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Longitudinal Evaluation of Patient Concerns After Surgery For Head and Neck Cancer

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Abstract

The primary purpose of this study was to investigate and describe the longitudinal effects of shoulder and neck mobility, strength, and quality of life (QOL) following neck dissection (ND) surgery and identify the concerns of head and neck cancer (HNC) patients. ND is one of the standard procedures for treating HNC, which results in many complications and dysfunctions that can have an effect on a patient's QOL.

The study had 27 eligible HNC participants who underwent ND, of which eight participated in the shoulder range of motion (ROM) and strength and 12 participated in the QOL patient-reported outcomes analysis. The study followed participants' pre-surgery, 1-month and 4-months post-surgery in order to determine the longitudinal effects of ND on shoulder (ROM, shoulder strength, neck ROM), and patients QOL. The study administered the Patient Concerns Inventory- Level of Importance questionnaire (PCI-LOI), Shoulder Pain and Disability Index (SPADI), Neck Dissection Impairment Index (NDII) and the University of Washington- Quality of Life questionnaire (UWQOL) to obtain patient-reported outcomes on QOL. Additionally, measures of ROM and strength on shoulder flexion and external rotation, along with neck ROM were used to determine shoulder and neck dysfunction.

The study identified that patients report increases in shoulder pain and dysfunction post-surgery (1-month follow-up) and continued up to 4-months post-surgery. Additionally, patient-reported QOL decreased post ND and is perceived to be low by patients up to 4-months post ND. Identification of patient concerns and the changes in mobility, pain and QOL should assist in the management of the post-surgical recovery plan for HNC patients following ND. Additionally, the study suggests the importance of expanding the health care team for HNC patients in order to improve the pain, dysfunction and decrease in QOL experience by these patients.

Keywords: neck dissection, head and neck cancer, patient concerns, range of motion, strength, and quality of life

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List of Abbreviations

Abbreviation	Term
END	Extended neck dissection
HNC	Head and neck cancer
HPV	Human papillomavirus
IJV	Internal jugular vein
LHSC	London health science center
MRND	Modified radical neck dissection
ND	Neck dissection
NDII	Neck dissection impairment index
PCI	Patient concerns inventory
PCI-LOI	Patient concerns inventory-level of importance
QOL	Quality of life
ROM	Range of motion
RND	Radical neck dissection
SAN	Spinal accessory nerve
SCM	Sternocleidomastoid muscle
SND	Selective neck dissection
SPADI	Shoulder pain and disability index
UWQOL	University of Washington quality of life

Glossary of Terms

Term	Definition
Cancer	A classification of diseases that is characterized by non-typical growth of cells in the body, which tends to proliferate in uncontrolled ways forming lumps of masses of tissue called tumors.
Carcinoma	Cancer that originates in the skin or tissues lining body organs.
Chemoradiation	A treatment that combines chemotherapy and radiotherapy. Used before and after surgery to reduce the size and risk of cancer re-occurrence.
Chemotherapy	A systemic anticancer treatment that involves injecting a chemical into the body (given by IV) that binds to and kills tumor cells.
Devascularization	The occlusion or destruction of blood vessels that supply parts or organs that results in an interruption of circulation.
Malignant	Occurring in severe form, frequently resulting in death. Can also classify cancerous tumors, which invade and destroy nearby tissue.
Metastases	The process by which cancer transfers in the body from its origin to other distinct locations in the body.
Microtrauma	Referring to small injuries or lesions in the body.
Otolaryngology	Oldest medical specialty in the United States. Physicians in this field are trained in medical and surgical management along with treatment for diseases and disorders of the ear, nose, throat (ENT), and other head and neck related structures.
Premalignant lesions	Atypical tissue with abnormal microscopic appearance, which has greater development of cancer

Quality of life	Degree of satisfaction a person has in normal life activities.
Radiotherapy	Cancer treatment which uses ionizing radiation to deliver an optimal dose to a particular area of the body with minimal damage to normal tissue.
Radiation fibrosis	The scarring and thickening of connective tissue due to repeated radiation treatment.
Range of motion (ROM)	The extent to which a person's joint can be maneuvered in different directions.
Sarcoma	A group of malignant tumors arising from connective tissue.
Squamous cell	Flat cells that make up most of the cells in the outer layer of the epidermis, passages of respiratory and digestive tracts and hollow organs of the body.
Tumor	Abnormal mass of tissues, classified as benign or malignant (cancer).
Traction	Procedure that involves manually pulling a part of the body for beneficial effect.

Chapter 1

1 Introduction

In 2015, an estimated 196,900 Canadians were diagnosed with cancer (Canadian Cancer Statistics, 2015). Cancer continues to be the leading cause of death among adults in Canada (Canadian Cancer Statistics, 2015). Carcinoma is the most common type of cancer, which develops within the lining of epithelial cells. Squamous cell carcinoma is the category for which these carcinoma cells lie beneath the outer surface of the skin or from within the lining of organs (National Cancer Institute, 2015).

Head and neck cancer (HNC) is a classification of carcinomas that arise within the head and neck region of the body. The most common type of HNC that accounts for the majority of tumors in this area is squamous cell carcinoma (Martins et al., 2015). There are five areas in the head and neck region where cancer has the potential to form: salivary glands, paranasal sinuses and nasal cavity, larynx, pharynx and the oral cavity (National Cancer Institute, 2015). The main risk factors for HNC are the excessive use of alcohol and tobacco (Argiris, Karamouzis, Raben, & Ferris, 2008). However, some studies do suggest that poor oral hygiene, radiation exposure, UV light exposure, use of marijuana, nutrition, genetic susceptibility, occupational exposure, presence of premalignant lesions and viral infections have potential to increase the risk of cancer in the head and neck regions (Argiris, Karamouzis, Raben, & Ferris, 2008; Ariyawardana & Johnson, 2013; Galbiatti et al., 2013; Lambert, Sauvaget, de Camargo Cancela, & Sankaranarayanan, 2011; Mashberg, Boffetta, Winkelman, & Garfinkel, 1993; Moore, Chamberlain, & Khuri, 2004; Zhang et al., 1999).

Treatment options for HNC patients have evolved and surgery has become the primary form of treatment; a neck dissection (ND) is the main option for HNC surgeons. Over the years, this surgery has been modified to remove diseased tissue while preserving functional structures. Radiotherapy and chemotherapy are also treatment options that are part of the post-surgical treatment plan for certain HNC patients. In the past, HNC patients were treated with extensive ND surgery, which resulted in patients enduring chronic pain, disfigurement and poor overall function (Shaw et al., 2016). However,

organ preservation has become the focus of care with chemotherapy and radiotherapy as adjunctive therapies for malignant cancers. Thus, with the advent of radiotherapy, chemotherapy, and ND modifications, surgeons are able to perform more selective and modified procedures to preserve function and minimize disfigurement (Ghosh-Laskar et al., 2015; Watkins, Williams, Mascioli, Wan, & Samant, 2011).

Cancer of the head and neck can be very complicated where patients undergo invasive surgeries and therapies that may result in physical dysfunction and complications. Shoulder dysfunction is one of the common complications following ND surgery. Pain, reduced range of motion (ROM), and loss of sensation can manifest post ND (Speksnijder et al., 2013). This reduction in ROM is primarily due to sacrificing the accessory nerve, which results in paralysis of the trapezius muscle (Dijkstra et al., 2001). Although this is the case for many HNC patients, some patients could experience little to no shoulder dysfunction or pain. Shoulder dysfunction could range from severe to minor but there are generally some effects on the individual's quality of life (QOL).

Head and neck cancer is a disease that has potential to affect patients in physical ways but also in psychological and social ways, thereby influencing patients' QOL. HNC patients can be affected by the array of concerns that arise at different points during treatment as well as the stress endured during their recovery. Surgery can often alter the appearance or functional abilities of patients; this may lead to issues that alter the lives of these patient's post-surgery. Changes to their lifestyles can impact their QOL leading them to experience feelings of depression with poor outcomes (Ghazali et al., 2013; Speksnijder et al., 2013). A HNC patient is often left to try and self-manage the changes endured after surgery, which have the potential to bring up many concerns for everyday life. However, addressing patients concerns is not always part of the follow-up consultations with surgeons, which can lead these concerns to be unaddressed (Moore et al., 2004). With physical and emotional distress having a large impact on QOL, it is important to identify and address the issues in order to minimize the recovery period in order to allow for improvements in QOL post-surgery.

1.1 Objectives of the study

Head and neck cancer is complex with surgery and treatment causing physical, social and emotional distress. The QOL decline associated with HNC can raise many concerns affecting patients following surgery and treatment. It is important to identify the concerns affecting patients in order to address them during routine follow-ups. It is also of equal importance to examine the physical dysfunction of the head and neck in order to determine what patient needs should be addressed in order to prevent the decline of QOL. Identifying the dysfunction, QOL and patient concerns may lead to the incorporation of an interdisciplinary team of health workers such as physiotherapists, speech pathologists, dietitians, social workers and occupational therapists into the recovery plan for HNC patient's post-surgery. These interdisciplinary teams can work with the surgeons on addressing patient concerns and disabilities such as pain, reduced ROM, swallowing difficulties and speech difficulties in order to preserve the patient's QOL post-surgery.

The primary purpose of this thesis was to investigate and describe the longitudinal effects of shoulder and neck mobility, strength, and QOL following ND surgery and identify the concerns of HNC patients. The first objective of this study was to identify the HNC patient concerns, QOL, pain and changes in shoulder and neck mobility that arise during their long-term follow-ups (1-month & 4-month). The second objective was to identify the changes in ROM and strength of the neck and shoulder areas over long-term follow-up (1-month & 4-months).

Chapter 2

2 Review of literature

Head and neck cancer has been known to surgeons since the 18th century, however there were no surgical attempts to remove disease once it had spread into the lymph nodes or other areas in the head and neck region. It was in the 19th century when surgeons started to use the ND surgery to control HNC (Silver, Rinaldo, & Ferlito, 2007). George Crile was acknowledged as the pioneer of modern ND as he was the first to describe a technique of surgery where the removal of all lymph nodes had led to surgical success (Ducic, Young, & McIntyre, 2010). Since then, the surgery has advanced in order to improve the techniques that are currently used to control HNC. In conjunction with surgery, where surgeons now use modified techniques to preserve certain anatomical structures, the prescription of chemotherapy, radiation or radioactive iodide therapy are ordered by surgeons to prevent the spread/development of further cancer.

Head and neck cancer has shown to present patient challenges post-surgery due to the nature of the ND surgery, where critical body structures have the potential to be damaged (eg. tumor, surgery, adjuvant therapy). When critical structures are damaged, they can leave the patient with physical dysfunctions. When patients experience functional deficits they experience decreases in their QOL (Rathod et al., 2015). Additionally, post-surgical adjuvant therapy and the recovery plan for HNC patients tends to be extensive where they can be undergoing adjuvant therapy and hospital follow-up visits for up to 5-years' post-surgery. The HNC patients overall QOL was shown to decrease post- surgery due to dysfunction, where more conservative ND surgeries are associated with better QOL (Shah et al., 2001). Research on HNC patients has shown that with nerve-sparing surgeries and more conservative ND patients experience less dysfunction and report higher QOL (Eickmeyer et al., 2014; Shah et al., 2001). With QOL being negatively affected by ND surgery due to dysfunctions and the course of recovery, it is important to identify the association and the possible concerns that patients may experience.

2.1 Etiology

Epithelial malignancies that arise from the soft tissues lining the oral cavity, nasal cavity, pharynx, paranasal sinuses, larynx and salivary glands are classified as HNC. About 90% of these tumors are classified as squamous cell carcinomas (Argiris et al., 2008; Ariyawardana & Johnson, 2013; Lambert et al., 2011). Causality of HNC has been attributed to environmental or lifestyle factors, however it can also be a combination of both. Environmental and/or lifestyle factors that have been shown to influence the development of HNC include smoking, exposure to smoking, consuming alcohol, poor oral hygiene, radiation exposure, ultra-violet light exposure, and marijuana use (Lambert et al., 2011; Moore et al., 2004). Several studies have documented increasing evidence of the human papillomavirus (HPV) attributing to the cause of some HNC (Kjaer et al., 2016; Sankaranarayanan, Masuyer, Swaminathan, Ferlay, & Whelan., 1998). Although these factors can all contribute, smoking and heavy alcohol consumption are the dominant contributing factors for HNC.

According to the Public Health Agency of Canada, there will be 196,900 new cases of cancer diagnosed in 2015 of which 100,500 are expected to be males and 96,400 females (Canadian Cancer Statistics, 2015). For the Canadian male population, 2.9% of the cases were oral cancer, 1.4% thyroid, and 0.9% larynx. For females, 5% were thyroid, 1.5% oral and 0.2% larynx. Larynx cancer is decreased in the number of cases per year, mostly due to the strong association with smoking and alcohol consumption as risk factors. Thyroid cancer diagnosis has shown an increase, which is mostly due to ‘over diagnosis’ by surgeons. Surgeons ‘over diagnose’ thyroid cancer to try to prevent the spread of HNC by which they will remove the thyroid if it is suspicious for development of cancer in the future in order to not spread disease into the lymph nodes or head and neck region. There is also more diagnostic testing, which allows for more cases to be caught at early stages (Canadian Cancer Statistics, 2015).

2.2 Surgeries

Head and neck cancer can present very complicated cases. Previously, surgery and radiotherapy have been considered the primary treatment approach. Today, the aim of surgery is to preserve organ function while simultaneously improving survival

outcomes. However, this is not always possible as the plan for treatment is dependent on the severity of the disease as well as the type of surgery performed. The purpose of the ND surgery is to remove the head and neck tissue/structures (usually lymph nodes) in order to prevent, control and remove present HNC.

2.2.1 Radical Neck Dissection

The radical neck dissection (RND) described by Crile in 1906 as the standard procedure for HNC surgery, involved the removal of fibrofatty tissue, lymph nodes (Levels I-V and those surrounding the parotid gland – see Figure 2.1), the spinal accessory nerve (SAN), internal jugular vein (IJV) and the sternocleidomastoid (SCM) muscle (Watkins et al., 2011); this procedure was the standard for any form of HNC. However, with the focus of preserving organs, this procedure is now used for patients with advanced HNC. Other procedures that focus on preservation are considered to be modifications of the RND.

2.2.2 Modified Radical Neck Dissection

The modified radical neck dissection (MRND) must preserve one or more of the non-lymphatic structures. Thus this surgery removes the lymph node groups (levels I-V- see Figure 2.1) but must preserve the SAN, the IJV or the SCM muscle (Oz & Memis, 2009; Subramanian, Chiesa, Lyubaev, & Aidarbekova, 2006). There are three types of MRND that generally specify which of the three muscle structures have been preserved. Type I preserves the SAN, Type II varies but generally preserves the combination of SCM and SAN, or IJV and SAN, and Type III preserves all three structures (Evans, Montgomery, & Gullane, 2009). This procedure is still extensive and is generally used for patients who present with large metastases, spread of the metastases to the supraclavicular lymph nodes, those who have had failed radiotherapy, or with multiple clinically positive nodes (Hong & Weber, 1995).

2.2.3 Selective Neck Dissection

The selective neck dissection (SND) is a procedure that removes lymph node groups that have a risk of metastastic cancer, and preserves those that would have normally been removed during a routine RND (Evans et al., 2009; Pagedar et al., 2009;

Watkins et al., 2011). The procedure is classified based on the lymph node region represented by levels I-V (see Figure 2.1). Level I consist of the nodes located in the submental and submandibular region, levels II-IV consists of nodes in the upper, middle and lower jugular area while level V consists of those located in the posterior triangle (Figure 2.1, Table 2.1). Each region is also subdivided for more accurate removal of the targeted nodes. This procedure is used for extracting lymph node groups that are at high risk of developing disease while preserving the lymph nodes that are at lowest risk. These patients may or may not have metastases but do have a high risk of metastatic development (Robbins et al., 2013). The procedure was developed to control regional metastasis while preserving the SAN, IJV and SCM to reduce post-surgical dysfunction as well as decrease the morbidity that is reported post RND (Pagedar et al., 2009).

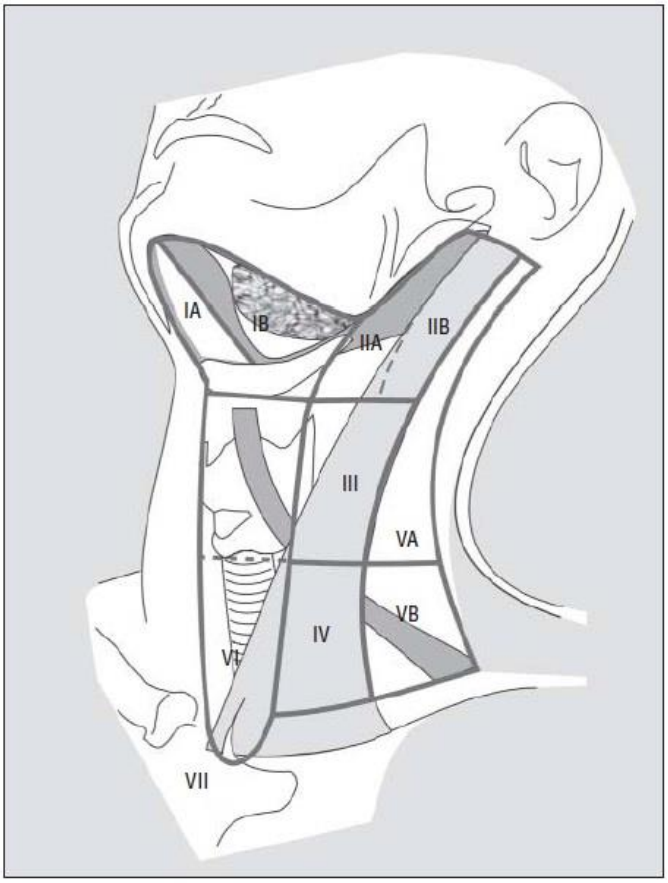

Figure 2.1 Anatomic diagram of left neck depicting neck dissection boundaries of the neck levels and sublevels. Level I- submandibular triangle region, Level II- upper jugular region, Level III- middle jugular region, Level IV- lower jugular region, Level V- posterior triangle region. Adapted from Robbins et al., 2008.

Table 2.1 Description of leveling of cervical lymph nodes

Cervical Lymph Node Level	Sublevel	Location Description
Level I	Ia*:* Submental nodes Ib*:* Submandibular nodes	Submandibular Triangle
Level II	IIa: Upper jugular nodes anterior to cranial nerve IX IIb: Upper jugular nodes posterior to cranial nerve IX	Upper Jugular
Level III	III	Middle Jugular
Level IV	IVa: Lower jugular nodes behind clavicular head of sternocleidomastoid IVb: Lower jugular nodes behind sternal head of sternocleidomastoid	Lower Jugular
Level V	Va: Spinal accessory nodes Vb: Supraclavicular nodes	Posterior Triangle

(Chummun et al., 2004; Ferlito et al., 2009)

2.2.4 Extended Neck Dissection

Extended neck dissection (END) is the procedure used for more advanced metastases. The END involves the removal of lymphatic and non-lymphatic structures that are not routinely removed during the RND (Ferlito, Robbins, Silver, Hasegawa, & Rinaldo, 2009; Robbins et al., 2013). This could include lymph nodes such as the parapharyngeal, superior mediastinal or perifacial nodes, as well as the carotid artery, skin, hypoglossal and vagus nerves or paraspinal muscles.

2.3 Chemotherapy

Chemotherapy is used to treat various cancers. The treatment aims to eliminate cancer tumors (growths) or slow the rate of cancer cell growth (National Cancer Institute, 2015). Additionally, it is used to ease cancer symptoms by shrinking tumors that are causing discomfort or problems. Chemotherapy can be administered in many different forms (ex. intravenous, oral, injection), however it is not localized and has the potential to destroy other healthy cells and organs causing severe side effects and possible organ

failure. Studies have shown that chemotherapy has the ability to improve survival and improve QOL in certain cancers (Dillman, Herndon, Seagren, Eaton Jr., & Green, 1996; Glimelius et al., 1996). For HNC patients, chemotherapy has not been shown to improve survival or QOL (Hughes & Frenkel, 1997; Vermorken & Specenier, 2010), however it has played a valuable role in getting an initial treatment response in order to proceed with further treatment. Combinations of chemotherapy and other therapies have been shown to increase survival in HNC patients (Cognetti, Weber, & Lai, 2008).

2.4 Radiotherapy

Radiotherapy is used to treat a variety of cancers, where high-energy radiation in regulated doses is carefully targeted to eliminate cancer cells. This therapy is localized, which is set to inhibit cancer cell growth in a selected area. Radiotherapy is intended to cure the patient from cancer cell growth, however it also has the ability to damage normal cells leading to side effects of therapy (Baskar, Ann-Lee, Yeo, & Yeoh, 2012). Treatment usually targets small amounts of normal tissue surrounding the cancerous area due to essential movements (e.g. breathing) during therapy as well as to reduce the likelihood of recurrence of the cancer spreading to the neighboring cells (National Cancer Institute, 2010). Radiotherapy along with surgery are the primary treatments for HNC. Radiotherapy has shown to prolong survival for individuals with HNC, providing a 30-35% 5-year survival rate (Bonner et al., 2006; Bourhis et al., 2006) but less than 25% of cases surviving overall post-radiation (Adelstein et al., 2003).

2.5 Radioactive Iodine (I-131)

Radioactive iodine therapy is primarily used for patients diagnosed with thyroid cancer. This involves the patients consuming a liquid/capsule of radioactive iodine, which destroys the thyroid gland and its cells (American Cancer Association, 2016). This therapy has the ability to destroy cancer cells with little effect on the rest of the body. Typically patients who have undergone surgery where part of the thyroid is preserved or have had the cancer spread to lymph or other parts of the body will be prescribed this therapy in order to decrease the recurrence of thyroid cancer (Kim, Kim, Kim, & Shong, 2014).

2.6 Range of Motion

The ROM refers to the motion or distance a person is able to move a limb around a joint in a particular direction. Reduced ROM is one of the complications experienced by patients who undergo ND surgeries (Eickmeyer et al., 2014; Ferlito, Rinaldo, Silver, Shah, et al., 2006). In the past, ND surgeries included the removal of the SAN, which innervates the trapezius muscle whose primary role is to stabilize the scapula. Without the stabilization of the scapula the shoulder tends to drop and protract causing limited ROM (Speksnijder et al., 2013). Limited ROM (temporary/permanent) can also be experienced in patients following modified procedures of the ND even with nerve preservation. Some possible causes of this dysfunction seem to be tied to consequences post-surgery where traction, microtraumas, or devascularizations of the nerve have taken place (Shankar & Means, 1990; Soo, Guiloff, Oh, Della Rovere, & Westbury, 1990). Along with surgery, fibrosis may also play a role in causing a negative effect on shoulder function. Surgical excision of HNC along with radiotherapy can lead to fibrosis formation around the areas of tissue deficit as well as the radiation field (Ferlito, Rinaldo, Silver, Gourin, et al., 2006; Shaw et al., 2016).

Shoulder complaints due to reduced ROM and pain post-ND can also have a large impact on an individual's QOL. Lifestyle choices, careers/jobs, activities, hobbies and other activities can be changed due to the limits of movement or the pain experienced. It is also important to consider those patients who undergo radiotherapy and chemotherapy as part of the post-surgical treatment. These individuals could experience decreases in ROM due to fibrosis, which can lead to a prolonged recovery and could be the origin of psychological problems (Stuiver et al., 2008).

2.7 Strength

Shoulder dysfunction can also include reduced strength in the head and neck regions due to impaired muscles/nerves from surgery or adjuvant therapy (radiation/chemotherapy). In long-term survivors, strengthening exercises are usually recommended to prevent the reduction of strength in the head and neck regions that contribute to shoulder dysfunction (Murphy & Deng, 2015).

2.8 Patient Concerns and Quality of Life

The HNCs may affect patients physically, emotionally and socially. Their concerns surrounding their disease and treatment can impact the individual's QOL. However patient concerns with regards to experience and the suffering experienced still tend to be under-reported with routine follow-ups with their clinicians. Research has shown fear to play a role in the under-reporting of patients' concerns during follow-up. Patients do not want the cancer to set them back in their recovery with delayed treatments (Moore et al., 2004). Clinical follow-ups tend to be kept short and brief due to the busy nature of clinics and the number of patients a surgeon has to see during clinic time (Ghazali et al., 2013). Patients may not bring up their concerns, nor may surgeons probe any concerns patients may have. These concerns are thus left unaddressed and could increase as time post-surgery elapses. Under-addressed concerns post-surgery can affect an individual's health-related QOL where they can experience many different physical complications and dysfunctions limiting their ability to perform activities of everyday life, which could pose challenges. Additionally, they may experience mental and emotional distress due to decreased functional abilities, challenges and possible changes to appearance post-surgery which all contribute to the QOL of these patient's post-surgery.

Chapter 3

3 Methods

3.1 Objective

The primary purpose of this study was to investigate and describe the longitudinal effects of shoulder and neck mobility, strength, pain and QOL following ND surgery and identify the concerns of HNC patients. First, we sought to identify the long-term HNC patient concerns, QOL, pain and changes in shoulder and neck mobility by providing patient-reported outcome measures before surgery, at 1-month and at 4-month follow-ups. The Patient Concerns Inventory-Level of Importance (PCI-LOI), Shoulder Pain and Disability Index (SPADI), Neck Dissection Impairment Index (NDII), and the University of Washington-Quality of Life Scale (UWQOL) were used to identify patient concerns related to participants' health and QOL along with patient-reported pain and changes in shoulder and neck mobility. In addition, the study aimed to identify the changes in ROM and strength of the neck and shoulder areas over long-term follow-up caused by ND surgery for HNC patients. The effect was measured by assessing the ROM and strength of the neck and shoulder at pre-surgery, 1-month and at 4-months follow-ups.

3.2 Participant Selection

3.2.1 Inclusion Criteria

Individuals were eligible to participate in the study if they were: (1) over the age of 18, (2) patients at LHSC (Victoria Hospital), (3) diagnosed with HNC, (4) scheduled for a pre-admission visit at Victoria Hospital, (5) scheduled for ND surgery, (6) physically able to perform the measures, and (7) able to understand and communicate in English.

3.2.2 Exclusion Criteria

Participants were ineligible for the study if they: (1) had language barriers, (2) were unable to perform physical measures, (3) did not have HNC, (3) presented with

thyroid cancer and underwent a central ND, (4) underwent ND for reconstruction, or (5) underwent bilateral ND.

3.3 Recruitment

Ethical approval for the study was provided by the Health Sciences Research Ethics Board of Western University (Appendix A). Participants were recruited from the Otolaryngology clinic at LHSC (Victoria Hospital). The participants eligible for ND surgery were diagnosed with HNC and identified by the head and neck surgeons upon initial consultation. The eligible participants were approached and recruited by the investigator at their scheduled pre-admission clinic appointment held at LHSC approximately a week before their scheduled surgery. During the pre-admission appointment, the participants were provided with a letter of information and consent form (Appendix B) from the study investigator. The investigator answered questions and obtained written consent from those that wished to participate.

3.4 Procedures

The study investigator performed initial data collection at the pre-admission appointment. The investigator measured the participants' shoulder ROM (flexion & external rotation), shoulder strength (flexion & external rotation), and neck ROM (rotation) using the designated measuring instruments. Following the measurements, participants were asked to fill out the four patient-reported outcome questionnaires (PCI-LOI, SPADI, NDII, UWQOL). All information was collected by the investigator during the pre-admission appointment.

Participants underwent ND surgery following the pre-admission appointment on their scheduled date. Patients were admitted into hospital post-surgery for approximately seven days before being discharged home. Follow-up appointments with the surgeons were scheduled by the Otolaryngology clinic at LHSC Victoria Hospital. The investigator approached the participants in the Otolaryngology clinic during their scheduled follow-up appointment (approximately 1-month & 4-month post-surgery) where they were asked to fill out the patient-reported outcomes questionnaires and subsequently measured on their neck and shoulder ROM and strength.

3.4.1 Shoulder ROM

To assess the shoulder ROM, flexion and external rotation measures were taken. The participant was directed to stand for the shoulder flexion measure with their hands by their side (neutral position). The J Tech Dualer IQ Digital Inclinometer was placed in the middle of the participant's bicep (upper arm) with a strap. The neutral position measure was determined by leveling the inclinometer to "0". The participant was then directed to lift their arm from the neutral position, along the sagittal plane, initiating shoulder flexion to a position where they were at their maximum flexion without discomfort or pain. The measurement was recorded at the maximum position, then the participant was directed to return their arm to the neutral position. Participant measures were retaken if the participant had a flexed elbow or had moved into the coronal plane of motion. This measurement was repeated three times on each side; repeat measures were taken at 1-month and 4-months.

To determine the shoulder external rotation, the participant was asked to lie supine on the bed with their arm positioned at a lateral angle of 45°(approximately) from the body, with their forearm perpendicular (i.e. elbow at 90°). The inclinometer was placed on the wrist with a strap around the styloid process of the radius and ulna. The neutral position was determined by leveling the inclinometer at "0" in this set position. The participant was then asked to laterally rotate their arm along the transverse plane to a maximal external rotation point when they felt no pain or discomfort. The measure was recorded and the participant was asked to move their arm back to neutral position. The measure was retaken if the individual did not maintain the 90° angle at the elbow or if they extended the arm into the sagittal plane. This measurement was taken three times and repeated on both arms; repeat measures were taken at 1-month and 4-months.

3.4.2 Shoulder Strength

In order to determine the shoulder strength, flexion and external rotation measures were used. To measure the shoulder strength using flexion, the participant was asked to stand in the neutral position (same as shoulder flexion position) where the MicroFet2 dynamometer was placed and held by the investigator on the participant's bicep. The participant was directed to lift their arm from the neutral position, along the sagittal plane

and resists the force that was gradually applied by the investigator. The patient was directed to resist the investigator's force for five seconds. The measurement was recorded after the five seconds. If the patient felt pain or discomfort the measurement was stopped. This was repeated three times on both sides; repeat measures were taken at 1-month and 4-months.

To assess the shoulder strength using external rotation, the participant was asked to sit on the bed/chair in an upright position. The investigator directed the participant to tuck their upper arm into the side of their trunk and hold their forearm flexed at the elbow at 90°, perpendicular to the upper arm. This was the neutral starting position. The MicroFet2 was placed and held by the investigator lateral to the styloid process of the ulna. The participant was directed to push against the MicroFet2 while laterally rotating their forearm. The investigator gradually applied counter-force, which the participant was directed to resist for five seconds, then the final measure was taken. The measure was terminated if the participant felt pain or discomfort. The measure was retaken if the participant abducted the arm, flexed the wrist, or did not hold against the MicroFet2 for five seconds. This was repeated three times on each side; repeat measures were taken at 1-month and 4-months.

3.4.3 Neck ROM

To determine the neck ROM, the participant was asked to lie supine. The investigator attached the digital inclinometer to the apex of the participant's head using a strap. The participant was asked to stare straight at the ceiling where the inclinometer was leveled to "0", which was considered the neutral starting position. The participant was directed to laterally rotate their head in the transverse plane from the neutral starting position to a maximal point without pain or discomfort. The measure was recorded at the maximal point where the investigator then directed the participant to return to neutral position. This measure was performed three times on each side. The measure was retaken if the participant flexed their head, or laterally bent their neck and head. Repeat measures were taken at 1-month and 4-months.

3.5 Outcome Measurements and Psychometric Properties

3.5.1 Patient Concerns Inventory- Level of Importance

The Patient Concerns Inventory (PCI) has been used in clinics to help highlight patient concerns and facilitate discussions during a follow-up appointment (Ghazali et al., 2013). The PCI addresses a wider range of concerns than other questionnaires, which allows patients to address individualized concerns that can be documented and used to guide patient consultations and promote multidisciplinary care (Rogers, El-Sheikha, & Lowe, 2009). The PCI-LOI was developed in an earlier study (Arulananda Doss, 2013) which added a level of importance scale to the original PCI for the purpose of gathering patient concerns and their level of importance. The addition of the level of importance scale was to allow HNC surgeons and healthcare providers to easily detect the concerns of high importance to the patient and address them during follow-up appointments. The PCI-LOI allows patients to identify concerns and subsequently quantify their concerns through a numeric scale (1-7 with higher scores indicating more concern).

The PCI-LOI assessed level of importance and the major concerns of each participant with respect to their ND surgery. The questionnaire looks at four different domains; Physical & Functional Well Being (30 concerns), Social Care & Social Well Being (9 concerns), Psychological Emotional & Spiritual Well Being (14 concerns), and Treatment Related (2 concerns). These domains have items (concerns) that are ranked by the participant using a 7-point rating scale (1-none, 2-very small, 3-small, 4-moderate, 5-fairly great, 6-great, 7-very great) to obtain the importance of each concern. Higher scores on the PCI-LOI imply greater concern and importance to the patient. Additionally, there is a section that allows the patient to address other concerns that may have been missed that they feel have great importance to them, and there is space to write down the ranking of the top three concerns over the past week.

The study by Arulananda Doss (2013) provided preliminary validation of the PCI-LOI which is also deemed to be a reliable instrument used with HNC patients. Arulananda Doss showed a moderate negative correlation with the UWQOL questionnaire at 1-month post-surgery (r=-0.42), and a moderate correlation with the

SPADI at 1-month post-surgery (r=0.57). This allows for the interpretation of findings for the purpose of describing patients during follow-up time.

3.5.2 Shoulder Pain and Disability Index

The Shoulder and Pain Disability Index (SPADI) is a patient-reported outcome questionnaire that was developed to measure patients' present shoulder pain and disability (Breckenridge & McAuley, 2011). For this study, the SPADI was used to evaluate shoulder pain and disability for participants who have undergone the ND surgery for their HNC. The questionnaire consists of two domains - Pain and Disability. The Pain domain is composed of a 5-item subscale, while the Disability domain consists of 8-items. Each item is scored using a visual analog scale that ranges from 0 (no pain/no difficulty) to 10 (worst pain imaginable/so difficult required help). Higher scores indicate more pain or disability with an activity. The SPADI results in a subtotal for each domain as well as an average of the scores. The SPADI can also be combined as a total score to provide the patient with an overall pain and disability score for the participants' shoulder.

The SPADI is strongly correlated for shoulder pain and difficulty scores to actual pain and difficulty which was determined through a cross-sectional analysis on shoulder questionnaires. (Paul et al., 2004; Roy, MacDermid, & Woodhouse, 2009). Paul et al (2004) found that the SPADI demonstrated good construct validity and was the most responsive to change. Roy et al. (2009) demonstrated that the correlation of the SPADI to other shoulder-specific scales was high ($r \geq 0.70$) and also reported excellent reliability (weighted average 0.89). This study concluded that the SPADI had shown to be a valid tool for evaluating pain and disability for different shoulder conditions. The instrument scores have been used in clinical and research settings to identify shoulder pain and disability in a diverse range of patients (Struyf, Geraets, Noten, Meeus, & Nijs, 2016; Teoh, Jones, Robinson, & Pritchard, 2016).

3.5.3 Neck Dissection Impairment Index

The Neck Dissection Impairment Index (NDII) is a patient-reported outcome questionnaire that is specifically designed for patients with HNC. The NDII was created to identify patients' unique disease-related problems that affect their QOL following neck

dissections (Taylor et al., 2002). The NDII was used in this study to evaluate the changes in QOL of patients with HNC. It specifically examined the dysfunction of the shoulder and how they are affected in daily activities. The NDII has a total of 10 questions related to pain, stiffness, self-care, physical activities, social activities, leisure/recreational activities and work. Each question was answered based on a Likert scale with five options; each option was scored from 1-5 (5-not at all, 4-a little bit, 3-a moderate amount, 2-quite a bit, 1-a lot). A score closer to 5 denoted a greater QOL and minimal to no disability. The scored responses were converted to an overall score out of 100 (Goldstein et al., 2014; Taylor et al., 2002).

The NDII has been used to assess the long-term effects on QOL in HNC patients post-ND related to shoulder dysfunction with good convergent validity (Taylor et al., 2002). Taylor et al. (2002) has shown the NDII to be a reliable instrument for assessing shoulder dysfunction in HNC patients demonstrated by a test-retest correlation (r=0.85) and good internal consistency (r=0.95).

3.5.4 University of Washington Quality of Life Questionnaire

The University of Washington Quality of Life (UWQOL) questionnaire is one of the most commonly used scales to report patient-reported QOL in HNC (Laraway & Rogers, 2012). Initially published with nine domains, this questionnaire now has 12 domains to accommodate the missing questions about shoulder function that are important to head and neck surgeons (Laraway & Rogers, 2012). The UWQOL scale was used in this study to investigate 12 aspects of QOL (Pain, Appearance, Activity, Recreation, Swallowing, Chewing, Speech, Shoulder, Taste, Saliva, Mood, and Anxiety). These questions are geared towards the individual's cancer and how it affects each aspect of health-related QOL. The total score was obtained by converting the patient responses to a score using the UWQOL specific scale. Additionally, the questionnaire asks for the patient/participant to indicate up to three important items of the UWQOL for the past week. At the end of the UWQOL, the participant is asked three questions about their overall QOL, which allows them to answer based on a 6-point qualitative scale (Outstanding, Very Good, Good, Fair, Poor, Very Poor). Higher scores on the UWQOL indicated greater patient-reported QOL.

The UWQOL questionnaire has been extensively validated and deemed reproducible and reliable in determining the QOL of patients with HNC (Hassan & Weymuller, 1993; Kazi R, Johnson C, Prasad V, De Cordova J, Venkitaraman R, Nutting C, 2008; Laraway & Rogers, 2012; Weymuller A, Alsarraf R, Yueh B, Deleyiannis W, Coltrera D, 2001). Hassan et al, (1993) showed that the UWQOL had a high reliability ($r > 0.90$).

3.5.5 MicroFET2 Handheld Dynamometer

The MicroFet2 (HOGGAN Health Industries, Salt Lake City, 2011) is a handheld dynamometer used to document muscle weakness/impairment. This tool allowed the patient to exert a maximal amount of force against the device giving a peak force score for the muscle being tested thus documenting the shoulder weakness/impairment in study participants. The MicroFet2 uses 0.2 lb (4.4N) increments for reporting measurements. The measurement time was a minimum of five seconds, operating on the high threshold setting. This setting allowed for the control of false starts due to 3.0 lb of force to be exerted before the tool began recording.

This dynamometer has been validated to assess shoulder muscle strength in a clinical setting (Johansson et al., 2015; Mentiplay et al., 2015; Stark, Walker, Phillips, Fejer, & Beck, 2011). Johansson et al, (2015) showed the dynamometer to have an excellent intratester reliability (ICC=0.87-0.85) and intertester reliability (ICC=0.71) and an excellent test-retest reliability (ICC>0.71). The handheld dynamometer has been used as a reliable tool in other clinical trials to measure shoulder strength on individuals post-surgery (Hamdi et al., 2008; Westrick, Duffey, Cameron, Gerber, & Owens, 2013).

3.5.6 J Tech Dualer IQ Digital Inclinometer

The J Tech Dualer IQ Digital Inclinometer (JTECH MEDICAL, Salt Lake City, 2005) was used to measure and document patients' active ROM around the shoulder and neck joints. The tool was placed in static mode, which enabled the testing of the patients' range of motions in a static position. This allowed for the measurement of a single joint movement isolating the shoulder or neck in which the end-point of the range of motion was recorded. The J Tech Dualer IQ Digital Inclinometer uses degrees (angles) to measure the ROM values.

The inclinometer has been used as a reliable and valid tool to measure shoulder ROM in clinical settings and clinical research (Furness, Johnstone, Hing, Abbott, & Climstein, 2015; Kolber, Fuller, Marshall, Wright, & Hanney, 2012; Kolber & Hanney, 2012). Kolber et al, (2012) showed the digital inclinometer to have excellent intrarater reliability (ICC≥0.95) when measuring shoulder mobility. Additionally, they reported strong concurrent validity between the digital inclinometer and goniometry.

3.6 Analysis

In order to describe the study population at preadmission, 1-month and 4-months post-surgery group mean, standard deviation, frequencies and percentages were used where appropriate. The data analysis was completed using IBM SPSS statistical software version 24 (IBM corp., USA).

3.6.1 First Objective

To identify the HNC patient concerns, QOL, pain and changes in shoulder and neck mobility that arise during their long-term post-surgery follow-ups (1-month & 4-month). For the first objective the patient-reported outcomes of each questionnaire were summed up appropriate to questionnaire instructions in order to determine total means. The means and standard deviations were used to describe the information obtained in the PCI-LOI, SPADI, NDII and UWQOL. Patient-reported outcomes were used in the analysis based on a subset of study participants that had provided data across three time-points. A one-way repeated measures ANOVA was conducted on the scores to determine if the obtained values showed significant differences across time (long-term follow-up). Additionally, two domains of the SPADI and four domains of the PCI-LOI were analyzed over three time-points to further investigate significant differences across long-term follow-up. The UWQOL was used to provide frequencies of patient responses to determine the top concerns of HNC patients.

3.6.2 Second Objective

To identify the changes in ROM and strength of the neck and shoulder areas over long-term follow-up (1-month & 4-months). To identify the ROM and strength of the HNC population, means and standard deviations were obtained for operated and non-

operated arms across all three time-points. In order to determine significant changes over time in ROM and strength, a subset of participants (n=8) with complete data were used in the analysis using a two-way repeated measures ANOVA.

3.6.3 Variability in n

When describing the population, data collected from 27 participants was used in order to determine the demographic characteristic of the HNC participants. When performing the longitudinal analysis, data that was complete (both arms and all time-points) for each measure was used in order to determine a change. Participant responses varied significantly across time-points for the outcome measures. The variability was due to the nature of the Otolaryngology clinic at LHSC (Victoria Hospital) where follow-up appointments are scheduled based on patient and surgeon availability and the patient's recovery plan. Some participants were scheduled for routine follow-ups at 1-month and 4-months, while others could undergo additional treatment (ex. adjuvant therapy) where they are seen at a later follow-up time. Variability also occurred as patients may have refused to participate in certain measures due to their physical condition or complications.

Chapter 4

4 Results

4.1 Patient Characteristics

A total of 49 patients were approached for the study, of which 44 patients (31 males, 13 females) agreed to participate. Post-surgical, 27 patients (20 males, 7 females) were deemed eligible to participate based on the inclusion/exclusion criteria (Figure 4.1). The average age for the participants (both male and female) at post-surgery was 64 years (min/max range 38-82 years). There were a total of one (3.7%) RND, five (18.5%) MRND, and 21(77.8%) SND surgeries performed on this patient population. Nine patients underwent reconstructive procedure in addition to their ND surgery. These classifications of reconstruction were as follows; one (3.7%) cervical facial rotation, one (3.7%) fibular flap, one (3.7%) pectoralis major flap, one (3.7%) scapular flap and five (18.5%) radial forearm flaps. At pre-admission, six (22.2%) participants reported pain among which five (83.3%) reported pain on the surgical side and one (16.7%) reported pain on both sides. At 1-month post-surgery pain was reported in eight (47.1%) participants and at 4-months post-surgery pain was reported among three (30%) participants. In total, 10 patients underwent adjuvant therapy in addition to their ND. One (3.7%) participant underwent chemotherapy, one (3.7%) underwent radio-iodine therapy, three (11.1%) had both chemotherapy and radiation, and five (18.5%) had radiation. Table 4.1 describes patient characteristics.

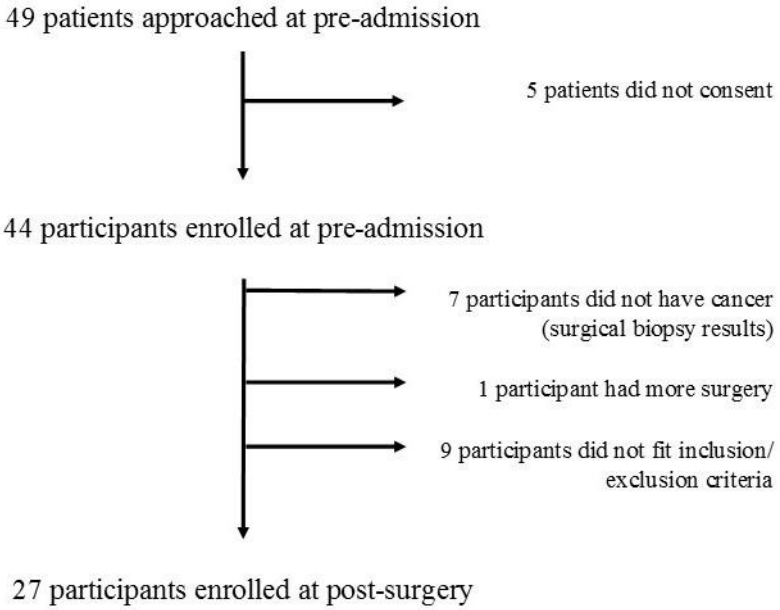

Figure 4.1 Participant Enrollment

Table 4.1 Patient Characteristics [n (%)]

Participant Demographics	Total Participants (n=27)
Age, Years	
Mean (minimum-maximum)	64 (38-82)
Gender	
Male	20 (74.1)
Female	7 (25.9)
Dominant side	
Left	2 (7.4)
Right	23 (85.2)
Ambidextrous	2 (7.4)
Side of surgery	
Left	18 (66.7)
Right	9 (33.3)
Surgery type	
Radical	1 (3.7)
Modified	5 (18.5)
Selective	21 (77.8)
Previous cancer diagnosis	
Yes	15 (55.6)
No	12 (44.4)

Days in hospital post-surgery	
Mean (minimum- maximum)	7 (2-19)
Pain reported	
Pre-admission	6 (22.2)
One month[1]	8 (47.1)
Four months[2]	3 (30.0)
Painful side pre-surgery[1]	
Left	3 (11.1)
Right	2 (7.4)
Both	1 (3.7)
Painful side one month[2]	
Operated	7 (41.2)
Non-operated	9 (52.9)
Both	1 (5.9)
Painful side four month[3]	
Operated	2 (20.0)
Non-operated	8 (70.0)
Both	1 (10.0)
Reconstructive flap	
Radial forearm	5 (18.5)
Scapular	1 (3.7)
Facial rotational	1 (3.7)
Fibular	1 (3.7)
Pectoralis Major	1 (3.7)
None	18 (66.7)
Adjuvant Therapy	
Chemotherapy	1 (3.7)
Radiotherapy	5 (18.5)
Radio-Iodine	1 (3.7)
Chemotherapy & Radiotherapy	3 (11.1)
None	17 (63.0)

n=number of participants

1 participant size n=27

2 participant size n=17

3 participant size n=10

Table 4.2 Number of participants that have completed strength and range of motion (ROM) measures at each time-point

Measure	Pre-surgery (n)		Post-surgery 1-month (n)		Post-surgery 4-month (n)	
	Operated side	Non-operated side	Operated side	Non-operated side	Operated side	Non-operated side
Flexion ROM	27	27	18	18	13	13
External rotation ROM	27	27	17	18	13	13
Lateral neck rotation ROM	24	25	18	18	13	13
Flexion strength	26	26	18	18	13	13
External rotation strength	27	26	17	17	13	13

Table 4.3 Number of participants completing questionnaires

Patient-reported outcomes	Pre-surgery	1-month	4-month
PCI-LOI[1]	27	21	15
SPADI[2]	27	21	15
NDII[3]	27	21	15
UWQOL[4]	27	21	15

[1] Patient Concerns Inventory- Level of Importance
[2]Shoulder Pain and Disability Index
[3] Neck Dissection Impairment Index
[4] University of Washington Quality of Life Questionnaire

Table 4.4 Number of participants with data for all time-points

Measure	Post-surgery, 1-month & 4-month (n)
Flexion (ROM)	8
External Rotation (ROM)	8
Lateral neck rotation (ROM)	6
Flexion (Strength)	8
External Rotation (Strength)	8
PCI-LOI[1]	11
SPADI[2]	12
NDII[3]	12
UWQOL[4]	11

[1] Patient Concerns Inventory- Level of Importance
[2]Shoulder Pain and Disability Index
[3] Neck Dissection Impairment Index
[4] University of Washington Quality of Life

First objective: To identify the HNC patient concerns, QOL, pain and changes in shoulder and neck mobility that arise during their long-term post-surgery follow-ups (1-month & 4-month).

To determine patient concerns, QOL, pain and changes to mobility across follow-up time, a one-way repeated measures ANOVA was conducted on patient-reported outcome scores for all questionnaires who completed data across all three time-points (PCI-LOI n=11, SPADI n=12, NDII n=12). The mean differences are described in Table 4.6. Analysis of the NDII data revealed a significant effect [$F(2, 22) = 14.73$, $p < .001$, $\eta_p^2 = .572$], indicating a significant decrease in patient self-rated dysfunction and neck pain over time. *Post hoc* tests revealed a decrease in NDII total score from pre-surgery to 1-month follow-up (92.29± 9.56 to 57.50±21.98), which was statistically significant ($p<0.001$) indicating decreases in patient self-rated dysfunction. Additionally, there was a statistically significant ($p=0.008$) decrease in total score from pre-surgery to 4-months follow-up, (92.29± 9.56 to 64.38±25.52). Lastly there was a non-significant increase in total NDII score from 1-month follow-up to 4-month follow-up (57.50±21.98 to 64.38±25.52).

Analysis of the SPADI total score revealed a significant effect [$F(2, 22) = 8.01$, $p < .002$, $\eta_p^2 = .424$], suggesting significant change in patient perceived shoulder pain and disability over time. *Post hoc* comparisons revealed an increase in SPADI score from pre-surgery to 1-month (6.60±2.78 to 25.45±5.09), which was statistically significant (p=0.005). In addition, there was a significant (p=0.04) increase in score from pre-surgery to 4-months follow-up (6.60±2.78 to 23.59±5.56). There was a non-significant decrease in score from 1-month to 4-months follow-up (25.45±5.09 to 23.59±5.56).

Additionally a time-effect was found among analysis of the SPADI pain [$F(2, 22) = 4.9$, $p < .017$, $\eta_p^2 = .308$], and disability [$F(2, 22) = 8.3$, $p < .002$, $\eta_p^2 = .429$], data points (Figure 4.2). For pain, *post hoc* tests revealed an increase in SPADI pain score from pre-surgery to 1-month follow-up (5.58±2.74 to 15.50±2.78), which was statistically significant (p=0.01). 1-month to 4-months follow-up and pre-surgery to 4-months follow-up showed no statistical significance. For SPADI disability, a *post hoc* test showed an increase in score from pre-surgery to 1-month (3.00±1.37 to 17.58±4.05), which was statistically significant (p=0.01). There was also a significant (p=0.03) increase in score from pre-surgery to 4-months follow-up (3.00±1.37 to 16.83±4.47). There was a non-significant decrease in score from 1-month to 4-months follow-up (17.58±4.05 to 16.83±4.47). Table 4.6 displays all *post hoc* differences.

The top concerns were obtained using the UWQOL and identified for all three time-points for all participants within the follow-up timeframe (Table 4.7). At pre-surgery, “Pain” and “Anxiety” were identified as the top concerns, while “Activity” was a top concern at 1-month and “Pain” at 4-months. “Pain” was the only top concern identified across all three time-points, while “Shoulder” and “Activity” were identified as top concerns across 1-month and 4-months follow-up. At pre-admission, 25/27 (92.6%) participants identified their concerns, while at 1-month 20/21(95.2%), and 4-months, 13/15 (86.7%) of patients identified their concerns.

When identifying the top concerns for the 11 patients who completed the study at all three time-points, “Pain” was the top concern at pre-admission, where “Shoulder” became a top concern at 1-month and 4-months follow-up. Figure 4.3 displays patient frequency responses of the top three concerns at each time-point for the 11 participants.

Table 4.5 Descriptive statistics for patient-reported questionnaires over three time-points for participants with complete time-point data.

Patient-reported outcome questionnaires		Pre-surgery		1-month post-surgery		4-month post-surgery	
	n	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**
PCI-LOI[1]							
Physical & functional well being		54.1	33.2	83.2	26.9	80.3	22.5
Social care & social well being		17.8	13.5	20.0	9.2	14.7	9.05
Psychological, emotional & spiritual well-being		25.8	10.1	36.9	14.9	31.2	13.1
Treatment related		3.7	2.1	5.4	3.5	2.8	1.5
Total Score	11	101.5	52.2	145.5	44.8	129.0	33.5
SPADI[2] (%)							
Pain score		5.6	9.4	15.5	9.6	13.8	11.2
Disability score		3.0	4.7	17.6	14.0	16.8	15.5
Total score	12	6.6	9.6	25.4	17.6	23.6	19.2
NDII[3] (%)							
Standardized score	12	92.3	9.6	57.5	22.0	64.4	25.2
UWQOL[4]							
Composite Score	11	79.1	14.5	62.7	16.4	71.4	10.8

[1] Patient Concerns Inventory- Level of Importance
[2]Shoulder Pain and Disability Index
[3] Neck Dissection Impairment Index
[4]University of Washington Quality of Life

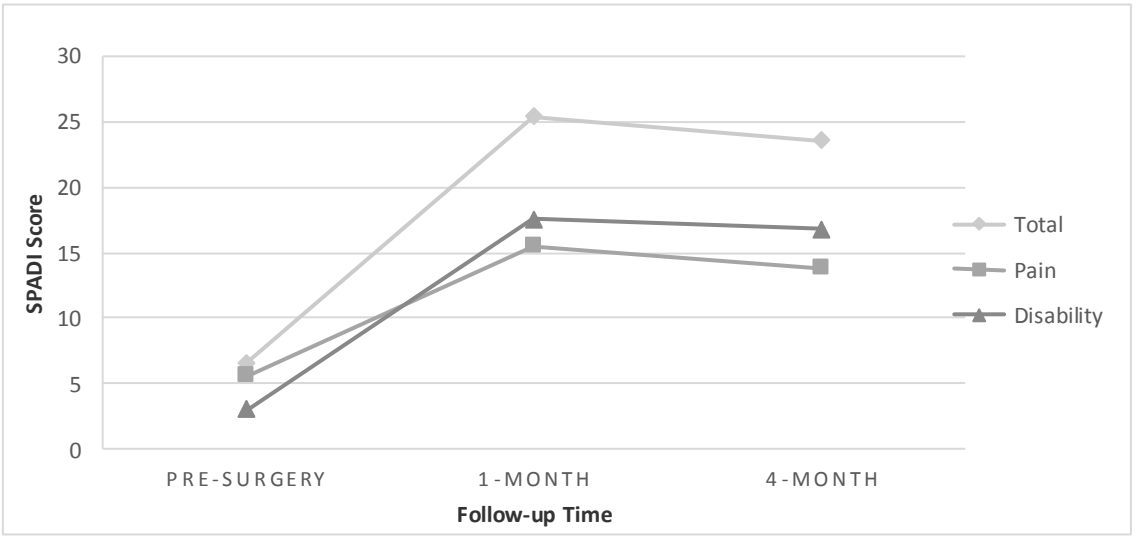

Figure 4.2 Shoulder Pain and Disability Index (SPADI) scores across all study time-points (SPADI score %) [n=12]

Table 4.6 Mean differences for *post hoc* time-point comparisons with significant SPADI and NDII scores

Patient-reported outcome questionnaires	Pre-surgery to 1-month	Pre-surgery to 4-months	1-month to 4-months
PCI-LOI[1]			
Physical & functional well being	29.1	26.2	-2.9
Social care & social well being	2.2	-3.1	-5.3
Psychological, emotional & spiritual well-being	11.1	5.3	-5.7
Treatment related	1.6	-0.9	-2.5
Total Score	44.0	27.5	16.5
SPADI[2] (%)			
Pain score	9.9	8.3	-1.7
Disability score	14.6	13.8	-0.8
Total score	18.9	17.0	-1.9
NDII[3] (%)			
Standardized score	-34.8	-27.9	6.9
UWQOL[4]			
Composite Score	-16.4	-7.7	8.7

[1] Patient Concerns Inventory- Level of Importance
[2]Shoulder Pain and Disability Index
[3] Neck Dissection Impairment Index
[4]University of Washington Quality of Life

Table 4.7 University of Washington Quality of Life Questionnaire (UWQOL) patient-reported top three concerns at three time-points for all patients (n = number of participant responses)

Rank	Concern (frequency)		
	Pre-surgery[1]	**1-month[2]**	**4-months[3]**
1	Pain / Anxiety (13)	Activity (10)	Pain (7)
2	Mood (8)	Shoulder (9)	Shoulder (6)
3	Appearance/Swallowing (6)	Pain (8)	Activity/Swallowing/Speech (5)

[1]n=58
[2]n=58
[3]n=40

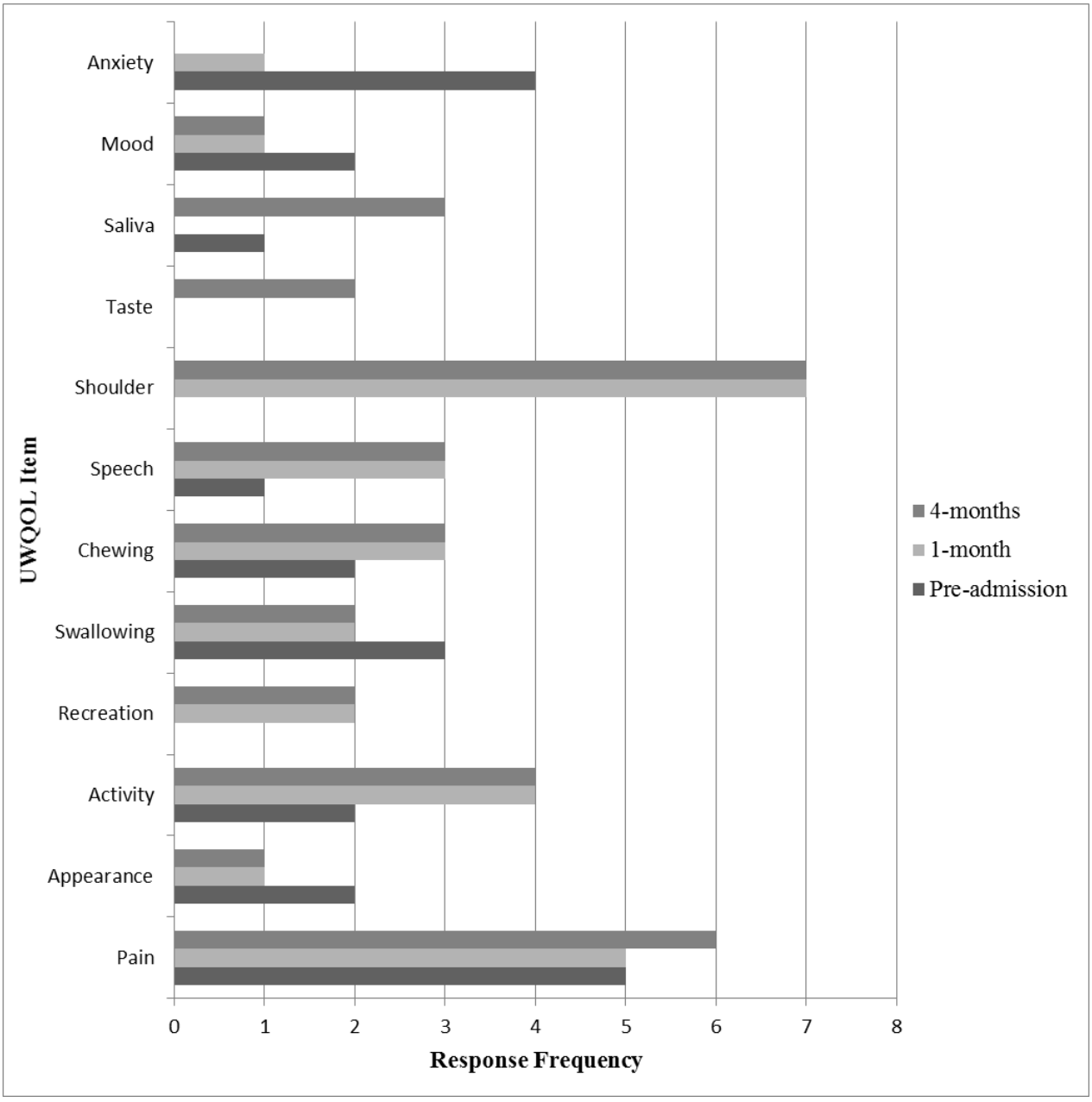

Figure 4.3 University of Washington Quality of Life Questionnaire (UWQOL) patient top three concern item response frequencies for all time-points (pre-surgery, 1-month, 4-months) [n=11]

Second Objective: To identify the changes in ROM and strength of the neck and shoulder areas over long-term follow-up (1-month & 4-months). The population was described using means and standard deviations for strength and ROM of both operated and non-operated arms for the eight individuals who completed all time-points (Table 4.8 & 4.9). The mean differences for participants (n=8) who completed all measures on both arms and across all three time-points are described in Table 4.10 & 4.11.

For shoulder flexion ROM, a significant two-way interaction effect between time and arm was identified [$F(2, 14) = 5.6$, $p < .017$, $\eta_p^2 = .443$], indicating significant change of the arm ROM flexion over the long-term follow-up.

Table 4.8 Mean and standard deviation for ROM measures at pre-surgery, 1-month and 4-months for eight participants with complete data (unit of measure= degrees).

	Pre-surgery				1-month post-surgery				4-month post-surgery			
Range of motion measure	**Operated side**		**Non-operated side**		**Operated side**		**Non-operated side**		**Operated side**		**Non-operated side**	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Shoulder Flexion	137.7	19.7	140.1	17.7	122.9	35.8	137.2	28.1	134.9	30.5	126.2	29.1
Shoulder external rotation	43.8	28.0	43.2	29.6	26.7	29.4	51.9	23.0	30.7	27.2	33.9	34.2
Neck lateral rotation[1]	62.4	11.6	67.2	15.1	54.2	22.8	47.3	19.7	47.8	18.2	45.1	21.5

[1] n=6

Table 4.9 Mean and standard deviation for strength measures at pre-surgery, 1-month and 4-months for eight participants with complete data (unit of measure =lb)

	Pre--surgery				1-month post-surgery				4-month post-surgery			
Strength measure	**Operated side**		**Non-operated side**		**Operated side**		**Non-operated side**		**Operated side**		**Non-operated side**	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Flexion	16.7	3.7	17.1	3.2	12.4	4.2	13.4	4.1	12.1	2.7	13.0	2.8
External rotation	19.7	5.7	20.9	7.3	16.3	7.2	18.0	4.5	19.1	8.5	18.2	4.7

Table 4.10 Mean differences for ROM measures for eight participants with complete data (unit of measure= degrees)

	Pre-surgery to 1-month		Pre-surgery to 4-months		1-month to 4-months	
Range of motion measure	**Operated side**	**Non-operated side**	**Operated side**	**Non-operated side**	**Operated side**	**Non-operated side**
Shoulder flexion	-14.8	-2.9	-2.8	-13.9	12.0	-11.0
Shoulder external rotation	-17.1	8.7	-13.1	-9.3	4.0	-18.0
Neck lateral rotation[1]	-8.2	-19.9	-14.6	-22.1	-6.4	-2.2

[1]n=6

Table 4.11 Mean differences for strength measures for eight participants with complete data (unit of measure=lb)

	Pre-surgery to 1-month		Pre-surgery to 4-months		1-month to 4-months	
Strength measure	**Operated side**	**Non-operated side**	**Operated side**	**Non-operated side**	**Operated side**	**Non-operated side**
Shoulder flexion	-4.3	-3.7	-4.6	-4.1	-0.3	-0.4
Shoulder external rotation	-3.4	-2.9	-0.6	-2.7	2.8	0.2

Chapter 5

5 Discussion

5.1 General discussion

In this study, we identify and describe the long-term effects of shoulder and neck mobility, strength, and QOL following procedural ND and identify the concerns of HNC patients. The study sought to identify the long-term patient outcomes from pre-surgery at the 1-month and 4-months' follow-ups. This study also measured the changes of patients' shoulder ROM and strength at all three time-points in order to examine long-term shoulder dysfunction post-surgery. In order to examine patient concerns and QOL, appropriate questionnaires (SPADI, UWQOL, NDII, PCI) were distributed and answered by each participant at pre-surgery and follow-up appointments. The study was expected to present findings that suggested patients QOL deteriorated post-surgery, as well as patients concerns increasing with regards to shoulder dysfunction and pain. Additionally, shoulder function and mobility were investigated by measuring ROM and strength using a digital inclinometer and dynamometer. The shoulder function/mobility was expected to deteriorate post-surgery.

The following sections discuss the results of the study in more detail, how the current findings compare to previous research, the significance of the results, limitations of the study and recommendations for future HNC research.

5.2 Patient-reported Outcomes

The main findings of the study were the identification of patient-reported outcomes on dysfunction and pain at pre-surgery, 1-month and 4-months' follow-up on the NDII and SPADI questionnaires.

For the NDII, total scores revealed significant change over time, suggesting changes in patient-reported outcomes on disability and neck pain. The NDII also yielded a decline in scores from pre-surgery to 1-month and pre-surgery to 4-months, suggesting a decline in QOL due to disability and neck pain from pre-admission to the follow-up times. However, there was no significant change found in the NDII scores from 1-month

to 4-months' follow-up. These findings indicate that patients self-rating of pain and disability affecting their QOL declines up to 1-month post-surgery, and continues to be perceived as low up to 4-months post-surgery.

To date, there have been few studies that have utilized the NDII scores to investigate overall neck impairment effects and QOL long-term post ND. In a recent study by Wang et al. (2016) describing the effects on QOL long-term, they found that the NDII score did initially decline in the early (1.4-months) follow-up post-surgery. With regards to long-term follow-up (18-months) they reported findings that support an increase in NDII scores similar to pre-surgery. This study supports our findings up to the 1-month mark with significant declines in NDII total score, however our study at 4-months post-surgery does not show any significant improvement in NDII score. It may be important to notice that the total NDII score does increase slightly, which could be an indication of potential to improve with more post-surgery time, as supported by the Wang and colleagues study at 18-months post-surgery. Additionally, it is of value to note that Wang and his colleagues' study was designed for patients who were diagnosed with HPV, underwent ND and were post-chemoradiation which could show results specific to this population of patients. In addition, the NDII was used by Guldiken et al. (2005) to assess long-term shoulder impairment after functional ND. This study reported high overall NDII scores at 18-months' post-surgery. Although this study supports high NDII scores it was specifically focused on individuals with bilateral ND (total laryngectomy, partial laryngectomy and glossectomy), which were excluded from our study. In addition, that study did not have pre-surgical NDII scores to compare long-term change. Due to the lack of studies performed, the long-term follow-up NDII score decline found in our study contribute to the general findings that describe the change in QOL due to neck and shoulder dysfunction in the HNC population.

Our results of the SPADI questionnaire revealed a significant change over time, indicating that the ND had changed the patient-reported shoulder pain and disability over follow-up. With regards to the two follow-up time-points, our results showed a large increase in patient-reported outcomes on the SPADI total score both at 1-month and 4-months follow-up, indicating more pain and disability post ND. However, there was no notable change between the two follow-up time-points suggesting that the pain and

disability perceived by patients is still reported as high. These findings suggest that the pain and disability due to shoulder complaints continues to be a problem for the HNC patient post ND up to 4-months after surgery. This trend was also consistent when looking at the scores separately for SPADI pain and SPADI disability. This indicates that both pain and disability are reported as high by patients suggesting ongoing pain and dysfunction of the shoulder post ND.

Several studies have demonstrated that the pain and disability score increases post ND surgery. A study by McNeely et al (2004) examined progressive resistance exercise training on shoulder dysfunction in HNC survivors 12 weeks' post ND surgery, where an increase in SPADI score was shown in the control group that did not undergo therapy. Most recently Lanisnik et al (2016) and colleagues confirmed similar results showing an increase in SPADI scores up to 6-months indicating further deterioration of symptoms (increased pain and disability). Selcuk et al (2008) performed a study investigating nerve sparing ND surgeries and their effects on shoulder function, where they utilized the SPADI questionnaire to confirm that shoulder function scores increased from pre-surgery to 6-months post-surgery when comparing two nerve sparing ND surgeries. It is important to note that although their SPADI score increased, the study used bilateral ND patients, which were excluded from our study. That study also looked at nerve sparing surgeries, which were included among all ND surgeries in our study. The increase in SPADI scores presented in our study supports these aforementioned studies, which provides support for determining the QOL of ND patients at long-term follow-up with regards to pain and dysfunction of their shoulders.

In addition, this study was able to provide information with regards to patients' top concerns at each time-point. From the UWQOL questionnaire, we were able to determine that at preadmission, "Pain" was a top concern. During follow-up, the results showed "Shoulder" to be the top concern at 1-month and 4-months follow-up. The study also revealed patients top three concerns over all time-points, where "Pain", "Activity" and "Shoulder" become concerns for the patients at all follow-up time-points, in variable order.

5.3 Additional Findings

The study looked at patient-reported outcomes as well as physical ROM and strength measures. Our results for the PCI-LOI showed no significant findings when it came to the total score or the subcategories of the questionnaire.

Additionally, there was a significant finding when it came to shoulder flexion ROM, indicating a change in the operated and non-operated arm over time. However, with further investigation no significant findings were found to suggest any clinical importance. With regards to the arm ROM and strength measures there were no significant findings that were observed in our study.

5.4 Importance of Findings / Relevance

The importance of determining QOL of HNC patients using the NDII and SPADI questionnaires is to describe how the patient population is being affected due to their surgery. The results of our study contribute knowledge that allows us to describe the QOL of patients post ND with regards to how shoulder dysfunction and pain have affected their QOL over long-term follow-up. The NDII allows us to contribute findings that suggest that patients are experiencing a decline in QOL post-surgery and is continuous up to 4-months post-surgery. The SPADI showed that the HNC population is experiencing pain and disability due to the shoulder, which is affecting their QOL up to 4-months post-surgery. The relevance of these findings suggests that patients may not be given post-surgical treatment or support for shoulder pain and dysfunction to improve QOL from the healthcare team. This is important to recognize, as patients have limited time with the surgeon during follow-up appointments where their concerns are being under-addressed. Knowing the general concerns and what the QOL of patients' is post ND surgery will allow for the development of a healthcare team that can provide treatment/support for these individuals immediately post-surgery.

This study identified the top three concerns of patients to be "Shoulder", "Pain" and "Activity", along with a decline in QOL due to shoulder pain and dysfunction, suggesting the shoulder to be a major issue long-term for patients. It is with these results that the addition of healthcare workers such as physiotherapists to the post-surgical healthcare team would allow for patients to address their concerns and allow therapists to

work with patients to improve QOL and their shoulder dysfunction. Deganello et al (2016) study showed acupuncture improved NDII scores and pain post ND. Physiotherapists have the qualifications to be trained in acupuncture and in other areas that have proven to improve pain and dysfunction of the HNC patients post ND. It is also of importance to recognize the time frame of which QOL declines as this is where intervention should take place in order to minimize the decline in QOL and address patient concerns right away.

5.5 Limitations

The study was able to identify patient-reported concerns and dysfunction with regards to their head and neck post ND. Although the research was able to provide some description, there were some unavoidable limitations. The first limitation to this study was the small sample size used in the analysis. Despite our best efforts, we had a large recruitment, which decreased dramatically as follow-up occurred. Therefore, it is important to note that with HNC research the sample size may decrease as follow-up occurs due to the nature of the disease, the patients, and their need for care. Patients that undergo the ND each have individualistic treatment plans post-surgery along with different rates of recovery. These reasons have impacted our study where some patients had different follow-up times requested by surgeons, resulting in missing measures for specified follow-up time in our study. Others had complications post-surgery and this resulted in patients not wanting to participate during follow-up. For future studies it may be of benefit to focus specifically on one surgery such as the SND. Due to the SND being more conservative than others and performed more frequently it could benefit the study where the follow-up treatment times are more consistent and the patients are likely to participate. Secondly, our research conducted in this study was done on a small sample size. A larger sample size may have allowed for the measures of our study to reflect the significance in shoulder dysfunction represented by the results of the patient-reported questionnaires. Therefore, the study should involve a larger participant sample in order to improve the significance of findings within the measures collected in the study. A larger sample size will allow for the findings to be generalized to the HNC population resulting in a more concrete description of the post-surgical population.

Thirdly, the study investigated shoulder mobility by using ROM (arm flexion, arm external rotation & neck rotation) and strength measures (arm flexion & external rotation). These findings were insignificant which may have been due to the small sample size used in the analysis. We did see decreases in both ROM and strength but they were non-significant. The measures chosen in the study present a limitation in itself that we did not use all possible shoulder movements to investigate shoulder dysfunction. The study did not measure ROM and strength for arm abduction, which could present important findings about shoulder dysfunction. When researching ND and the effects on shoulder dysfunction it is important to include any shoulder movement that would be affected by damage to the SAN with denervation of the trapezius muscle or damage to the brachial plexus.

5.6 Suggestions for Future Studies

The use of multiple measures to describe the HNC patients post ND have provided a guide to future research. Future studies should increase the initial sample size in order to overcome the loss of participants to allow for more patient information to be collected post ND surgery to describe its long-term effects. Additionally, it may be of benefit to include only ND that dissects the posterior triangle of the neck or those that are more conservative. This could help isolate the SAN and the dysfunction caused in the shoulder, as the SAN runs though ND levels II and V. Additionally, it could increase the number of follow-up participants due to consistency in follow-up treatment and time. Lastly studies should include ROM and strength for all arm motions including arm abduction to investigate shoulder dysfunction in HNC patients.

5.7 Conclusion

The results show that patients' concerns, QOL, shoulder and neck mobility following ND surgery for HNC patients are changing from pre-surgery to follow-up. They can be identified using patient-reported outcome questionnaires that address patient concerns, QOL, and shoulder pain and mobility. Our results showed that patient-reported pain and dysfunction increased post-surgery and remain an issue for up to 4-months. Additionally, our results showed that patients report a loss of QOL for up to 4-months post-surgery due to impairment of their neck. "Shoulder", "Pain" and "Activity" were

found to be the top three concerns reported by patients on the UWQOL over long-term follow-up.

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Appendix A- Ethics approval

Western Research

Research Ethics

Western University Health Science Research Ethics Board
HSREB Annual Continuing Ethics Approval Notice

Date: November 30, 2015
Principal Investigator: Dr. Bert Chesworth
Department & Institution: Schulich School of Medicine and Dentistry\Epidemiology & Biostatistics,Western University

Review Type: Expedited
HSREB File Number: 103096
Study Title: Patient Concerns Following Head and Neck Surgery for Cancer
Sponsor:

HSREB Renewal Due Date & HSREB Expiry Date:
Renewal Due -2016/09/30
Expiry Date -2016/10/29

The Western University Health Science Research Ethics Board (HSREB) has reviewed the Continuing Ethics Review (CER) Form and is re-issuing approval for the above noted study.

The Western University HSREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use Guideline for Good Clinical Practice (ICH E6 R1), the Ontario Freedom of Information and Protection of Privacy Act (FIPPA, 1990), the Ontario Personal Health Information Protection Act (PHIPA, 2004), Part 4 of the Natural Health Product Regulations, Health Canada Medical Device Regulations and Part C, Division 5, of the Food and Drug Regulations of Health Canada.

Members of the HSREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Appendix B- Letter of information and consent

Letter of Information

Research Study: Longitudinal Evaluation of Patient Concerns After Surgery for Head and Neck Cancer

Study Investigators: Bert Chesworth, PhD Associate Professor & Co-Supervisor School of Physical Therapy	Tom Overend, PhD Associate Professor & Co-Supervisor School of Physical Therapy
Co-Investigators: Cathy Anderson, PT, MSc Physiotherapist London Health Sciences Centre, 800 Commissioners Road East, London	John Yoo, MD Chief - Dept. of Otolaryngology Victoria Hospital, London Health Sciences Centre
Kevin Fung, MD Associate Professor Dept. of Otolaryngology Victoria Hospital, London Health Sciences Centre	Danielle MacNeil, MD Assistant Professor, Dept. of Otolaryngology Victoria Hospital, London Health Sciences Centre
Anthony Nichols, MD, Assistant Professor, Dept. of Otolaryngology Victoria Hospital, London Health Sciences Centre	Tara Keating, PT, BScPT Physiotherapist Victoria Hospital, London Health Sciences Centre.
Graduate Student Investigator Isabel Wozniczka, MSc (candidate) Graduate Program in Health and Rehabilitation Sciences, Western University	

Background Information and Purpose:
You are being invited to participate in a research study to determine the concerns of patients before and after the neck dissection surgery scheduled by your surgeon in the Otolaryngology Clinic at Victoria Hospital, London Health Sciences Centre. The purpose of this letter is to provide you with information that will allow you to make an informed decision about taking part in this study.

Details of the study:
We are asking you to participate because we wish to determine what your concerns are before and after the surgery. In addition we would like to know the effect of surgery on your shoulder and neck function by evaluating their mobility and strength, before and after surgery and during the course of your follow-up visits.

We are giving this letter of information only to people who are scheduled for neck dissection surgery at Victoria Hospital. If this situation does not apply to you, we would request you not to take part in this study.

This study is being conducted under the direct supervision of Dr. Bert Chesworth, who works at the School of Physical Therapy at Western University. He will supervise this study along with the following co-investigators: Dr. Tom Overend, Graduate supervisor, Associate Professor, School of Physical Therapy; Dr. John Yoo, Chief, Department of Otolaryngology, Victoria Hospital, London Health Sciences Centre; Dr. Kevin Fung, Associate Professor, Department of Otolaryngology, LHSC; Dr. Danielle McNeill, Assistant Professor, Department of Otolaryngology, LHSC; Dr. Anthony Nichols, LHSC, Assistant Professor, Department of Otolaryngology, LHSC; Cathy Anderson, Physiotherapist, LHSC; Tara Keating, Physiotherapist, LHSC; and Isabel Wozniczka, graduate student, Health and Rehabilitation Sciences program, Faculty of Health Sciences, Western University.

If you agree to participate in this study you will be initially contacted by a nurse or surgeon in the head and neck clinic at Victoria Hospital, LHSC. The nurse or surgeon in the head and neck clinic will introduce you to Isabel Wozniczka, our co-investigator, who will be collecting the information for this project. They will assist Isabel Wozniczka with the consent process for patients willing to volunteer for the study.

The data collection will start prior to your scheduled neck dissection surgery. Following the neck dissection surgery, data will be collected at 3 different time points.

- 3 to 4 weeks post-surgery prior to radiation treatment (data collected at the follow-up clinic visit)
- 3 months post-surgery after radiation treatment (data collected at the follow-up clinic visit)
- 6 months post-surgery (data collected at the follow-up clinic visit)

The study will include completion of the following questionnaires:
1. Patients Concerns Inventory (PCI)
2. Shoulder Pain And Disability Index (SPADI)
3. Neck Dissection Impairment Index (NDII)
4. University of Washington Quality of Life Scale

Isabel Wozniczka will also be evaluating your shoulder and neck mobility and your shoulder strength using the following instruments:
1. Shoulder Mobility – a device to measure the amount of arm movement
2. Neck Movements – a device to measure the amount of neck movement
3. Shoulder Strength – a device that measures force generated by arm muscles

Health records of participants will be accessed to determine details of the surgery.

Risk and Benefits:
You will not be placed at any risk or harm in this study. You are expected to have some stiffness and pain in the shoulder and neck areas caused by the surgery, and there might be some discomfort while completing the questionnaires or while Isabel Wozniczka measures the shoulder and neck movements and shoulder strength, but this is expected to be relatively mild and should abate quickly following the completion of the outcome measure tools.

There are no direct benefits to you due to your participation in the study but the results of the study can be helpful for future research and researchers. The results of the study will also help the clinical fraternity and patients in the future to have a better understanding about patients' concerns and surgical effects on their neck and shoulder function following surgery. Your participation in this project will not involve any additional costs to you, and you will not receive compensation for your participation.

Confidentiality:
Your confidentiality will be respected. Your name and chart number are collected so that your hospital chart can be retrieved to obtain the details of your surgery. Your year of birth is obtained to calculate your age, since age is considered to be an important aspect of shoulder and neck mobility and function. This information will always be kept in a locked cabinet once Isabel Wozniczka has completed collecting your data. No information that discloses your identity will be released or published, without your explicit consent to the disclosure. All records will be given a code number to be used on all data collection forms.

If the results of the study are published, your name will not be used and no information that discloses your identity will be released or published without your explicit consent to the disclosure. All of the information collected will be kept in locked filing cabinets and shredded after seven years.

Representatives of Western University's Health Sciences Research Ethics Board may contact you or require access to your study related records to monitor the conduct of the research.

Voluntary Nature of Study/Freedom to Withdraw or Participate:
Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions or withdraw from the study with no effect on your future care at any time while in hospital or within one month following the conclusion of your involvement with the study. You do not waive any legal rights by signing the consent form.

If you agree to participate in this project, please sign the attached consent form, complete the contact information requested and return it to the person who gave this letter to you. You may keep this letter of information. A copy of your signed consent form will be made for you.

If you have any questions about this study, please contact Dr. Bert Chesworth
or Isabel Wozniczka

Questions:
If you have any questions about your rights as a research participant or the conduct of the study you may contact Dr. David Hill, Scientific Director, Lawson Health Research Institute.

Please initial to confirm reading this page _____

Primary Investigator
Bert M. Chesworth
BA, BScPT, MClScPT, PhD
Associate Professor
Department of Physical Therapy
University of Western Ontario
London, Ontario

Consent Form

" Longitudinal Evaluation of Patient Concerns After Surgery for Head and Neck Cancer"

Principal Investigator:

Dr. Bert M. Chesworth, School of Physical Therapy, Western University

I have read the Letter of Information, have had the nature of the study explained to me and I have agreed to participate. All questions have been answered to my satisfaction.

Name of participant (Print)

Signature of participant

Date

Name of person obtaining consent (Print)

Signature of person obtaining consent

Date

Appendix C- Pre-surgical data collection form

Appendix C

Pre-surgical Data Collection Form

Longitudinal Evaluation of Patient Concerns After Surgery for Head and Neck Cancer

Study ID..... **Testing Date:.....**

Gender: ..... **Year of birth: .....**

Does the patient describe an affected/painful side? Yes:…….No…….....
If yes: Left…….....Right……..... Both…….....

Dominant Side: Left:…….....Right……..... Ambidextrous:…….....

Shoulder ROM	Left				Right		
	M1	M2	M3		M1	M2	M3
Flexion							
External Rotation							

Shoulder Strength	Left				Right		
	M1	M2	M3		M1	M2	M3
Flexion							
External Rotation							

Neck Rom	M1	M2	M3
Flexion			
Extension			
Rotation (L)			
Rotation (R)			

Appendix D- Post-surgical data collection form

Post-surgical Data Collection Form

Longitudinal Evaluation of
Patient Concerns After Surgery for Head and Neck Cancer

Study ID..... **Testing Date:.....**

Does the patient describe an affected/painful side? Yes:…….No……...
If yes: Left…….....Right……..... Both…….....

Measurement Occasion

3 to 4 weeks post surgery ☐ **3 months post surgery** ☐ **6 months post surgery** ☐

Is the patient on chemotherapy? Yes:…… No:……..
If yes: Start Date:…… End Date:…….

Is the patient on radiotherapy? Yes:……. No:…….
If yes: Start Date:…… End Date:…….

Shoulder ROM	Left				Right		
	M1	M2	M3		M1	M2	M3
Flexion							
External Rotation							

Shoulder Strength	Left				Right		
	M1	M2	M3		M1	M2	M3
Flexion							
External Rotation							

Neck Rom	M1	M2	M3
Rotation (L)			
Rotation (R)			

Appendix E- Surgical details data extraction form

Surgical Details Data Extraction Form

Longitudinal Evaluation of
Patient Concerns After Surgery for Head and Neck Cancer

Study ID..... **Extraction Date:.....**
Type of Surgery:…….....
Date of Surgery:…….....

Details of Surgery:

Appendix F-SPADI questionnaire

Appendix F

SPADI (SHOULDER)

Study Number _____ Date_____

Time point _____

For the questions below, please circle the number that best represents your experience during the last week attributable to your shoulder problem.

PAIN SCALE	
How severe is your pain: (Circle the number that best describes your pain)	
1. At its worst.	No pain 0 1 2 3 4 5 6 7 8 9 10 Worst Pain Imaginable
2. When lying on involved side.	No pain 0 1 2 3 4 5 6 7 8 9 10 Worst Pain Imaginable
3. Reaching for something on a high shelf.	No pain 0 1 2 3 4 5 6 7 8 9 10 Worst Pain Imaginable
4. Touching the back of your neck.	No pain 0 1 2 3 4 5 6 7 8 9 10 Worst Pain Imaginable
5. Pushing with the involved arm.	No pain 0 1 2 3 4 5 6 7 8 9 10 Worst Pain Imaginable
DISABILITY SCALE	
How much difficulty did you have: (Circle the number that best describes your experience)	
1. Washing your hair.	No difficulty 0 1 2 3 4 5 6 7 8 9 10 So difficult required help
2. Washing your back.	No difficulty 0 1 2 3 4 5 6 7 8 9 10 So difficult required help
3. Putting on an undershirt or pullover sweater.	No difficulty 0 1 2 3 4 5 6 7 8 9 10 So difficult required help
4. Putting on a shirt that buttons down the front.	No difficulty 0 1 2 3 4 5 6 7 8 9 10 So difficult required help
5. Putting on your pants.	No difficulty 0 1 2 3 4 5 6 7 8 9 10 So difficult required help
6. Placing an object on a high shelf.	No difficulty 0 1 2 3 4 5 6 7 8 9 10 So difficult required help
7. Carrying a heavy object of 10 pounds.	No difficulty 0 1 2 3 4 5 6 7 8 9 10 So difficult required help
8. Removing something from your back pocket.	No difficulty 0 1 2 3 4 5 6 7 8 9 10 So difficult required help

Appendix G- NDII questionnaire

Neck Dissection Impairment Index

Study Number _____ Date _____

Time point _____

As a result of the cancer **TREATMENT OF YOUR NECK**, how much have you been bothered by the following over the past **4 WEEKS**? (Circle appropriate response)

1. Are you bothered by the neck or shoulder **pain or discomfort**?

   Not at all a little bit a moderate amount quite a bit a lot

2. Are you bothered by neck or shoulders **stiffness**?
   Not at all a little bit a moderate amount quite a bit a lot

3. Are you bothered by difficulty with **self-care** activities because of your neck or shoulder (For example, combing hair, dressing bathing, etc)?

   Not at all a little bit a moderate amount quite a bit a lot

4. Have you been limited in your ability to **lift light** objects because of your shoulder or neck?

   Not at all a little bit a moderate amount quite a bit a lot

5. Have you been limited in your ability to **lift heavy** objects because of your shoulder or neck?

   Not at all a little bit a moderate amount quite a bit a lot

6. Have you been limited in your ability to **reach above** for objects because of your shoulder or neck (for example, from shelves, tables, or counters)?

   Not at all a little bit a moderate amount quite a bit a lot

7. Are you bothered by your **overall activity** level because of your shoulder or neck?

   Not at all a little bit a moderate amount quite a bit a lot

8. Has the treatment of your neck affected your participation in **social activities**?

   Not at all a little bit a moderate amount quite a bit a lot

9. Have you been limited in your ability to do **leisure or recreational activities** because of your neck and shoulder?

   Not at all a little bit a moderate amount quite a bit a lot

10. Have you been limited in your ability to do **work** (including **work** at home) because of your neck or shoulder?

    Not at all a little bit a moderate amount quite a bit a lot

Appendix H- PCI questionnaire

London Health Sciences Centre

Western UNIVERSITY · CANADA

Appendix H - Head & Neck Cancer

Patient Concerns Inventory – Level of Importance Rating

Study Number: _____ Date: _____

Time point: _____ Version 01-May-2014

We would like to know what is important to you with respect to undergoing Neck Dissection Surgery.
Please indicate how important the following items are to you 'during the last week'.
For each item, please tick the box ☑ that indicates how important the issue is to you.

PHYSICAL & FUNCTIONAL WELL-BEING:	LEVEL OF IMPORTANCE						
Concerns	None 1	Very Small 2	Small 3	Moderate 4	Fairly Great 5	Great 6	Very Great 7
Appetite							
Arm / hand							
Bowel habits							
Breathing							
Chewing / eating							
Coughing							
Dental health / teeth							
Dry mouth							
Energy levels							
Fatigue/tiredness							
Hearing							
Indigestion							
Mobility							
Mouth opening							
Mucus							
Nausea							
Pain in the head / headache							
Pain in the neck							
Pain elsewhere							
Regurgitation							
Salivation							
Shoulder							
Sleeping							
Smell							
Sore mouth							
Swallowing							
Swelling							
Taste							
Vomiting / sickness							
Weight							

More next page ➔

SOCIAL CARE & SOCIAL WELL-BEING:	LEVEL OF IMPORTANCE						
Concerns	None 1	Very Small 2	Small 3	Moderate 4	Fairly Great 5	Great 6	Very Great 7
Home care							
Lifestyle issues (smoking / alcohol)							
Money							
Recreational activities or hobbies							
Relationships							
Speech / voice / being understood							
Support for my family or friends helping with my care							
Well-being of my dependents / children							
Well-being of my spouse / partner							

PSYCHOLOGICAL, EMOTIONAL & SPIRITUAL WELL-BEING:	LEVEL OF IMPORTANCE						
Concerns	None 1	Very Small 2	Small 3	Moderate 4	Fairly Great 5	Great 6	Very Great 7
Appearance							
Anger							
Anxiety							
Coping							
Depression							
Fear of the cancer coming back							
Fear of medical or surgical complications							
Intimacy in relationships							
Memory							
Mood							
Self-esteem							
Sexuality							
Spiritual / religious aspects							
Personality & temperament							

More next page ➔

TREATMENT RELATED:	LEVEL OF IMPORTANCE						
Concerns	None 1	Very Small 2	Small 3	Moderate 4	Fairly Great 5	Great 6	Very Great 7
Feeding tube							
Wound healing							

OTHER CONCERNS: (*Please indicate below*)

Have we missed anything?

Please indicate in your own words anything else that is important to you; but was not covered in the above sections

	LEVEL OF IMPORTANCE						
Other Concerns	None 1	Very Small 2	Small 3	Moderate 4	Fairly Great 5	Great 6	Very Great 7

TOP 3 CONCERNS: (Please indicate below)

In the space provided below, using your own words, please tell us your TOP 3 CONCERNS in the past week

Thank you for taking the time to complete this questionnaire.
Your assistance in providing this information is very much appreciated.

Appendix I: UWQOL questionnaire

Study Number_____ Date_____
Time Point_____

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

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

1. Pain. (Check one box: O)

   D I *have* no pain.
   D There is mild pain not needing medication.
   o I *have* moderate pain - requires regular medication (codeine or nonnarcotic).
   D I *have* severe pain controlled only by narcotics.
   o I *have* severe pain, not controlled by medication.

2. Appearance. (Check one box: 0)

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

3. Activity. (Check one box: O)

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

4. Recreation. (Check one box: 0)

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

5. Swallowing. (Check one box: O)

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

6. Chewing. (Check one box: O)

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

7. Speech (Check 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. (Check 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. I cannot work due to problems with my shoulder.

9. Taste. (Check 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. (Check 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. (Check 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. (Check 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?
Chec up to 3 boxes.

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

GENERAL QUESTIONS

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

- Outstanding
- Very good
- Good
- Fair
- Poor
- Very poor

Please describe any other issues (medical or nonmedical) that are important to your quality of life and have not been adequately addressed by our questions (you may attach additional sheets if needed).

Curriculum Vitae

Name: Isabel Wozniczka

Post-secondary Education and Degrees:
York University
Toronto, Ontario, Canada
2009-2014 B.Sc.

Honours and Awards:
Western Graduate Research Scholarship
2014-2015, 2015-2016

Related Work Experience:
Teaching Assistant
School of Physical Therapy
Western University
London, Ontario, Canada
Fall/Winter 2014-2015, 2015-2016

Anatomy Laboratory Assistant
York University
Toronto, Ontario, Canada
2013-2014

Physiotherapy Assistant- Volunteer
Institute of Sports Medicine and Wellness Center
Toronto, Ontario, Canada
2012-2014

Physiotherapy Assistant – Volunteer
No Boundaries Physiotherapy Clinic
Toronto, Ontario, Canada
2013

Acquired Brain Injury Rehabilitation Unit Volunteer
Toronto Rehabilitation Institute
Toronto, Ontario, Canada
2013-2014

Oral Presentations:

Wozniczka, I. (March 2015). *Osteoporosis and water exercise*. Presented at the 3 Minute Thesis (3MT) research communication competition, London, Canada.

Wozniczka, I. (February 2015). *The effects of water exercise on osteoporosis*. Presented at the 8th annual Health and Rehabilitation Science Conference, London, Canada.

Lectures:

" *Osteoporosis*" Physical therapy in community setting course (PT9524)- School of Physical Therapy, Western University, London, Ontario. March, 2016.