer group. This is an issue that is often overlooked in the laryngeal cancer population, because the assumption is that swallowing is not a concern (Doyle & Keith, 2005; Lazarus, 2005). Also, the oral cancer group identified trouble with teeth + jaw, whereas the laryngeal cancer group did not identify this domain as having a significant impact on their QOL. While this finding was anticipated given the site of the lesion and the effects of treatment, dental problems have long been a problem reported by those who undergo laryngectomy, particularly in association with lost teeth (Doyle, 1994; Myers, 2005), but unfortunately one that is often diminished in its impact. The present data provide evidence that dental problems are of importance to those who experience them secondary to cancer treatment.

HNQOL. Participants identified several domains on the HNQOL ranking sheet including talking, chewing, eating, swallowing, work/finances, appearance, and emotion within the top three choices. Specifically, the oral group identified chewing, eating, talking, swallowing, work/finances, and appearance as the domains that impact their QOL most significantly. Those diagnosed with laryngeal cancer identified swallowing, talking, chewing, and eating as being areas of most significant impact to their QOL. Differences in the rankings between the two groups included twice the frequency of swallowing problems in the laryngeal group as compared to the oral group on the HNQOL. When compared to that observed on the EORTC, this finding provides confirmation that such areas are judged to be of considerable importance for both groups.

Also, those with oral cancer reported twice the frequency of chewing problems when compared to the laryngeal group. This finding may be related to the teeth + jaw impairments identified in the EORTC ranking by the oral group. Thus, it would appear that some continuity between questions posed on the EORTC and those from the HNQOL instruments does exist and that these questions address an important functional dimension.

Additionally, and of interest with the HNQOL, those with oral cancer identified work/finances and appearance as being significant domains affecting their QOL. Problems with finances can isolate individuals, thus leading to further impact on social participation and overall QOL. Further, issues related to appearance directly impact on an individual's self esteem and social interactions. Concerns related to work/finances and appearance may be associated with a third factor that was found to be significantly different between the two groups, that being the difference in age.

More specifically, participants in the oral cancer group (M = 53.9, SD = 5.9) were noted to be significantly younger than the participants in the laryngeal cancer group (M = 64.7, SD = 4.9). This finding is consistent with the current statistics, reporting that oral cancers are being diagnosed in a younger population than in the past (Canadian Cancer Encyclopedia – Canadian Cancer Society, 2007). This difference in age might contribute, at least so some extent, to work-related problems, because the mean age of the oral group is below that of retirement age. Thus, the inability to work and to provide income to a younger family may have a more significant impact on an individual's overall QOL. Further, the diagnosis of cancer at an earlier age when individuals can have a host of other immediate responsibilities, such as children, could certainly create increased emotional burden, with direct social implications, thus, adding stress to relationships. In this regard, age always must be considered as a potential variable of importance on measures of QOL.

UWQOL. For the UWQOL ranking sheet, participants identified several domains including chewing, speech, saliva, swallowing, appearance, activity, and pain within the top 3 choices. Specifically, the oral cancer group identified the domains of chewing, speech, appearance, swallowing, pain, activity, and saliva as the top three most important areas affecting their QOL. The laryngeal cancer group identified swallowing, speech, chewing, and saliva as their three most important concerns. Interestingly, both groups identified chewing approximately 20% of the time, whereas on the HNQOL the oral group was nearly twice as likely to identify chewing as a problem area. Again, swallowing in the laryngeal group is identified twice as often as a concern compared to the oral cancer group. Additionally, appearance is once again identified in the oral group as a domain affecting QOL, whereas it is not identified as such for the laryngeal group.

What is of interest across findings for both groups is that all the areas noted as of concern are those that carry a relationship to social interactions and activity. That is, the inability to eat publicly or to have concerns about one's appearance may have very different "external" consequences than a concern such as pain. That does not mean that pain cannot restrict one's function. The issue that is clear here is, however, that all of the activities ranked as being of direct importance to these participants are directly linked to social performance broadly defined. Clearly, the impact of changes in eating and swallowing carry with it a substantial potential for social impact. That is, the inability to eat or swallow with ease and comfort can result in individuals withdrawing from a variety of social activities where these abilities are required. Such restrictions would range from eating in public places such as restaurants to less public, but potentially of equal importance, having meals with family. Similar, one's appearance is without question a critical component of concern that carries with it the real and significant possibility of social withdrawal. Thus, the social impact of deficits in eating and swallowing, and changes in appearance (even if relatively minor from a medical standpoint) have considerable implications relative to one's everyday functioning and social well-being.

QOL and Speech

Although there is clear evidence that one's voice is affected by the treatment of laryngeal cancer, especially when treatment involves total laryngectomy (Doyle, 1994) and radiation treatment (Fung, et al. 2001; Lotempio et al., 2005), this study did not find a significant difference between the two groups regarding the level of impact speech and talking has on QOL. A recent study by Moukarbel, Doyle, Day, Franklin, Yoo, and Fung (2008) that involved comparison of voice-related QOL outcomes for different methods of alaryngeal speech found a significantly higher level of QOL for individuals utilizing tracheoesophageal (TE) speech as compared to esophageal speech and electrolaryngeal speech. This finding suggests that speech is a domain that is less disabling for individuals who utilize TE speech when compared to those using other methods of alaryngeal speech. In the present study, individuals in the laryngeal cancer group used communication methods including TEP speech and voicing that occurred with at least one vocal fold preserved (i.e., those who underwent a partial laryngectomy). Thus, the high level of functioning on the speech domains for those in the laryngeal cancer group appear to be consistent with the study by Moukarbel et al. (2008). However, this finding should not be interpreted to suggest that voice and speech deficits do not create disability for those currently evaluated in this project.

Summary of Findings From Domain Rankings

Overall, talking/speech and eating/swallowing are areas of concern/disability identified by both groups but to different extents. The laryngeal cancer group consistently identified swallowing problems and did so approximately twice as often as did those in the oral cancer group. The prominence of swallowing problems as an area of concern demands that full efforts be taken in the clinical environment to question individuals about such potential problems and to actively seek to eliminate or to reduce the deficits. Concerns about talking/speech were generally identified as an area of importance for both groups. However, and for obvious reasons, talking/speech deficits were identified slightly more often for the laryngeal group, a finding that has longstanding support in the literature (Doyle, 1994; Eadie & Doyle, 2005; Hassanein et al., 2001; Lotempio et al., 2005; Vilaseca et al., 2006; as well as others).

Participants in the oral cancer group identified chewing/teeth + jaw twice as often as those in the laryngeal cancer group for the EORTC and HNQOL, but equally as important for both groups on the UWQOL. Appearance was consistently identified in the top three ranking on all three tools, however, not as frequently as the other domains mentioned. Finally, work/finances was identified more frequently by the oral cancer participants as an area of concern affecting their QOL. This observation is unique and although based on a small comparative population in the present study, is worthy of further study in the future.

Although not included in the top three items of importance, sexuality (only on EORTC, as it was not included on the other tools) was identified within the top six domains by 5 (oral, n = 3, laryngeal, n = 2) of the 16 participants who ranked domains. Thus, almost 1/3 of those who participated reported concerns in this important functional domain. Interestingly, this topic is not covered by the other questionnaires and historically has not been typically covered in other QOL questionnaires or via general counseling efforts. While limited information is available on this topic specific to those with head and neck cancer, it is suspected that two factors may influence its lack of attention in many venues. First, because so many significant physical changes typically exist following treatment for head and neck cancer, aspects of sexuality may not be considered in the context of the larger "health and recovery" hierarchy. Second, it is very possible that aspects of sexuality are not discussed because it is an area that people are generally uncomfortable discussing; this may be true both for those who are being treated for head and neck cancer, as well as the professionals who serve them (Doyle, 1994, 2005; Doyle & Keith, 2005; Myers, 2005). However, the findings from this study indicate that when the sexuality domain is identified, it is noted in association with a significant degree of impairment. In providing a comparative example, speech was a domain often identified in the three most important areas of concern and was found to approach significance on the statistical tests performed (HNQOL "speech" $p<0.107$; EORTC "speech" $p<0.153$). In contrast, "less sexuality" was identified among the six most important domains affecting QOL, and the domain approached significance on the statistical tests performed ($p<0.095$). Thus, continued efforts that seek to offer broad levels of support and counseling relative to issues of sexuality appear warranted.

What the Findings Suggest

The findings from the ranked domain assessment suggest that an overall QOL score (regardless of the instrument used) does not adequately capture the variable levels of disability individuals' experience. This is true both globally, as well as on a domain specific basis. Participants were quite consistent in their identification of domains that affect their QOL, and were able to place them in order of relative importance with a level of consistency across tools. Though some exceptions did exist, namely, the domain of "chewing" on the UWQOL, this may be attributed to the fact that there is some variability of domains covered by the different tools. This fact may lead to the inclusion of domains that are most relevant to individuals' QOL, and thus, improve the detection ability of the tool by including those domains that are most relevant. The findings also support Deleyiannis et al. (1999) and Weymuller et al. (2000a) in their proposal that a weighting scheme be applied to tools to allow for greater level of relevance to the QOL and level of disability of the individual.

Research Question 2: Are the current questionnaires able to detect these differences?

EORTC

The EORTC C30 combined with the head and neck module (H&N35) were designed to cover a wide range of functional/symptomatic concerns for those who have been treated for cancer. The two questionnaires are designed to be completed together, because the C30 covers general questions associated with the treatment of cancer whereas the H&N35 focuses on specific issues that are identified as being prominent in those who have been treated for head and neck cancer. While the EORTC instruments are widely used outside of North America, its application has been less prominent in Canada and the United States despite the clarity of its content and the unique approach to assessing generic health issues, in addition to those that are cancer site specific. Thus, the EORTC does seek to distinguish more general functional problems (e.g., Do you have any trouble doing strenuous activities like carrying a heavy shopping bag or suitcase?) from those that might be anticipated due to the site-specific nature of head and neck malignancies (e.g., Have you had problems opening your mouth wide?). Overall, the EORTC does appear to offer a valuable index of QOL related areas.

Several domains were found to have p values approaching accepted levels of significance suggesting that some differential performance by disease site may exist. This suggestion is, however, quite tentative and cannot be generalized to the larger populations studied; thus, the external validity of this current finding must be considered with caution. With this written, the results of the t-test revealed several domains including "appetite loss" ($p < 0.133$), "pain" ($p < 0.012$), "speech" ($p < 0.153$), "social eating" ($p < 0.176$), "less sexuality" ($p < 0.095$), and "weight loss" ($p < 0.017$) to be of potentially differential concern between groups. Although these levels did not emerge at the a priori accepted level of significance, these probabilities noted should not be disregarded. Appetite and sense of smell and taste are closely related, and both can be significantly impacted in the treatment of oral and laryngeal cancer. Radiation affects saliva causing it to become sticky and often "ropey" which can have negative implications on desire to eat as eating mastication becomes increasingly difficult. This treatment also effects the sense of taste, with patients often complaining that food tastes like sawdust or changes the taste of foods dramatically, which, in turn, leads to decreased appetite. Finally in total laryngectomy, surgery causes redirection of airflow to a stoma, drastically reducing, if not eliminating airflow to the mouth and nose, thus decreasing ability to taste and smell food.

HNQOL

The University of Michigan HNQOL is a widely used tool covering many domains associated with issues relating to QOL in individuals who have been treated for head and neck cancer. Once again, several domains were found to have *p* values that approached significance (i.e., speech and pain), with the oral cancer group showing lower scores for the "pain" domain, indicating greater problems with this area of concern. The laryngeal cancer group displayed lower scores in the "speech" domain as would be expected given the expected laryngeal-based problems that they are likely to experience.

Composite Ranking of Total Scores of All Three Questionnaires

In an effort to investigate if one questionnaire provided a more comprehensive view of the deficits or levels of disability experienced, each participant's overall scores for each questionnaire were ranked from highest score to lowest score. This procedure was completed in order to assess whether individuals performed significantly better or significantly worse on one tool over the other, and thus, act as an indication of general ability to detect and/or consistency across each tool. Each participant's scores were ranked, and the ranking was completed twice – once with each overall score for the three tools, and once with the EORTC tool overall scores split (total score for the C30, and total score for the H&N35). In evaluating the overall trends in performance, there were no patterns to the rankings, indicating no gross discrepancy in ability to detect site of cancer between the tools. However, when investigating individuals' scores, some patterns did emerge. Those patterns were evident when comparing the two EORTC measures (C30 and H&N35 module).

EORTC C30 and H&N35 Module: Comparison of Individuals' Scores

Based on findings of this project, a question arises regarding individuals' scores on the H&N35 module. That is, one would predict that participants would have had a higher level of impairment (i.e., a lower overall score on this module) because it is designed to address specific domains/areas of concern relative to this population. This was not found in the rankings. In fact, 38.9% (n=7) of the total number of participants' highest scores (indicating lowest level of impairment/best QOL) was found on the H&N35 module relative to all three tools. Additionally, 42.9% (n=3) of those who indicated best level of QOL on the H&N35 module also revealed the worst level of functioning/lowest level of QOL for the general cancer module, the C30. Further, 72.2% (n=13) of participants indicated a higher score on the H&N35 module compared to the C30 module. This appears to indicate one of two scenarios. First, either the H&N35 module is not able to detect all the issues/areas of concern facing QOL in the head and neck cancer population, or second, there are areas of concern that are not specific to head and neck cancer which are affecting the participants' QOL. If the former is the case, further investigation as to the specific areas missing from the tool should be conducted. If, for example, an area of critical importance to a given individual is not included, a dimension that potentially carries substantial importance may be excluded from the metric that is gathered. However, if the latter is true, perhaps some of the issues facing this population lie in the treatment side effects not specific to head and neck cancer. In this case, more generalized influences of a cancer diagnosis and its treatment may be demonstrated, raising the larger issue of one's psychological status and the effects that such chances may have on the individuals. Although issues concerning psychological well-being have been addressed by several authors (Doyle, 1994; Palmer & Graham, 2002), it remains relatively unexplored and does provide a valuable area of future clinical study.

In considering the limitations of QOL instruments with respect to areas of inquiry that may be "missing" from particular tools, there exists a need to gather such information. Recalling that within this study individuals were offered the opportunity to provide additional information or embellish their concerns, limited information was obtained. Thus, the ability to provide a means of gathering such information is critical if one seeks to obtain the clearest picture of one's QOL. The use of written tools alone may be insufficient to meet these needs, however, written tools have primarily been developed to expedite the gathering of information in a relatively time-efficient manner. Under these circumstances, more basic and perhaps more "generic" issues are most frequently covered. Although this type of information is of critical importance, the ability to gather and to document a more comprehensive picture of one's overall QOL status is essential. Therefore, merging standard written questionnaires with more detailed follow up interviews may serve to shed additional light on the complex concerns, fears, and expectations that obviously influence evaluations of QOL. This again raises questions about how complete any given tool is to one's status at a fixed point in time.

As identified previously, this investigation attempted to gather information pertaining to the ability to detect site of cancer of the three tools used. This was carried out by offering an additional information sheet, where each participant could indicate the degree to which each tool addressed areas of concern affecting his/her individual QOL. Overall, participants indicated that the questionnaires addressed all or most of the issues affecting their QOL. Although some individual responses were gathered, they often were idiosyncratic and sparse. One participant indicated all three questionnaires reflected "only a few" areas affecting his QOL, however, he did not include any additional information in the spaces provided as to the other domains that were not covered. This would indicate that, in general, the tools covered most if not all issues affecting the participants' perceived QOL. Nevertheless, the idiosyncratic nature of the information that was provided implies that each person should be viewed individually, and consequently, efforts that focus on providing an opportunity to acknowledge specific areas of concern that are relevant to him/her is necessary.

This observation begs the question of "why" was additional information *not* provided? Because questionnaires were completed at home, the ability to have direct access to a clinician or other professional reduced the possibility of additional information being provided. Had this been done in clinic, it might be suggested that a clinician would be available to ask and then systematically pursue what areas were missing. Therefore, the written tool alone may be insufficient if one's desires to gather more than generalized information on QOL status. Providing an additional information sheet creates the opportunity for participants to describe any issues or concerns affecting their QOL that have not been covered by the given tools. It is necessary to point out that doing so alone does not insure that information on specific problems is brought forward. The reason for such limitations may extend from issues such as being embarrassed or reticent about raising concerns (e.g., issues of sexuality), a desire not to take more of the health care team's time, to not being able to do so because of literacy restrictions. Thus, formalized opportunities to speak to someone that is known and for which some relationship has been established would be of benefit. This role could easily be filled by a speech-language pathologist who frequently has extended and longer-term contact with such individuals.

Differences Among the Tools

When collectively studying the tools utilized in this project, there are several differences that warrant discussion. First, while the three tools do address many of the same domains, such as talking/speaking, eating, swallowing, appearance, mood/emotion, pain, and overall QOL, there are several domains not uniformly covered in each tool. As previously mentioned, the EORTC addresses the issue of sexuality, as well as questions regarding social eating and social contact, none of which are addressed in the other two tools. The EORTC does not, however, address concerns regarding chewing, whereby the other two questionnaires do. Finally, the HNQOL does not address problems with saliva as an isolated concern with larger implications on functioning (i.e., eating, swallowing, oral hygiene, etc.). Incorporation of some or all of these domains into the instruments can provide a more complete assessment of issues relating to QOL in those treated for head and neck cancer. Together, all three tools assess a broad array of concerns and topics that are of importance, but none appears fully complete in its assessment.

Another difference between the tools exists in the manner in which questions are posed. Both the EORTC and HNQOL provide questions followed by Likert scale answers where the individuals must check the appropriate level of impairment/degree to which the preceding statement is true (not at all, a little, etc.). The UWQOL, however, employs a different manner of response, whereby the individual must choose from a series of sentences describing their impairment on an identified issue (e.g. Pain – "I have no pain", "There is mild pain not needing medication", etc.). This observation again points to the importance of literacy in not only being able to understand the question(s) posed, but the interpretation of the responses offered. Overall, however, the questionnaires appear to use similar language and level of difficulty in addressing the areas of concern.

Research Question 3: Can a weighting system be developed that will give an accurate assessment of the areas of concern that are affecting QOL for each individual?

This project initially attempted to develop a ranking and weighting system for the purpose of allocating relative weightings to domains identified by individuals. The goal behind seeking weighted descriptions was pursued in order to provide a more complete indication of the areas of relative concern affecting QOL. Deleyiannis et al. (1999) and Weymuller et al. (2000a) support the concept of applying a weighting scheme to questionnaires in order to give more accurate and representative scores as judged by the individual. However, to date, there has been no approach offered as to how to complete this task. Although the ranking aspect appeared to be completed adequately in this study, individuals identified difficulty with completion of the weighting system (i.e., the use of the pie-chart segmentation task). This may be attributed to the nature of the pie-chart task. Despite several pictured and written instructions and specific examples, this task was not easily interpreted by the participants. A pilot study of the weighting system with participants of the same age range did not reveal these difficulties. Although participants in the pilot study were matched for age, perhaps the level of education may have exceeded that of the participants in the study, as all four pilot participants completed a minimum of one university degree. Thus, while the concept of weighting has great practical appeal and clinical importance, at present, the method used herein did not prove successful. Methods of determining relative weightings of domains underlying the larger concept of QOL are necessary and deserve continued attention both empirically and clinically.

Clinical Implications

In quantifying QOL by imposing numerical summaries of overall functioning and level of disability, questionnaires are attempting to represent important subjective impressions through numerical means. The desire to obtain numerical representations is based on the belief that doing so results in an "objective" measure. However, QOL is not an objective index in that multiple entities influence its perception by individuals. Based on the present data, individual differences clearly exist. In regard to evaluating an individual's overall QOL, it is evident from the variable findings of this study that indexing each person may be possible, but indexing a group becomes much more problematic. Hassan and Weymuller (1993) support this finding by explaining "even patients with a similar oncologic site and stage who receive identical treatment can differ in their own assessment of quality of life." While it cannot be assumed that one individual will perform identically to another, when certain trends emerge, the area of topical importance certainly must be acknowledged.

Beyond the obvious concern about the relatively small populations explored in this project, the lack of clear and easily discernable trends in the present data relative to differences between the two groups may be a result of one of two scenarios. First, it may be suggested that there truly is no difference between the groups in the domains that affect their QOL. Similarly, it might be suggested that the questions posed on the tools are not specific enough to the specific area of functioning covered by the domain/area of concern. For example, "swallowing" may be impaired in both those with oral cancer and laryngeal cancer, yet the type of impairment or disablement is a result of different functions or sites of cancer. An individual with an oral cancer (e.g. hemiglossectomy) may have trouble with "swallowing" characterized by problems forming a cohesive bolus, difficulty propelling the bolus, penetration of material due to reduced intrabolus pressure, and therefore, fear of swallowing. In contrast, one with laryngeal cancer (e.g., total laryngectomy), may experience problems with "swallowing" characterized by difficulty in having the bolus move through the pharynx due to stenosis secondary to scarring and side effects of radiation treatment (e.g., fibrosis). As illustrated by these examples, both individuals would experience problems with "swallowing", but those problems would be characterized by very different symptoms and based on different sites of lesions. Thus, questions relating to broad domains of impairment may be interpreted by individuals in a very different ways, thus, providing information regarding their level of disability and functioning that can be misinterpreted by clinicians.

Clinical implications of these possible misinterpretations center around the importance of expanding on the results of questionnaires for each individual; simply taking the score of the tool as a direct indication of an individual's QOL does not suffice. Clinicians should be encouraged to probe further into the symptoms associated with the areas of disability/reduced QOL discovered from the tools in an effort to appreciate fully the source of the disability. This not only strengthens the relationship between patient and clinician, leading to increased trust and disclosure, but the information gathered by exploring the responses to these questionnaires would give direction to treatment of specific features of swallowing, communication, speech, and other domains.

Additionally, and as noted earlier in this discussion, follow up explorations of responses offered via written instruments is essential. That is, although questionnaires provide a reasonable method of identifying the presence of problems and perhaps their relative impact, if areas are not addressed, they may be missed. If brief, follow-up discussions between a clinician and the individual completing the questionnaire could be conducted, other issues may emerge such as the impact on social functioning or participation. If such issues are identified, they may be targeted for direct intervention as necessary (e.g., medication to relieve pain, appropriate referrals for depression and related mental health concerns, etc.). Further, within the head and neck oncology management system, a speech-language pathologist may provide the ideal resource for such continued contacts specific to the long-term monitoring of QOL and the identification of unique problems that may not be addressed using standard tools.

Limitations

The present study should be considered as a preliminary investigation. Due to limited availability of participants and the resulting small sample size, the external validity of these data is limited. Future efforts to expand population participation in efforts to gather additional information would be of great value. While the response rate for the oral cancer group was high (87%), the response rate for the laryngeal cancer group (43%) was quite low. Other studies utilizing mail out survey methods of similar questionnaires have achieved response rates ranging from 62% (Terrell, et al., 1998) to

76.4% (Vilaseca et al., 2006). It should be noted, however, that many studies did not publish response rates perhaps due to poor compliance. In this project, the individuals who did not return the packages (mostly in the laryngeal group) were generally younger (M = 56.5, SD = 5.9) than those who did return questionnaires. This fact may indicate that younger individuals may have less time for participation as they may continue to work, and did not have the time to complete the package. Also, all individuals who did not return the packages were men, and within the laryngeal group, all had undergone total laryngectomy. Thus, some age- and/or gender-based issues may be present and these deserve careful assessment in the future.

Overall, the age of participants was significantly different between groups. The average age of oral cancer participants was 53.9 (range 45-64) and for laryngeal cancer participants was 64.7 (range 56-71). QOL and level of disability/functioning can be more severely affected in younger groups, as these individuals generally are still employed, more active in social networks, may have dependent children, and have more familial responsibilities. Thus, the impact of cancer and deficits associated with its treatment may have more significant implications on their lives, such as financial troubles secondary to inability to work, and social withdrawal.

In regard to the desire to have individuals indicate a weighted degree of relative importance for areas assessed, this task met with disappointing results. In hindsight, and despite appearing quite simple at face value, the design and use of the pie chart as a means of establishing a relative weighting scale may have been too difficult or too complex to complete. In fact, several (three) participants either did not complete this part of the project, or failed to complete the pie scale adequately. Feedback regarding the ease of completion, as well as any additional information was obtained from two participants. Comments included complaints regarding the inherent difficulty associated with completing pie scale. Although it was anticipated that this task would be easy and quite intuitive, it proved otherwise for this group of participants. As previously mentioned, a pilot study to test the ease of completion of the weighting scale did not reveal problems. If an easier method of weighing the domains could be identified, this may lead to greater level of determining instrument's ability to detect different sites of cancer. One method that was suggested by a participant included assigning simple percentages to each domain. Such tasks may offer increased ease in completing the weighting task.

Future Research

The present study was a preliminary investigation of several questions that emerged from a comprehensive review of the literature. As there was no precedent for the weighting scheme, the concept for the weighting procedure was an initial attempt. Although the pie scale appeared to be straightforward and simple, feedback from some participants revealed that it was a difficult task. In future studies, it is recommended that weighting be assigned via percentages given to ranked domains by each participant, as was suggested by one participant in a debriefing session. This may lead to a greater level of compliance and increased ability to detect site of cancer of the scale. Further, more specific information may shed light on the level to which certain domains lead to disability and reduced overall QOL in individuals who have undergone treatment for head and neck cancers. With increased ability to detect and compliance (leading to larger sample size), researchers may also be able to delineate whether there are areas of concern that are more or less relevant to QOL for patients with oral cancer versus laryngeal cancer.

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Appendix A

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:
Your birthdate (Day, Month, Year):
Today's date (Day, Month, Year): 31

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

Please go on to the next page

During the past week:	Not at All	A Little	Quite a Bit	Very Much
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

30. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

EORTC QLQ - H&N35

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

During the past week:		**Not at all**	**A little**	**Quite a bit**	**Very much**
31.	Have you had pain in your mouth?	1	2	3	4
32.	Have you had pain in your jaw?	1	2	3	4
33.	Have you had soreness in your mouth?	1	2	3	4
34.	Have you had a painful throat?	1	2	3	4
35.	Have you had problems swallowing liquids?	1	2	3	4
36.	Have you had problems swallowing pureed food?	1	2	3	4
37.	Have you had problems swallowing solid food?	1	2	3	4
38.	Have you choked when swallowing?	1	2	3	4
39.	Have you had problems with your teeth?	1	2	3	4
40.	Have you had problems opening your mouth wide?	1	2	3	4
41.	Have you had a dry mouth?	1	2	3	4
42.	Have you had sticky saliva?	1	2	3	4
43.	Have you had problems with your sense of smell?	1	2	3	4
44.	Have you had problems with your sense of taste?	1	2	3	4
45.	Have you coughed?	1	2	3	4
46.	Have you been hoarse?	1	2	3	4
47.	Have you felt ill?	1	2	3	4
48.	Has your appearance bothered you?	1	2	3	4

Please go on to the next page

During the past week:		**Not at all**	**A little**	**Quite a bit**	**Very much**
49.	Have you had trouble eating?	1	2	3	4
50.	Have you had trouble eating in front of your family?	1	2	3	4
51.	Have you had trouble eating in front of other people?	1	2	3	4
52.	Have you had trouble enjoying your meals?	1	2	3	4
53.	Have you had trouble talking to other people?	1	2	3	4
54.	Have you had trouble talking on the telephone?	1	2	3	4
55.	Have you had trouble having social contact with your family?	1	2	3	4
56.	Have you had trouble having social contact with friends?	1	2	3	4
57.	Have you had trouble going out in public?	1	2	3	4
58.	Have you had trouble having physical contact with family or friends?	1	2	3	4
59.	Have you felt less interest in sex?	1	2	3	4
60.	Have you felt less sexual enjoyment?	1	2	3	4

During the past week:		**No**	**Yes**
61.	Have you used pain-killers?	1	2
62.	Have you taken any nutritional supplements (excluding vitamins)?	1	2
63.	Have you used a feeding tube?	1	2
64.	Have you lost weight?	1	2
65.	Have you gained weight?	1	2

Code: ____________________
Date: ____________________

University of Washington Quality of Life Questionnaire
(UW-QOL v4)

This questionnaire asks about your health and quality of life **over the past seven days**. Please answer all of the questions by ticking one box for each question.

---

1. **Pain.** (Tick one box: ☑)

☐ I have no pain.
☐ There is mild pain not needing medication.
☐ I have moderate pain - requires regular medication (e.g. paracetamol).
☐ I have severe pain controlled only by prescription medicine (e.g. morphine).
☐ I have severe pain, not controlled by medication.

2. **Appearance.** (Tick one box: ☑)

☐ There is no change in my appearance.
☐ The change in my appearance is minor.
☐ My appearance bothers me but I remain active.
☐ I feel significantly disfigured and limit my activities due to my appearance.
☐ I cannot be with people due to my appearance.

3. **Activity.** (Tick one box: ☑)

☐ I am as active as I have ever been.
☐ There are times when I can't keep up my old pace, but not often.
☐ I am often tired and have slowed down my activities although I still get out.
☐ I don't go out because I don't have the strength.
☐ I am usually in bed or chair and don't leave home.

4. **Recreation.** (Tick one box: ☑)

☐ There are no limitations to recreation at home or away from home.
☐ There are a few things I can't do but I still get out and enjoy life.
☐ There are many times when I wish I could get out more, but I'm not up to it.
☐ There are severe limitations to what I can do, mostly I stay at home and watch TV.
☐ I can't do anything enjoyable.

5. **Swallowing.** (Tick one box: ☑)

☐ I can swallow as well as ever.
☐ I cannot swallow certain solid foods.
☐ I can only swallow liquid food.
☐ I cannot swallow because it "goes down the wrong way" and chokes me.

6. **Chewing.** (Tick one box: ☑)

☐ I can chew as well as ever.
☐ I can eat soft solids but cannot chew some foods.
☐ I cannot even chew soft solids.

7. **Speech.** (Tick one box: ☑)

- ☐ My speech is the same as always.
- ☐ I have difficulty saying some words but I can be understood over the phone.
- ☐ Only my family and friends can understand me.
- ☐ I cannot be understood.

8. **Shoulder.** (Tick one box: ☑)

- ☐ I have no problem with my shoulder.
- ☐ My shoulder is stiff but it has not affected my activity or strength.
- ☐ Pain or weakness in my shoulder has caused me to change my work / hobbies.
- ☐ I cannot work or do my hobbies due to problems with my shoulder.

9. **Taste.** (Tick one box: ☑)

- ☐ I can taste food normally.
- ☐ I can taste most foods normally.
- ☐ I can taste some foods.
- ☐ I cannot taste any foods.

10. **Saliva.** (Tick one box: ☑)

- ☐ My saliva is of normal consistency.
- ☐ I have less saliva than normal, but it is enough.
- ☐ I have too little saliva.
- ☐ I have no saliva.

11. **Mood.** (Tick one box: ☑)

- ☐ My mood is excellent and unaffected by my cancer.
- ☐ My mood is generally good and only occasionally affected by my cancer.
- ☐ I am neither in a good mood nor depressed about my cancer.
- ☐ I am somewhat depressed about my cancer.
- ☐ I am extremely depressed about my cancer.

12. **Anxiety.** (Tick one box: ☑)

- ☐ I am not anxious about my cancer.
- ☐ I am a little anxious about my cancer.
- ☐ I am anxious about my cancer.
- ☐ I am very anxious about my cancer.

Which issues have been the most important to you during the past 7 days?
Tick ☑ **up to 3 boxes.**

- ☐ Pain
- ☐ Appearance
- ☐ Activity
- ☐ Recreation
- ☐ Swallowing
- ☐ Chewing
- ☐ Speech
- ☐ Shoulder
- ☐ Taste
- ☐ Saliva
- ☐ Mood
- ☐ Anxiety

GENERAL QUESTIONS

Compared to the month before you developed cancer, how would you rate your health-related quality of life? (Tick one box: ☑)

☐ Much better
☐ Somewhat better
☐ About the same
☐ Somewhat worse
☐ Much worse

In general, would you say your **health-related quality of life** during the past 7 days has been: (Tick one box: ☑)

☐ Outstanding
☐ Very good
☐ Good
☐ Fair
☐ Poor
☐ Very poor

Overall quality of life includes not only physical and mental health, but also many other factors, such as family, friends, spirituality, or personal leisure activities that are important to your enjoyment of life. Considering everything in your life that contributes to your personal well-being, rate your **overall quality of life** during the past 7 days. (Tick one box: ☑)

☐ Outstanding
☐ Very good
☐ Good
☐ Fair
☐ Poor
☐ Very poor

Code: ______
Date: ______

Head and Neck Quality of Life
University of Michigan HNQOL

INSTRUCTIONS: This survey is designed to assess how much you are bothered by your Head and Neck condition and/or treatment.
Please answer every question by marking one box. If you are unsure about how to answer, please give the best answer you can.

1. As a result of your head and neck condition or treatment, over the past FOUR WEEKS how much have you been BOTHERED by your...

	Not at all	Slightly	Moderately	A lot	Extremely
Ability to **talk** to other people					
Ability to **talk on the phone**					

2. As a result of your head and neck condition or treatment, over the past FOUR WEEKS how much have you been BOTHERED by problems with...

	Not at all	Slightly	Moderately	A lot	Extremely
Volume of your voice					
Clarity of your voice					
Difficulty opening your mouth					
Dryness in your mouth while **eating**					
Chewing food (for example, pain, difficulty opening or closing your mouth, moving food in your mouth, or teeth or denture problems)					
Swallowing **liquids**					
Swallowing **soft foods and/or solids**					
Your ability to **taste food** (for example, loss of taste, and /or loss of appetite due to poor taste)					
Pain, burning, and/or discomfort in your mouth, jaw, or throat					
Shoulder or neck **pain**					

3. Over the past FOUR WEEKS, how often did you take pain medication?...

Never Rarely Sometimes Frequently Always

4. Over the past FOUR WEEKS how much have you been bothered by...

	Not at all	Slightly	Moderately	A lot	Extremely
Concerns or worries about your **appearance** related to your head and neck condition or treatment					
Emotional problems related to your head and neck condition or treatment					
Embarrassment about your **symptoms**					
Frustration about your condition					
Financial worries due to medical problems					
Worries that your condition will get worse					
Physical problems related to your head and neck condition					

5. Were you working (employed) prior to being diagnosed with cancer?

Yes No

5A. **If yes,** did your **doctor** declare you unable to work due to your head and neck condition or treatment?

Yes No

6. Have there been other problems related to your head and neck condition that were not mentioned? If so, please write them in the spaces below and tell us how much this problem has bothered you. (For instance, if your treatment included surgical transfer of tissue from a donor site to the head and neck, does the donor site bother you)

a. ________________________________ Not at all Slightly Moderately A lot Extremely
b. ________________________________ Not at all Slightly Moderately A lot Extremely
c. ________________________________ Not at all Slightly Moderately A lot Extremely

7. For the past FOUR WEEKS, please rate your OVERALL amount of disturbance or BOTHER as a result of your head and neck cancer condition.

Not at all Slightly Moderately A lot Extremely

8. Overall how satisfied are you with your Head and Neck cancer treatment at this hospital?

Not at all Slightly Moderately A lot Extremely

9. Overall how would you rate your response to treatment?

Poor Fair Good Very good Excellent

10. Approximately how long did it take you to answer this questionnaire?

____ minutes

11. How difficult was it to complete this questionnaire?

Not at all Slightly Moderately Very Extremely

Appendix B

Domains addressed with the UW-QOL, EORTC (and associated modules), and the HN-QOL instruments.

Domains	UW-QOL	EORTC-QLQ-C30 & EORTC-QLQ-HN35	HN-QOL
Pain	✓	✓	✓
Eating/swallowing	✓	✓	✓
Senses	✓	✓	✓
Speech/communication	✓	✓	✓
Social eating		✓	
Social contact		✓	
Sexuality		✓	
Emotion	✓	✓	✓
Appearance	✓	✓	✓
Saliva	✓	✓	
Chewing	✓		✓
Shoulder problems	✓		✓

Appendix C

Weighting Sheet

Quality of life is a measure used to evaluate an individual's perception of their life. According to the World Health Organization, it is a concept that covers a variety of areas, and incorporates a person's physical health, psychological state, level of independence, personal beliefs, social relationships, and relationship to features of the environment. It gives an *overall indication of a person's satisfaction of his/her life* in relation to his/her goals, expectations, and standards.

On the following page is a list of factors that affect overall quality of life. In this exercise please pick six items/areas that have the most important influence or impact on your quality of life.

In **step one**, please indicate your six choices by placing a check or X in the appropriate boxes. An example is provided for you.

Step 1 - EXAMPLE
Factors affecting quality of life:

- ☐ Traveling
- ☐ Reading
- ☑ Independence
- ☐ Watching television
- ☐ Hobbies
- ☑ Attending social events
- ☑ Family
- ☑ Communication/speaking
- ☑ Eating
- ☐ Finances
- ☐ Health
- ☑ Positive mood/attitude
- ☐ Friends/social network

In **step two**, please list the six choices in order of importance, placing the most important choice first, followed by the second most important choice, and so on. An example is provided for you.

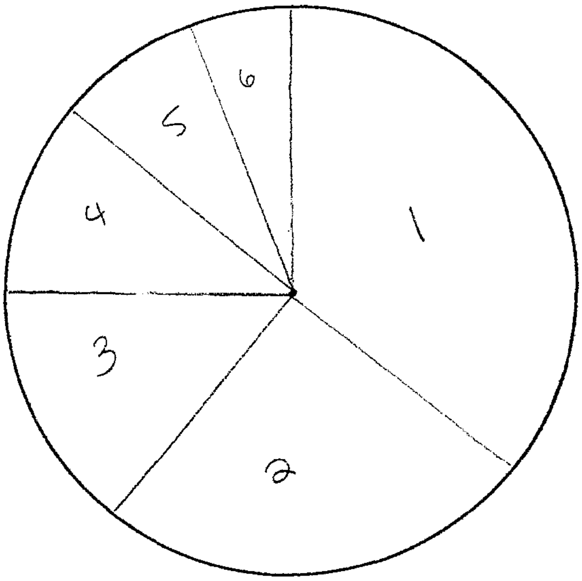
Step 2 - EXAMPLE
Please place the items you have marked in order of importance
(1 – most important, 2 – second most important etc.)

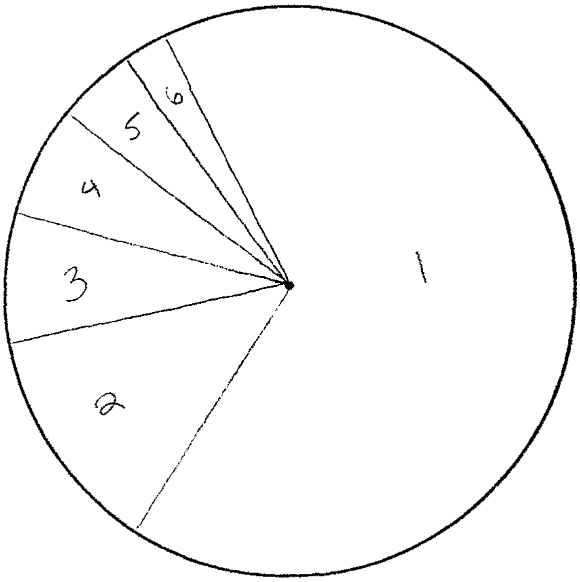
1 Family
2 Communication
3 Independence
4 Eating
5 Social events
6 Positive mood

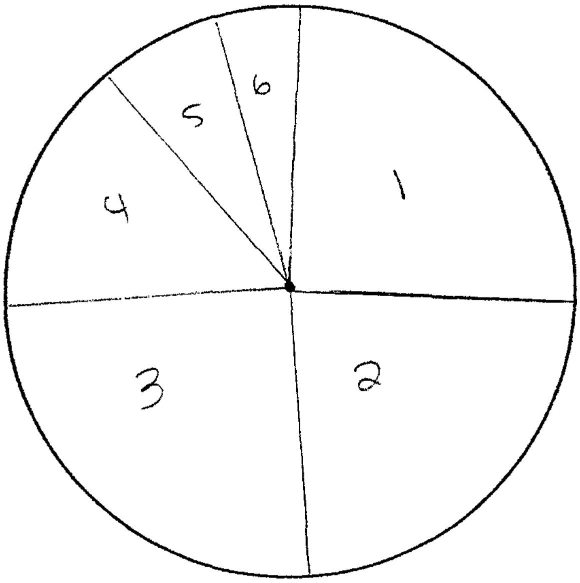
In **step three**, please indicate how important each choice is, ***relative to the other choices***, by dividing the areas of the diagram. In other words, if factor #1 makes up 50% of your quality of life, then mark down half of the circle as #1. Several examples are provided for you.

Step 3 - EXAMPLES

Please indicate how important each choice is *relative to the other choices* by dividing up the diagram.







Appendix D
Demographics

Participant Code	Gender	Age	Stage of cancer	Treatment modality	Months post surgery
			Oral Group		
O1	Male	61	T2N1	Chemo, Radiation	n/a
O2	Female	53		Surgery	14
O3	Female	59	T2N1Mx	Surgery, Radiation	11
O4	Female	54	T2	Surgery	10
O5	Female	47	T3N2M0	Chemo, Radiation	n/a
O6	Male	46	T2N0	Surgery	13
O7	Female	57		Surgery	9
O8	Female	45		Surgery	16
O9	Male	53	T3N1b	Surgery, Chemo, Rad	12
O10	Male	64	T2N0	Surgery	10
O11	Male	57	T3N0	Surgery	8
O12	Male	49	T2N1	Surgery	21
O13	Male	55	T2N0	Surgery	8
Mean		53.85			12
Standard Deviation		5.87			3.89
Range		45-64			8-21
			Laryngeal Group		
L1	Male	64	T2	Surgery, Radiation	20
L2	Male	71	T1b	Surgery, Radiation	13
L3	Male	56	T3N1	Surgery, Radiation	13
L4	Male	65	T1a	Surgery	11
L5	Female	66	T3N1Mx	Surgery, Radiation	20
L6	Female	66	T2	Surgery	23
Mean		64.67			16.67
Standard Deviation		4.89			4.93
Range		56-71			11-23
			Both Groups		
Mean		57.26			13.65
Standard Deviation		7.50			4.73
Range		45-71			8-23

Appendix E

Summary of component domains and number of related questions in each for the EORTC (and associated modules), HNQOL and the UWQOL measurement instruments.

European Organization for Research and Treatment of Cancer Quality of Life Questionnaire(EORTC-QLQ-C30) and the Head and Neck module (EORTC-QLQ-H&N35)

Domain	Number of questions for given domain
Pain	6
Swallowing	4
Teeth and jaw	2
Saliva	2
Senses	2
Appearance	1
Talking/speaking	3
Emotion	4
Work/finances	2
Leisure/social activities	2
Overall QOL/health	2

University of Michigan Head and Neck Quality of Life (HNQOL)

Domain	Number of questions for given domain
Talking/voice	4
Eating	1
Chewing	1
Swallowing	2
Senses	1
Pain	2
Appearance	1
Emotion	4
Work/finances	2
Overall QOL	1

University of Washington Quality of Life Questionnaire version 4 (UW-QOL v4)

Domain	Number of questions for given domain
Pain	1
Appearance	1
Activity	1
Recreation	1
Swallowing	1
Chewing	1
Speech	1
Shoulder	1
Taste	1
Saliva	1
Mood	1
Anxiety	1
Health-related QOL	2
Overall QOL	1

Appendix F

The following is information on the psychometric properties for each questionnaire used in this study.

Questionnaire	Validity	Reliability
UW-QOL	Criterion validity range between 0.79 to 0.85 Compared with the Karnofsky scale and the Sickness Impact Profile	Criterion reliability range from 0.74 to 0.89 Intrarater reliability = .95
EORTC	Construct validity: Correlation of less than 0.70 = high discriminant validity of the cancer specific scales	Cronbach's alpha: Pain 0.81 Swallowing 0.82 Senses 0.72 Speech 0.74 Social eating 0.87 Social contact 0.83 Sexuality 0.95
HN-QOL	Authors used UW-QOL, the FACT (Functional Assessment in Cancer Treatment), and the EORTC to compare with the HN-QOL. Not reported but hypothesized to be valid	Domain test-retest reliability scores Cronbach alpha: Communication 0.93 Eating 0.87 Emotion 0.88 Pain 0.79 Pearson Product: Communication 0.81 Eating 0.89 Emotion 0.92 Pain 0.82

References for this table: UW-QOL (Hassan & Weymuller, 1993), EORTC (Bjordal et al., 2000), HN-QOL (Terrell et al., 1997)

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Use of Human Subjects - Ethics Approval Notice

Principal Investigator: Dr. P.C. Doyle
Review Number: 13959E **Review Level:** Expedited
Review Date: January 30, 2008
Protocol Title: Differential Assessment of Quality of Life in Individuals with Oral and Laryngeal Cancer: A Preliminary Investigation
Department and Institution: Communication Sciences & Disorders, University of Western Ontario
Sponsor:
Ethics Approval Date: February 22, 2008 **Expiry Date:** December 31, 2008
Documents Reviewed and Approved: UWO Protocol, Letter of Information and Consent, Telephone Script.
Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
b) all adverse and unexpected experiences or events that are both serious and unexpected;
c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. John W. McDonald

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