MEASURING MULTI-DIMENSIONAL WELLNESS AFTER TOTAL LARYNGECTOMY AMONG PEOPLE YOUNGER THAN 55 YEARS OF AGE

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ABSTRACT

This study described how younger adults' (i.e., <55 years of age) wellness outcomes are impacted after having a total laryngectomy (TL) and assessed the relationship between wellness and communication participation. A survey was distributed to individuals with head and neck cancer (HNC) via online Facebook support groups, professional contacts, and vendor newsletters. This survey included the Five Factor Wellness Inventory (FFWEL) to measure participants comprehensive wellbeing and the Communication Participation Item Bank (CPIB). Younger laryngectomees' total wellness scores were statistically compared to that of the normative FFWEL sample and to older laryngectomee participants (i.e. ≥ 65 years of age). A Pearson correlation coefficient was calculated to assess the relationship between wellness and communication participation. Results indicated that younger laryngectomees had significantly lower wellness characteristics as measured by the FFWEL than the normative population sample. Additionally, older laryngectomees had significantly lower wellness outcomes for most wellness characteristics than younger laryngectomees. Finally, communication participation for younger laryngectomees was significantly associated with a subset of wellness factors although explanations for some of the relationships were not always apparent. In conclusion, increased comprehensive wellness support is imperative for both younger and older individuals post TL.

To my aunt Lisa, for showing me how to lead with love and strength instead of fear and for all the advice you have given me along the way.

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TABLE OF CONTENTS

CHAPTER 1: LITERATURE REVIEW 1

CHAPTER 2: METHODS 32

CHAPTER 3: RESULTS 38

CHAPTER 4: DISCUSSION 56

BIBLIOGRAPHY 68

APPENDIX A: MEDICAL HISTORY AND COMMUNICATION MODALITY SURVEY 77

APPENDIX B: COMMUNICATION PARTICIPATION ITEM BANK – GENERAL SHORT FORM 79

APPENDIX C: DESCRIPTIVE STATISTICS REGARDING PARTICIPANT DEMOGRAPHICS AND MEDICAL HISTORY 80

APPENDIX D: FIVE FACTOR WELLNESS INVENTORY (FFWEL) STATISTICAL RESULTS FOR YOUNGER AND OLDER ADULTS WITH A TOTAL LARYNGECTOMY 83

APPENDIX E: COMMUNICATION PARTICIPATION ITEM BANK (CPIB) STATISTICAL RESULTS FOR YOUNGER ADULTS 84

CHAPTER 1: LITERATURE REVIEW

A total laryngectomy (TL) can be a lifesaving procedure for individuals diagnosed with advanced laryngeal cancer, but it usually results in a significant decrease to one's quality of life (QoL) and wellbeing. As defined by the World Health Organization (WHO) QoL is, "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (WHO, 2022). QoL is envisioned to be a measurement of health: a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity (World Health Organization, 2006). Taking a broader perspective, the concept of wellness or wellbeing is defined by the WHO to be the optimal state of health and the highest form of a persons' or groups' physical, psychological, social, spiritual, and economical being, including fulfilment of ones' expectations in family, community, place of worship, workplace, and other settings.

The long-term wellness of people with a laryngectomy, otherwise known as laryngectomees[1], may be overlooked by physicians and clinicians who are often focused on treating the cancer at all costs and managing communication and swallowing impairments. Existing literature indicates that after receiving a TL several areas of an individuals' life are severely compromised as they must adjust to losing their voice (Costa et al., 2018; Ferrer Ramírez et al., 2003; Summers, 2017). Although the impact of a TL is likely to be substantial regardless of a person's age, an inverse relationship between age and a global QoL measure designed for people with head and neck cancer (HNC) has been reported (Palmer & Graham, 2004). However, overall wellness among laryngectomees, particularly those who are younger

[1] The term laryngectomees is used in this thesis to reference individuals who have had a total laryngectomy. That is, laryngectomee refers to the person who has had a laryngectomy. Laryngectomy is the surgical procedure. While laryngectomee is not person first language, it is the current preferred term chosen by most of this population.

than the typical person undergoing TL, has been understudied. It is the case that the average age for a TL has decreased in recent years while long term survival has increased. This means that some people with a TL are at a different stage of life, perhaps with active careers and different family roles, all of which might impact their sense of wellness. The relationship between a laryngectomee's ability to communicate in daily life situations and their overall wellness has also not been addressed. To date no study has attempted to focus on the unique wellness challenges that younger laryngectomees face by having a TL earlier in life.

This thesis focused on describing wellness and assessing the strength of the relationship between communication ability and wellness in laryngectomees < 55 years of age (i.e., younger laryngectomees). The literature review below first provides an overview of laryngeal cancer and the TL surgical procedure. Next, the common communication options used by laryngectomees are discussed, followed by an overview of models of wellness. Lastly, the potential implications of TL on younger adults are reviewed.

Laryngeal Cancer

Laryngeal cancer is a type of cellular malignancy that originates in the tissues of the larynx (Steuer et al., 2017). Because laryngeal cancer accounts for a third of all HNC, efforts to improve the quality of care for individuals with this malignancy are crucial (Mourad et al., 2017). Over the past three decades, the incidence of laryngeal cancer has increased by 12%, resulting in 12,620 new cases in 2021 within the United States alone (Nocini et al., 2020; PDQ Adult Treatment Editorial Board, 2021). However, mortality rates have declined by 5% in the U.S. with approximately 3,770 deaths a year (Nocini et al., 2020; PDQ Adult Treatment Editorial Board, 2021). While all individuals can develop laryngeal cancer, it primarily affects older adults with the average age of diagnosis being 65 years (Koroulakis & Agarwal, 2022). Among those

diagnosed, a higher prevalence is seen in males over females and among black individuals over white (Mourad et al., 2017).

Hoarseness of the voice and difficulty swallowing are often reported as initial symptoms of laryngeal cancer, followed by sore throat, cough, and otalgia (American Cancer Society, 2019). In severe cases, effects of the disease can be seen across the body including weight loss, difficulty breathing, hemoptysis, dysphagia, and aspiration. Koroulakis & Agarwal (2022) reported that smoking is the most significant risk factor for laryngeal cancer, attributing to 70% to 95% of diagnoses. Heavy alcohol consumption is also a significant risk factor for developing cancer of the larynx. Other possible risk factors include diets high in fat and low in green vegetables, human papillomavirus infection (HPV), advanced age, and exposure to gasoline fumes, paint, asbestos, and radiation (Mourad et al., 2017).

Staging & Evaluation of Laryngeal Cancer

For diagnostic purposes, the larynx is anatomically divided into three distinct sections in which cancer can occur. As reported by Steuer et al. (2017), the supraglottic larynx region is comprised of the laryngeal structures above the true vocal folds and includes the epiglottis, ventricular folds (false vocal folds), ventricles, aryepiglottic folds, and arytenoids. The glottis region consists of the true vocal folds and anterior and posterior commissures. The final division is the subglottic region which is comprised of the space between the glottis and inferior segment of the cricoid cartilage. Approximately two thirds of laryngeal cancers arise in the glottic region, followed by 30% originating in the supraglottic region, and very few cases occurring in the subglottic area (Markou et al., 2013). According to Nocini et al. (2020), 98% of laryngeal cancers are squamous cell cancers, with only a minority of cases being attributed to chondrosarcomas, leiomyosarcomas, and melanomas.

The staging system created by the American Joint Committee on Cancer is the most commonly used tool for describing the extent of laryngeal cancer prior to treatment (PDQ Adult Treatment Editorial Board, 2021). The staging system is based on three main elements: extent of the tumor (T), spread of cancer to lymph nodes (N), and metastasis (M) of cancer. In addition, each diagnosis is given a number I through IV, with IV indicating the most severe cases. One's clinical stage of laryngeal cancer is based on outcomes of several evaluations, imaging tests, and biopsies (Koroulakis & Agarwal, 2022).

Diagnosis of Laryngeal Cancer

Diagnosis of laryngeal cancer typically includes a range of assessments. A physical examination is initially performed to assess the extent and size of the tumor, the involvement of nearby structures, and to measure the impact on the vocal folds (Forastiere et al., 2018). An indirect laryngoscopy, mirror exam, fiberoptic endoscopy, and neck evaluation are often utilized in this initial examination (Koroulakis & Agarwal, 2022). A biopsy of the malignant tissue can be collected through a direct laryngoscopy of the main tumor, or through a fine-needle aspiration of an infected nodule (Dziegielewski et al., 2018). A contrast-enhanced computed tomography (CT) of the neck should be performed on tumors of all stages, and if the lesion is suspected to invade the hypopharynx an esophagogastroduodenoscopy (EGD) or barium swallow should be conducted (Forastiere et al., 2018). When conducting these assessments, vocal fold mobility, presence of distant metastatic lesions, involvement of the tongue base, thyroid cartilage, esophagus, or neck lymph nodes, and infiltration of the soft laryngeal tissue and muscles may be considered, among other outcomes (Koroulakis & Agarwal, 2022).

Treatment of Laryngeal Cancer

As reported in Steuer et al. (2017), the current five-year survival in treatable laryngeal cancer patients is 50% for supraglottic cancers and 80% for glottic cancers. Recent advances in laryngeal cancer treatment have led to greater use of organ preservation approaches that use chemoradiation as the primary cancer treatment instead of more invasive surgical options (Ruytenberg et al., 2018). Successful treatment of early-stage cases can typically be accomplished through a single course of direct radiation therapy or simple surgery (Koroulakis and Agarwal, 2022). Specifically in early T1-2N0 glottic cancer, local radiation or voice sparing surgery that does not remove the vocal folds is often an option. However, a TL is required in approximately 10% of T1 and 55% of T2 cases. Partial laryngectomy, laryngoscopic, and transoral laser excision have also been used to successfully treat glottic cancer (Ruytenberg et al., 2018). Similarly, early T1-2N0 supraglottic cancer can often be treated through the same methods, with the primary difference being concern for nodal metastases. Typical surgical approaches for T1-2 and low-volume T3 tumors include endoscopic resection and partial supraglottic laryngectomy, and neck dissection is often conducted in T2 and T3 tumors (Forastiere et al., 2018). In addition, adjuvant and definitive radiation therapy is often given to individuals with indicators of positive nodal disease, extracapsular extension, positive margins if surgery is used, or patients at-risk of cervical nodal stations (Yamazaki et al., 2017).

In contrast, locally advanced laryngeal cancers, such as T3-4N1-3, require more extensive, mixed treatment (Dziegielewski et al., 2018), up to and including complete removal of the larynx (i.e., total laryngectomy). Laryngeal preservation surgery occurs less frequently among severe cases, though definitive radiation combined with cisplatin chemotherapy is an effective option on occasion (Yamazaki et al., 2017). Typical treatment for advanced disease

includes conjoint chemotherapy and radiation as well as laryngectomy and adjuvant radiation therapy (Rosenthal et al., 2015).

Total Laryngectomy

A TL is a surgical procedure to remove the larynx (Hoffmann, 2021). This approach dates back to 1873 and has been long used as a method for treating individuals who have advanced hypopharyngeal and laryngeal cancer without significant metastases (Kramp & Dommerich, 2009). The primary target of this surgery is to control the spread of cancer and, secondarily, to preserve swallowing and speech functions (Andaloro & Widrich, 2021).

Who Receives a Total Laryngectomy

Advanced laryngeal and hypopharyngeal cancer, particularly T4a carcinoma, is the most common etiology that results in a TL (Petersen et al., 2018). In these advanced cases, a partial resection surgery cannot remove the primary tumor site entirely, and radiation and chemotherapy alone are typically not sufficient as an initial treatment (Haerle et al., 2011). Less commonly, a TL may be performed when there is severe laryngeal trauma that cannot be reconstructed, severe and chronic aspiration caused by palsy of cranial nerves, severe recurrent laryngeal papillomatosis, or complications after a partial resection of the larynx (Hoffmann, 2021). The recommendation to receive a TL is carefully determined by an interdisciplinary treatment team, and many physiological, anatomical, geographic, and occupational factors are involved. During treatment deliberation, Andaloro & Widrich (2021) stated that the most influential factors about the decision to do a TL are size and location of the tumor and state of the regional lymph nodes. Possible contraindications for a TL are incurable simultaneous tumors, advanced metastases, conditions that lead to high anesthetic risk, tumors surrounding the common or internal carotid artery, and tumors that metastasize to major tongue regions (Andaloro & Widrich, 2021).

Grover et. al. (2015) reported that approximately 36% of individuals who have T4a laryngeal cancer receive a TL, with the remaining 64% receiving larynx preservation chemoradiation. Despite these statistics, their research shows that individuals with advanced laryngeal cancer who receive larynx preservation treatment have significantly worse survival rates than those treated with a TL. This evidence also shows that the median survival rate for individuals with T4a laryngeal cancer who receive chemoradiation is 39 months compared to 61 months for those who receive a TL. Following the sex gap for laryngeal cancer cases, men are much more likely to receive a TL than women, and the average age of the procedure is approximately 63.4 years (Akil et al., 2017)

Total Laryngectomy Surgical Procedure Overview

A TL involves first making a U-shaped incision over the suprasternal notch, and the skin around the incision site is pulled forward (Hoffmann, 2021; Vahl & Hoffmann, 2019). Depending on if lymph nodes are involved, a neck dissection can be performed to remove some or all of the lymph nodes in the region. A neck dissection requires a larger U-shaped incision that runs approximately from one ear, down to the suprasternal notch, and up to the other ear which allows a large skin flap to be raised so the nodes throughout the neck and jaw can be accessed. The infrahyoid and suprahyoid muscles are then dissected, and the hyoid bone may be entirely removed if diseased. The laryngeal skeleton is then dissected from the pharynx (Hoffmann, 2021). This includes removal of the epiglottis, arytenoids, cricoid, and thyroid cartilages as well as all intrinsic laryngeal muscles and mucosa. In order to ensure adequate space for the swallowing tract to be maintained, the muscles of the upper esophageal sphincter and the inferior pharyngeal constrictor muscles are methodically preserved to the extent possible to allow reconstruction of a replacement for the upper esophageal sphincter called the

pharyngoesophageal (PE) segment (Agrawal & Goldenberg, 2008). At this point, a surgical fistula can be created in the common wall between the trachea and esophagus with insertion of a speaking valve if tracheoesophageal voice is desired. The muscles of the base of the tongue, the pharyngeal walls, and the upper esophagus are sutured together in a manner that creates the neopharynx ("new pharynx").

When closing the incision site, the various layers of pharynx and surrounding muscles must be sutured with care to minimize the risk of complications (Alicandri-Ciufelli et al., 2013). Skin around the incision is reconnected in layers with suction drains used to remove excess fluid around the surgical site (Hoffmann, 2021). During the surgical closure the trachea is turned out toward the front of the body and the neck flaps (elevated skin and muscle) are sutured to it in such a way that a permanent hole is created at the base of the neck. This hole is called the tracheostoma and is the only route of air passage into the lungs. In this manner, the upper airway is now completely separated from the lower airway. The entirety of this procedure can typically be completed in five to twelve hours (Andaloro & Widrich, 2021).

Communication Methods after a Total Laryngectomy

Primary Alaryngeal Communication Methods

As a result of a TL, laryngectomees lose the ability to verbally communicate when their vocal folds are removed (van Sluis et al., 2018). To compensate for this loss, three primary types of alaryngeal speech are utilized to allow individuals to orally communicate: esophageal speech (ES), tracheoesophageal speech (TES), and electrolarynx speech (ELS) (van Sluis et al., 2018). Each of these methods involves establishing a new vibratory source to create the voice. In ES, this new voice source is the PE segment, a narrowing that is created at the top of the esophagus when the surgeon closes the pharyngeal and esophageal region of the surgical field. The PE

segment essentially serves as the new upper esophageal sphincter that must open to allow food, liquid, and saliva to pass into the esophagus, and then close to prevent reflux of materials back up into the throat. This tissue can be set into vibration to create a voice. To do so, a person insufflates the esophagus – pressing or drawing air from the mouth, nose, and or throat past the PE segment and into the esophagus. This esophageal air is then volitionally returned up through the PE segment, setting it into vibration (Knollhoff et al., 2021; van Sluis et al., 2018). The sound created by the PE vibration is then altered by movements of the lips, jaw, and tongue to produce speech (van Sluis et al., 2018). With training, individuals using ES can control the pitch, rate, and volume of their speech to varying degrees (Kaye et al., 2017). Some potential limitations of this method include the long length of training required and the status of the PE segment itself which may be compromised due to surgery or radiation to the point it cannot vibrate (Knollhoff et al., 2021).

Similar to ES, TES also uses the PE segment as the new voice source (van Sluis et al., 2018). In TES, a fistula (i.e., puncture) is surgically created through the wall of tissue that separates the trachea and the esophagus. A one-way silicon valve called a TE voice prosthesis is placed in the fistula (Knollhoff et al., 2021). To create voice, a person inhales air through their tracheostoma, then occludes the stoma with their thumb (or with a special one-way valve) as they exhale; with the stoma occluded, the expiratory air is diverted through the voice prosthesis into the upper esophagus (Dwivedi et al., 2010). The esophageal air can then pass up through the PE segment, setting it into vibration, creating a voice that can be shaped into sounds and words by movement of the articulators. While TES is commonly used post-TL, there are some negatives including the need for an additional surgery (if not done at the time of TL), expenses associated

with purchasing voice prostheses and visiting an SLP to remove and replace worn out devices, and the possibility of a compromised PE segment (Staffieri et al., 2006).

Unlike the previous two alaryngeal communication methods, ELS utilizes an external sound source created by an electrolarynx. The electrolarynx is typically a handheld device that is held against one's cheek or neck (van Sluis et al., 2018). When activated by pushing a button, a small piston inside the device moves to strike a plastic disc resulting in sound generation. This artificially generated vibration is transmitted from the head of the electrolarynx against the neck or cheek, through the tissues of the body, subsequently setting into vibration the air that is sitting passively within the mouth and throat. Movements of the articulators can then shape the vibration into speech sound production. As with the other two options, ELS can serve as a functional voice source although it does have drawbacks such as the mechanical nature of the voice, the need to use a hand during talking in most instances, challenges in manipulation of voice pitch and loudness, and ongoing maintenance of the device itself (Knollhoff et al., 2021).

Secondary Alaryngeal Communication Methods

In addition to the primary alaryngeal oral speech options, there are other communication modalities that can be utilized after a TL. One approach that is becoming more commonly used are augmentative and alternative communication (AAC) devices. AAC methods include unaided modes of communication such as gestures, signs, or facial expressions, and aided modes such as communication boards and tablet devices and phone applications with voice output (Light et al., 2019). Because of the range of AAC possibilities with varying levels of complexity and features, this approach can be used as an efficient enhancement of communication after a TL (Repova et al., 2021). Specifically, Repova et.al. (2021) found that the AAC methods of voice banking and

personalized speech synthesis are particularly beneficial for individuals who may be struggling with alaryngeal speech after a TL.

A pneumatic artificial larynx (PAL) is another noninvasive communication option available after a TL. The PAL is an external device consisting of a small funnel that can be placed over the stoma to capture exhaled air, a reed or membrane over which the exhaled air passes, and a tube from the reed/membrane housing to the mouth that transmits the vibration that is created (Xu et al., 2009). In this manner, a person uses their own exhaled air to vibrate an artificial voice source outside the body, and the created sound is then diverted back into the mouth where the articulators can move to create speech sounds (Terada et al., 2007). Recent studies by Xu et. al. (2009) found that 96% of PAL users achieve successful speech capabilities and high levels of fluent and intelligible speech. PALs are relatively inexpensive and simple to use but have limits including the need to use at least one hand to manage the device when talking.

In addition to the several technological communication options, basic writing and mouthed speech are also sometimes used. While it may be time consuming, Happ et. al. (2005) found writing with a pen and paper is used 31% of the time as the primary method of communication despite having access to speech generating devices. Mouthed speech and lip reading are less researched but highly reported methods of communication used among laryngectomees, most often as an adjunct to one of the primary methods of alaryngeal communication. This approach includes individuals moving their lips as if speaking but without creating a sound, and receivers decoding messages based solely on visual and environmental contextual information (Bourguignon et al., 2020). Based on recent studies, Bourguignon et. al.

(2020) reports that lip reading is a critical method for understanding one's speech in situations when expressive communication is compromised.

Alaryngeal Communication Participation Post Total Laryngectomy

While each alaryngeal communication method offers a unique approach, all can serve as functional communication options post TL. The value of these approaches is highlighted by Clements et al. (1997) who found that laryngectomees that do not develop alaryngeal speech have the poorest communication, satisfaction, and QoL outcomes. However, evidence supports that despite their advantages, alaryngeal communication modalities still significantly differ from typical laryngeal voice and speech in essentially all regards. Differences among alaryngeal communication include reduced speech intelligibility and naturalness, limitations to pitch and loudness, and imprecise articulation (Knollhoff et al., 2021). These communication difficulties can be a major challenge for laryngectomees, especially within the first few months after a TL. Regardless of alaryngeal communication options, List et al. (1996) found that around 40% of laryngectomees experience significant communication limitations six months after their TL and often use writing as their primary method of communication. This is often due to the difficulty of acquiring the skill set the alaryngeal methods require.

The combination of these alaryngeal communication difficulties can reduce laryngectomees' ability to participate in daily events, negatively impacting individuals' QoL and social wellbeing (Eadie et al., 2016). Research to investigate factors associated with communication post TL by Dahl et al. (2022) found that reduced communication participation was associated with characteristics such as younger age at time of laryngectomy, poorer self-rated health, depressive symptoms, worse QoL, and limited social networks. Similarly, findings by Sharpe et al. (2019) reported that regardless of the methods of communication used,

laryngectomees reported negative changes to their communication abilities and decreased QoL after a TL. Limitations to communication capabilities is an important measure as strong, significant relationships have been found between communication participation and self-rated speech acceptability and voice handicap (Eadie et al., 2016).

Wellness

When providing treatment for people with chronic diseases, such as laryngeal cancer, the World Health Organization (WHO) and professional medical organizations emphasize the value of a holistic, comprehensive care approach that addresses all aspects of an individual's wellness. The concept of wellness as applied to laryngectomees was the central focus of this study with particular interest in learning the extent to which a person's ability to participate in daily communication relates to their wellness. As clinicians, SLPs are often focused on addressing the communication deficits of laryngectomees at the level of their impairments and disabilities, e.g., re-establishing a new voice source. In the last 15 – 20 years, a more concerted emphasis has been placed on addressing the laryngectomee in terms of their life participation (Eadie et al., 2016; Palmer & Graham, 2004). Attempts to focus on life participation have resulted in an emphasis on QoL and tools to track QoL, particularly voice related QoL. However, broader issues of wellness of laryngectomees that go beyond voice related quality of life remain understudied. In particular, there is limited information in the peer-reviewed literature regarding the relationship between one's ability to communicate after TL and their overall wellness. If there is a strong relationship and specific linkages between communication and certain aspects of wellness, therapeutic approaches that help bolster communication or other aspects of living as a laryngectomee can be emphasized.

In the sections below, the definition of wellness is explored. In doing so, related and overlapping constructs including QoL and health are also considered. The section concludes with

the presentation of three distinct approaches for measuring wellness, ranging from an individual to a national perspective.

Definitions of Wellness and Relationship to Other Constructs

The WHO defines wellness as the optimal state of health – the highest form of a person's or group's physical, psychological, social, spiritual, and economical being, including fulfilment of one's expectations in family, community, place of worship, workplace, and other settings (World Health Organization, 2006). The synonymous term "wellbeing" is often also used to describe this construct throughout literature. While the WHO definition of wellness is widely and internationally accepted, it is important to note that wellness or wellbeing can be defined in several ways depending on the perspective taken. For example, population-level wellness is a non-individualistic measure of wellbeing that considers the physical, emotional, and social health of a population by considering factors such as affordability of food, housing, and healthcare, safety of neighborhoods, and work environments of a population (Arora et al., 2016). Additionally, community-level wellness aims to measure similar factors within a certain defined group or segment of a population. As this report considers wellbeing on the individual level of a single laryngectomee, the WHO definition of wellness will be used.

A central component of overall wellbeing is health, which is described by the WHO to be, "a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity" (WHO, 2022). Based on this understanding of health, simply treating the physical body without considering how components such as mental and social health may be impacted by a disease or its treatment will not lead to improvements in total wellbeing. According to the WHO, attaining the highest standard of health is a fundamental right of all human beings without distinction of race, religion, economic, social condition, or political belief

(WHO, 2022). Therefore, it is critical that clinicians working with laryngectomees are aware of all areas of health and wellbeing to ensure individuals are treated with the highest level of care.

The concept of QoL has been well explored in TL related research and literature (Costa et al., 2018; Ferrer Ramírez et al., 2003; Summers, 2017). As defined by the WHO, QoL is, "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns" (WHO, 2022). When comparing QoL to wellness, it is evident that QoL is a somewhat narrower and fully subjective measurement of one's perspective of their health. This differs from wellness which aims to capture a broader representation of comprehensive health beyond perception and incorporates several additional health components, such as mental, social, spiritual, and occupational health, that are not routinely included in definitions of QoL. This distinction illustrates the importance of the present study as limited to no research that measures all areas of wellness among TL laryngectomees currently exists. Figure 1 below offers a visual representation of how the concepts of wellness, health, and QoL intersect and relate to one another.

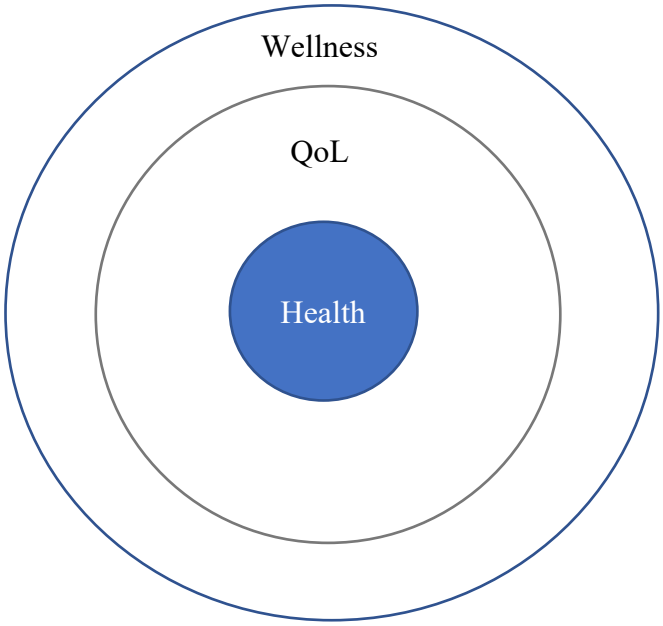
Wellness Models

Six Dimensions of Wellness Model

One model of individual level wellness to consider when creating a client-centered, holistic approach to treatment of disease is the Six Dimensions of Wellness model created by Dr. Bill Hettler (Hettler, 1976). This model provides a framework for understanding multidimensional wellness and examining how decline in any one dimension may result in poorer health outcomes.

Figure 1

Intersection of wellness, health, & QoL



As stated by Strout et al. (2016), wellness is an ever-changing process which is made up of six components: occupational, social, intellectual, physical, emotional, and spiritual wellbeing. Occupational wellness describes one's ability to contribute their personal skills to complete meaningful work. Social wellness is a person's ability to form and maintain supportive personal and community relationships. Intellectual wellness is a person's dedication to learning through continuous lifelong acquisition of knowledge and skills. Physical wellness includes one's commitment to physical activity, healthy eating, and health care use to achieve adequate self-care. Emotional wellness describes the ability to acknowledge personal responsibility for decisions and consequences with emotional grounding and positivity. Finally, spiritual wellness is one's commitment to having a purpose in life and a value system. Any one of these dimensions can influence the others, leading to increased or decreased overall wellness. For example, if one's physical wellness was lowered due to disease, their occupational wellness may

be negatively impacted as well if they cannot make meaningful contributions to work (Hettler, 1976).

WHO Health 2020 Framework

In addition to analyzing wellness on an individual basis, it can also be measured at the population level by taking a broader perspective and considering environmental factors in which the people live. To measure this broader conception of wellbeing, the WHO has designed the Health 2020 indicator framework that includes both subjective and objective factors of health (Kelley Ann Strout & Howard, 2012). Within this approach, wellness is investigated from a hedonic and eudaimonic position, while also incorporating social and contextual factors (Vik & Carlquist, 2018). The overall intent of addressing wellness at the population level is to improve overall health, reduce inequities in health based on various demographic factors, and shape the health system serving the population to be more people-centered (WHO 2020 Health Indicators document at https://www.euro.who.int/__data/assets/pdf_file/0011/317936/Targets-indicators-Health-2020-version3.pdf).

The hedonic perspective which is conceptualized as subjective wellbeing is a central component included in the Health 2020 indicator framework (Vik & Carlquist, 2018). At a basic level, this view holds that wellbeing is comprised of the presence of pleasure and absence of pain. The hedonic perspective is made up of two main components: affective and evaluative factors (Tay et al., 2014). The affective component is associated with a balance between positive and negative emotions and is typically measured through sampling data or surveys (Schwarz & Strack, 1999; Tay et al., 2014). The evaluative or cognitive component relates to one's life satisfaction and is measured through surveys on self-rated judgments of satisfaction (Tay et al., 2014; Vik & Carlquist, 2018). The other central perspective included in the Health 2020 indicators is the eudaimonic view which refers to a type of happiness or contentment that is

derived by living a meaningful life, achieving self-actualization, and striving towards reaching a person's highest potential (Tay et al., 2014; Vik & Carlquist, 2018). This perspective aims to measure one's meaningful endeavors and contributions in life as indicators of wellness (Ryan et al., 2008). Of note, this view aims to describe an individual's potential in a community as measured by their contributions to the collective welfare of the society. Ryan et al. (2008) also support that the eudaimonic view is made up of six distinct dimensions: self-acceptance, positive relationships with others, personal growth, purpose of life, environmental mastery, and autonomy.

In addition to the hedonic and eudaimonic perspectives, the Health 2020 framework integrates social wellness measures into the model to illustrate its importance on overall wellbeing. The social indicator approach suggests that there are individual and societal requirements that must be met to have a good life (Diener et al., 2009). These requirements may include the living and working conditions of a society, access to healthcare, or educational resources available to the public (Diener et al., 2009). Examples of social indicators that may be measured are poverty, life expectancy, and unemployment.

Hedonic and eudaimonic perspectives, as well as social indicators of wellness, are all considered important in deriving the WHO's Health 2020 indicator framework, which contains six target measures for assessing wellness at the population level: life satisfaction, availability of social support, percentage of population with improved sanitation facilities, Gini coefficient (income distribution), unemployment rate, and proportion of children not enrolled in education at official primary school age (Diener et al., 2009). This framework was created by taking a population level perspective of wellness, considering both individual factors and the context in which one lives. While this wellness model does have sound theoretical support, only one

indicator refers to subjective experience, and present literature suggests a more extensive inclusion of subjective measures would improve the framework (Robeyns, 2005).

Five Factor Wellness Inventory

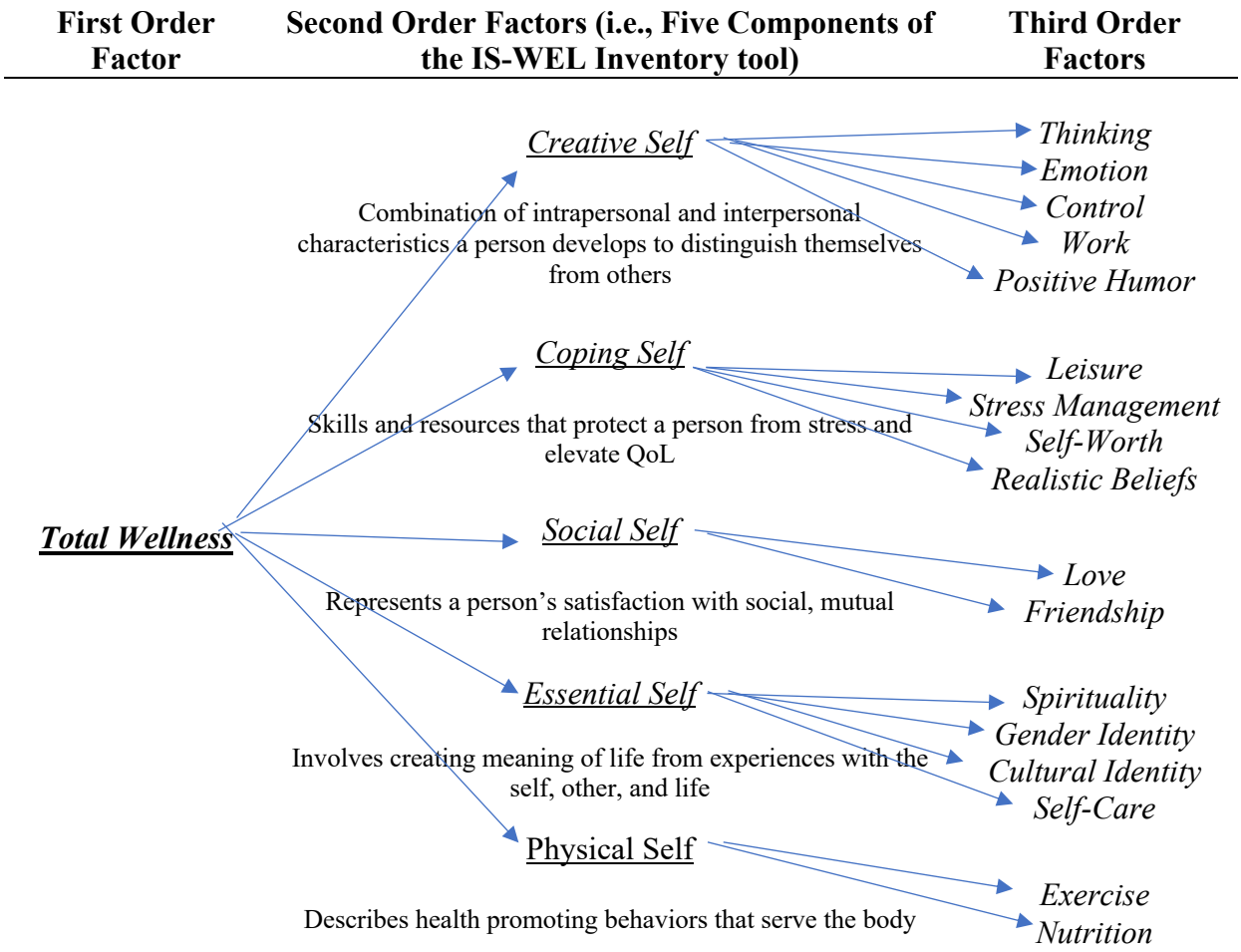
Meyers and Sweeney have systematically investigated wellness developing two models and ultimately deriving a now well-used tool: the Five Factor Wellness Inventory (FFWEL). Their conjoint models and the FFWEL serve as the primary theoretical wellness perspective for the current study. The two models they developed – the Wheel of Wellness model (WoW) and the Invisible Self Model (IS-WEL) – are founded on the principle that wellness involves integration of mind, body, and spirit (Vik & Carlquist, 2018). The WoW was the first model created by Myers and colleagues (2000), and it was comprised of 17 wellness areas based on five life tasks that they found central to an individual's wellness and functioning: work, friendship, love, self, and spirituality (L. R. Shannonhouse et al., 2016). Of these five life tasks, spirituality was believed to be the most central because it incorporates religious beliefs and individual ideas of one's purpose (Myers & Sweeney, 2007). While the WoW was a useful starting point in their systematic study of wellness, the relationships among the 17 areas was not supported with a high level of evidence and spirituality specifically was not found to be a significantly higher order factor over the others (Myers et al., 2000). For these reasons, Meyers and Sweeney sought to improve upon the WoW, subsequently resulting in the IS-WEL.

A foundational principal of the IS-WEL comes from Alfred Adler's concept of holism – that the self cannot be divided (Myers et al., 2000). At its core, the IS-WEL model represents how all components of wellness are interrelated and can be grouped into five factors (Myers & Sweeney, 2007). Similar to Hettler's Six Dimensions of Wellness model, the IS-WEL contends that changes to any single component of wellness can lead to changes in other components as all areas are interconnected. Under the five main components of the IS-WEL, 17 third-order factors,

including those from the WoW model, are subcategorized as different wellness areas. Figure 2 illustrates the IS-WEL's first, second, and third order factors of wellness (Myers et al., 2000).

Figure 2

IS-WEL first, second, & third order factors as presented in L. R. Shannonhouse et al. (2016) *with definitions of second order factors included*



Based on their early work on the WoW and IS-WEL, Meyers and Sweeney created the Five Factor Wellness Inventory (FFWEL). The FFWEL is an evidence-based survey tool that assesses wellness characteristics in order to inform individuals about their wellbeing and to support engaging in healthier lifestyles (Myers & Sweeney, 2007). Since its creation, the

FFWEL has been used to analyze wellness levels across diverse populations, such as adolescent males, cancer survivors, and professional counselors, in a large number of studies (Myers & Sweeney, 2007). The FFWEL consists of 91 scored items plus demographic questions that measure wellness and several experimental items (L. Shannonhouse et al., 2020). The single higher order factor that the survey aims to measure is *Total Wellness*, with the five IS-WEL second-order factors as main components and the 17 subcategory scales as third-order factors.

In addition, the FFWEL assessment includes scales on contextual variables and life satisfaction to measure the social and environmental factors of one's wellness (Myers & Sweeney, 2014b). As the FFWEL has been found by multiple sources, including Myers & Sweeney (2014b), to be a theoretically grounded assessment tool that offers a unique and holistic perspective of wellness through easy distribution of the survey, the current project utilized the FFWEL to measure wellbeing of individuals who have had a TL.

Implications of Total Laryngectomy on Adults < 55 years Old

Wellness Outcomes Following a Total Laryngectomy

The loss of the ability to speak can take a significant toll on many aspects of an individual's life (Perry et al., 2015). In the last three decades, the number of HNC survivors has increased; however these survivors face several comorbidities and persistent lifestyle challenges (Perry et al., 2015). As reported in several studies, individuals who undergo a TL often experience social, occupational, physical, and mental difficulties, impacting their QoL and wellbeing (Perry et al., 2015). According to a national survey study conducted by Palmer and Graham (2004) to evaluate the relationship between communication and QoL in alaryngeal speakers, individuals who report successful communication rate their overall QoL as significantly higher than those with poor communication outcomes. Current research on QoL after TL mostly comes from studies that aim to measure a single aspect of a laryngectomee's

health or their QoL. While some of these results can inform about overall wellness, no study to date has attempted to comprehensively measure wellness among this population. The following sections provide an overview of how the five central wellness measures of the FFWEL model can be impacted after receiving a TL.

Creative Self

The *Creative Self* is subcategorized as the factors of *thinking, emotions, control, work,* and *humor.* Related to the areas of *thinking, emotions,* and *control*, mental health is a major component of QoL that many laryngectomees report is affected after their TL (Ferrer Ramírez et al., 2003; Perry et al., 2015). Results from a cross-sectional study found that TL survivors showed significantly higher levels of anxiety and depression than the normative sample (Perry et al., 2015). Similar findings that approximately 22-30% of individuals who use a voice prosthesis after a laryngectomy experience psychological comorbidities, such as anxiety and depression, were reported in a qualitative research study by Ferrer Ramírez et al. (2003). Unfortunately, if left untreated, these negative mental health outcomes can lead to serious implications. Recent research by Osazuwa-Peters et al. (2018) indicated that HNC survivors are about twice as likely to commit suicide compared to individuals with other types of cancers.

These mental health implications and lack of control over one's abilities can make returning to work after a TL difficult. However, there has been relatively little consideration of the issue of return-to-work in recent years other than by Costa et al. (2018). They reported that 53% of TL survivors returned to work after their procedure. Osazuwa-Peters et al. (2018) found that limited job opportunity is one of the most common complaints among laryngectomees. The issue of work and return-to-work following TL may be of particular importance to younger laryngectomees who have the surgical procedure while they are still employed and for whom

many years of continued work had been planned. Finally, it is important to note that no research currently exists on measuring humor among laryngectomees.

Coping Self

Few studies have focused on how elements of the *Coping Self* are impacted after a TL. The *Coping Self* is comprised of the third order factors of *leisure, stress management, self-worth,* and *realistic beliefs.* Some information on these components can either be ascertained or predicted based on studies addressing aspects of QoL in the TL population. In terms of leisure and recreational activities, at least two studies have identified that many laryngectomees cannot partake in favorable physical or social activities that they enjoyed prior to their surgery (Palmer & Graham, 2004; Perry et al., 2015). Although not directly assessing leisure activities, Ackerstaff et al. (1994) reported that a substantial number of laryngectomees experience changes to their ability to smell, taste, and swallow which can be devasting for people who enjoy food (Palmer & Graham, 2004; Perry et al., 2015) and which could reasonably be inferred to impact social activities that revolve around meals. Additionally, one might predict that laryngectomees with significantly altered communication abilities may find that leisure activities that are social in nature are challenging. For example, Ackerstaff et al. (1994) reported a statistically significant correlation between frequency of telephone calls and anxiety about speaking; for laryngectomees who consider such social communication as part of their preferred leisure activities, a limitation in their activity might be anticipated if it, in fact, elevates their anxiety.

In terms of stress management among laryngectomees, Yang et al., (2021) found that coping strategies vary among this population. They reported that initially after surgery most patients demonstrated social withdrawal, avoided communication, and exhibited higher irritability and impatience. However, other patients adapted well to the lifestyle changes and embraced a new self-identity through persistent exercise and motivation. Wang et al. (2019) have

also reported reduced stress management capabilities among laryngectomees and elevated levels of psychological distress.

Self-worth is often highly impacted among TL survivors (Yang et al., 2021) with many reporting they cannot do tasks and fulfill roles as they did prior to surgery, potentially causing a change in the way they value themselves. The research on mental health and psychological impact of TL also is relevant when considering self-worth post-TL. As noted above, laryngectomees often suffer from anxiety, depression, and suicidal ideation as a result of their loss of functioning (Yang et al., 2021) which may be a reflection of changes in their self-worth. Additionally, early on after the procedure many individuals demonstrate low self-esteem (Osazuwa-Peters et al., 2018; Summers, 2017).

Currently there is no research reported on how realistic beliefs are impacted after a TL. The extent to which a laryngectomee establishes realistic beliefs following the surgery could be influenced by a number of factors such as pre-operative counseling, post-operative interventions (SLP, counseling, etc.), and mental health status, among others. However, direct investigation of this issue and others within the *Coping Self* domain are needed to better understand whether and in what ways coping is impacted after TL.

Social Self

The *Social Self* is comprised of two third order factors: *friendship* and *love* (Costa et al., 2018; Offerman et al., 2015; Summers, 2017). The loss of one's voice can be extremely isolating as speech is typically a primary mode of communication and socialization. Direct investigation of the *friendship* factor is not available in the literature, but more generally, issues of social isolation have been considered. About 40% of individuals report experiencing social withdrawal after their TL (Summers, 2017). Similarly, Perry et al. (2015) found that compared to a

normative sample, laryngectomees demonstrate a significant decrease in social relationships after their procedure. This social isolation can negatively affect many life activities and result in avoiding community activities, limiting communication in social settings, and withdrawing from relationships with family, spouses, and peers (Offerman et al., 2015). These implications are often not only experienced by survivors, but also by family members of the laryngectomee (Offerman et al., 2015).

The other third order factor of the *Coping Self,* namely *love*, has also not been directly studied in the TL population. In terms of an impact on loving relationships, reported that 35% of spouses say that they experienced changes to their social life after their significant other had a laryngectomy. Additionally, 31% experienced change in sexual relationships. However, as indicated in Myers et al. (2004), love does not necessarily infer sexual intimacy as sex and true love sometimes have little in common. Thus, this subcategory also refers to how isolation, alienation, and separation from intimate and close relationships are associated with poor health conditions and outcomes (Lightsey, 1996).

Essential Self

How one views themselves and their beliefs can change dramatically after a TL. The concept of creating meaning from your life is represented in the FFWEL by the *Essential Self,* which is made up of the third order factors of *spiritualty, gender identity, cultural identity,* and *self-care.* There is some limited information related to the second order factor of the *Essential Self* from the work of Lightsey (1996) who studied how laryngectomees "make meaning" (p. 2639) after their surgery. Specifically, their results indicated that a loss of self-expression often accompanied TL which impacted self-identity and lead to reframing part of oneself. The study demonstrated that laryngectomees tend to adjust their self-perception to match their disability and disfigurement – this can lead to changes in communication participation, individualized

expression, food preferences, and social roles. This same research group has also found that after a laryngectomy, patients reform and negotiate their social interactions due to changes to their self-expression, abilities, and roles (J. Bickford et al. (2019)).

The third-order factor of *self-care* has only been addressed in a single study in the TL literature. According to Almonacid et al. (2016), following a TL those who engage in self-care have been found to have reduced anxiety levels post-laryngectomy.

The third-order factor, *spirituality,* has not specifically been studied among those who have had a TL. The *gender identity* factor has been partially addressed relative to laryngectomees in that some unique aspects of the TL experience among women have been explored. Namely, a study by Sluis et al. (2020) examined the experience women have following a TL. They found that women report having issues returning to work, caring after others, and engaging in spousal relationships, intimacy, and social interactions – as also found in , Offerman et.al. (2015). Another similar study by Cox et al. (2015) described the differential impact a TL has on women, including how women's physical, psychological, and social functioning are uniquely impacted after the procedure.

Finally, the factor of *cultural identity* that might influence a laryngectomee's well-being has not been directly investigated. It is known that racial disparities in laryngeal cancer treatment and outcomes exist. For example, Shin & Truong (2015) found that black patients were more likely to be diagnosed with laryngeal cancer at a younger age, with a later-stage disease, and greater likelihood of undergoing a TL than white patients. It was also found that regardless of age, primary treatment, year of diagnosis, tumor grade, or nodal status, a significant 5-year survival difference based on race exists. Additionally, when it comes to laryngeal preservation therapy for advanced laryngeal cancer cases, Hou et al., (2012) discovered that black individuals

were significantly less likely to have larynx preservation treatment than other races. These apparent inequities illustrate how one's race may influence their TL diagnosis and management and by extension could impact their post-TL experience and outcomes. However, studies directly investigating how a laryngectomee's race shapes how they view themselves have not been reported. Other aspects of cultural identity beyond race, such as values, language, gender identity, and norms, have not been addressed in the literature relative to how a laryngectomee creates meaning from their life after TL.

Physical Self

Physical Self is the final second order factor in the FFWEL model. Physical functioning and limitations have been a primary focus in the TL literature. The FFWEL physical factor has two third-order factors that are *nutrition,* and *exercise.* The ability to speak, eat, and breathe independently are physical procedures that can be lost or significantly altered after a TL (Palmer & Graham, 2004). Palmer & Graham (2004) found that TL survivors experienced a significant decrease in overall physical health compared to a normative sample. This reduction to functional abilities has been found to be correlated to QoL, with individuals not being able to perform household or work-related tasks or eat on their own as they could prior to the surgery (Palmer & Graham, 2004). Additionally, the act of alaryngeal speaking can also be mentally and physically fatiguing after only 30 to 60 minutes of speech (Palmer & Graham, 2004). As measured by the voice handicap index, Tiple et al., (2016) reported that laryngectomees, both those with and without voice rehabilitation therapy, reported impairment to their physical functioning.

In terms of physical exercise levels among laryngectomees, Hlozek & Hledíková (1989) found that loss of fitness was one of the most common self-reported complaints of patients. Similarly, an experimental study by Marszałek et al. (2005), which measured laryngectomees'

aerobic efficiency levels through a mechanical track test, found that physical activity levels significantly decrease after TL. Lack of overall physical exercise among this population was also noted in by Büntzel et al. (2016). Of those who did partake in exercise, Büntzel et al., (2016) found that all patients interviewed reported some positive impact of sports on their wellbeing.

Nutrition is a significant area of concern after a TL as typical feeding and swallowing is often compromised. Additionally, other treatments such as chemoradiation can alter one's ability to eat, energy level to partake in meals, taste, and feelings of hunger, all of which could have an impact on a person's nutrition. More generally, it is known that malnutrition is an elevated risk among those with HNC, not just those with a TL (Santos et al., 2021). A number of studies have documented a wide range of swallowing alterations after TL (e.g., Starmer et al., 2008; Terlingen et al., 2018; Wulff et al., 2021; Zenga et al., 2018; Ziegler et al., 2021) which may be severe enough to necessitate non-oral feeding options. Pernambuco et al. (2013) performed a series of case studies and found that patients with dysphagia reported that swallowing had a moderate to severe impact on their communication, fear levels, eating durations, and QoL. Lennie et al. (2001) reported that among laryngectomees there were significant changes to eating, negatively impacting nutritional intake.

Total Laryngectomy Among Adults Less than 55 Years of Age

As of 2017, the average age of a TL was 63.4 years, with the typical range between approximately 43 to 84 years (Akil et al., 2017). While the proportion of laryngectomy procedures among patients older than 65 years has decreased by 5% (from 48% to 43%) between 1997 to 2008, the mortality rates have stayed stable despite the younger patient age (Akil et al., 2017). This trend indicates that an increased number of younger individuals are receiving TL

(Maddox & Davies, 2012). Additionally, there is a large sex difference between TL patients with 79% being male and 21% being female (Maddox & Davies, 2012).

Much of the current research available regarding TL focuses on patient outcomes without specific consideration of younger laryngectomees. Despite the increasing number of younger adults that receive TL, very little literature and research has been done to examine the potentially unique challenges this population may face by having the surgery earlier into adult life.

Typically, adults under the age of 55 years have financial, occupational, familial, and social responsibilities that differ from their older counterparts. For example, the average age of retirement in the U.S. is 64 years among men and 62 years among women (Maddox & Davies, 2012). Given the age range of laryngectomees, there are many who would fall within an age range where employment is expected. With only about 15% of individuals able to return to work after having a TL, a substantial number of laryngectomees may be left out of the workforce, potentially creating a host of outcomes that might include financial hardship, altered role in the family, and changes to self-worth and self-identity. The fact that a younger laryngectomee may have many more years of life to live post TL compared to someone in their 60's or beyond, also could influence the life goals a person sets and the financial stability that they may or may not be able to establish.

Adults who are in their 50's, 40's, or younger when they have a TL are also likely to be in different stages of parenting, adult caregiving, and other roles that may be altered following their TL, potentially impacting their wellbeing. Younger adults typically live a more physically active, social, and high demanding lifestyle than older individuals (Whitaker & Bokemeier, 2018). For example, a young father who receives a TL may still be expected to physically attend to his children, effectively communicate at home and work, financially support his family,

participate in group events and meals, and may desire leisure time connecting with friends. As discussed in the previous sections, TL can negatively impact many of these areas that contribute to one's wellness. Major changes to capabilities and wellbeing can lead to changes in self-identity as laryngectomees must re-establish a new normal for the duration of their lives. While this new self-identity may be a challenge for some, younger adults who may live for many more years after their surgery have the opportunity to become comfortable with their new selves, find new senses of purpose and beliefs, and discover aspects of themselves that make them proud. Alternatively, younger laryngectomees could conceivably perceive greater (or perhaps different types of) weight on themselves as they try to navigate their life role for many years and decades, potentially leading to despair or feelings of hopelessness. Thus, a primary objective of this study was to investigate how total wellbeing is affected among laryngectomees less than 55 years of age.

Statement of Purpose and Research Questions

Comprehensive wellness is understudied among TLs. Specifically, wellness among younger laryngectomees and the unique challenges this population may face have not been considered in the existing literature. Based on previous findings from QoL studies, there is reason to anticipate that one's communication participation may impact their wellness levels. Understanding if such relationships exist and determining in what domains wellness is most impacted in TL could serve to inform the intervention approaches clinicians use to support the best wellness outcomes for TL patients. The current study addressed these issues by examining how a range of wellness components as measured by the FFWEL and communication participation as measured by the Communication Participation Item Bank (CPIB) are impacted after a TL among individuals under the age of 55 years.

There were three purposes of this study. The first was to determine if younger laryngectomees report wellness characteristic that differ from individuals without a laryngectomy. The second was to determine if younger laryngectomees differ in terms of wellness from older laryngectomees. The third purpose was to measure the strength of the relationship between wellness and communication participation for younger laryngectomees. The specific research questions (RQ) and hypotheses (H) were as follows:

RQ1: Do individuals under the age of 55 years who have had a TL because of cancer report wellness characteristics as reflected in the FFWEL that differ from the normative data set?

H1: Individuals under the age of 55 years who have had a TL because of cancer will report lower wellness scores in all areas of the FFWEL compared to the normative sample.

RQ2: Do individuals under the age of 55 years who have had a TL because of cancer report wellness characteristics as reflected in the FFWEL that differ from individuals 65 years of age and older who have had a TL because of cancer.

H2: Individuals under the age of 55 years who have had a TL because of cancer will report lower wellness scores in all areas of the FFWEL compared to individuals 65 years of age and older who have had a TL because of cancer.

RQ3: What is the strength of the relationship between wellness and communication participation in adults under the age of 55 years who have had a TL?

H3: Individuals under the age of 55 years who have had a TL will demonstrate a moderate to strong positive relationship between wellness and communication participation.

CHAPTER 2: METHODS

Participants

The primary population for this study was adults 18 to 54 years of age (i.e., younger group) who had a TL because of laryngeal cancer. For comparative purposes in RQ3, adults 65 years of age and older (i.e., older group) who received a TL were also recruited. These age groups were intentionally chosen due to the different social, occupational, familial, and financial roles that correspond to younger versus older adults. The study was reviewed and determined to be exempt by the Michigan State University institutional review board (IRB #00007655).

Inclusion criteria for the TL participants were: a TL because of laryngeal cancer, 18 to 54 years or over 64 years old at the time of survey completion, living in the United States, and at least six months post TL. Exclusion criteria were: currently undergoing radiation or chemotherapy treatment, TL for reasons other than laryngeal cancer, and neurological conditions or diseases with the potential to impact communication (e.g., stroke, traumatic brain injury, Parkinson's disease, amyotrophic lateral sclerosis, etc.). Inclusion and exclusion criteria were determined based on participant attestation on the opening page of the online survey that included a description of the study.

Instruments

Medical History and Communication Modality (MHCM) Survey

A study-specific survey was constructed in Qualtrics to gather information on participants' medical history and communication. No personal identifying information was collected. Data collected in this section included information on participants' medical condition(s), such as hearing loss, cognitive impairments, mental health, and physical or mobility limitations. Information on participants' location and stage of cancer, surgical procedures, radiation therapy, and chemotherapy history were gathered. Participants also were asked to

identify their primary mode of communication. Options listed included: TE speech, EL speech, ES speech, PAL speech, AAC, and "other" with a place to describe how they communicate. The survey also asked if they were currently or have ever received services from a speech-language pathologist (SLP), and if so, details about the timing, duration, and focus of that intervention were elicited. A complete version of questions asked in this intake survey can be found in appendix A.

Communicative Participation Item Bank

The second questionnaire included in the Qualtrics survey was the Communicative Participation Item Bank (CPIB), which is an instrument designed to measure the impact of adults' communication conditions across different environments and life situations (Baylor et al., 2013). Baylor and colleagues (2009) created the CPIB with the goal of determining how a respondent's condition interferes with participation in a range of communication situations. This instrument was designed to be a self-report outcome questionnaire used to measure verbal communication in research, clinical practice, and clinical trials (Baylor et al., 2013). Since its creation, the CPIB has been used to examine the impact of communication conditions in numerous populations, such as adults with spasmodic dysphonia, multiple sclerosis, and HNC, and has been found to have strong psychometric properties (Baylor et al., 2009).

The general short form of the CPIB consists of ten questions that asks a person to rate the extent to which their communication condition impacts specific communication situations (Appendix B) (C Baylor et al., 2009; Carolyn Baylor et al., 2013). For each item, participants rated the extent of impact on a four-point scale: very much (0), quite a bit (1), a little (2), and not at all (3). The CPIB is freely available for use, typically as a paper-pencil questionnaire. For this study, the instructions, questions, and rating scale were recreated in Qualtrics to allow for online data collection. Estimated time for CPIB completion was one to four minutes.

Five Factor Wellness Inventory

The FFWEL is available for purchase for public use through Mind Garden (https://www.mindgarden.com/99-five-factor-wellness-inventory#horizontalTab3), an online publisher of psychological assessments and instruments (Myers & Sweeney, 2014b). There are several variations of the FFWEL available depending on the population of interest and the type of survey distribution being implemented. These options include survey forms specifically for individual use, group report use, teen use, and adult use. Additionally, researchers can choose to distribute the survey in either a paper and pencil hardcopy or remote online version. For the present study, licenses were purchased to allow online distribution of the adult version of the FFWEL. This license allowed recreation of the FFWEL items in an online survey platform, i.e., Qualtrics. On average, the FFWEL took participants approximately 10 to 20 minutes to complete (Myers & Sweeney, 2014a).

Procedures

A single Qualtrics questionnaire was created with the MHCM, CPIB, and FFWEL as separate blocks in that order. Care was taken to ensure that the format of the standardized assessments (CPIB, FFWEL) was replicated from the hard copy versions as precisely as possible. Participants were informed that they had the option to forgo any of the questions they did not feel comfortable answering; however, verbiage was included to encourage participants to complete all questions on standardized assessments otherwise it might not be possible to calculate their CPIB and FFWEL scores.

A brief study description, invitation to participate, and link to the Qualtrics survey were posted on several Facebook groups, all of which are TL and HNC support and educational groups: Laryngectomy Support; Lary's Voice; WebWhispers Facebook group; International Association of Laryngectomees; Esophageal Speech Support; Head, Neck, Throat, and Oral

Cancer Group; Laryngectomy-Glossectomy Group; Let's Talk Laryngectomy Support Group; Smoky Mountain Head, Neck, Throat, and Oral Cancer Group, Head and Neck Cancer Alliance; Head and Neck Cancer Support Group; Head and Neck Cancer Survivors; Head, Neck and Oral Cancer Support Group; Head and Neck/Oral Cancer Chat and Support; Oral Cancer Club; Throat and Oral Cancer Survivors; and HPV+Throat Cancer Survivors and Caregivers. In addition to Facebook, the Qualtrics link was also distributed directly to TL and HNC support group leaders, professional contacts, and vendors of laryngectomy products, including Lauder Enterprises, InHealth Technologies, and Atos Medical. An explanation of the research purpose, inclusion and exclusion criteria, as well as researchers' contact information were included in the online recruitment posts which were approved by MSU IRB. A link to the Qualtrics survey was posted on August 5th, 2022. A reminder to complete the survey was sent out three weeks after opening the survey. Over this time, study participation was monitored closely to measure engagement. The survey was closed on September 13th, 2022 after 10 days without any new survey submissions. That is, the survey was open for 5.5 weeks. At that point, the completed survey responses were downloaded.

Analysis Approach

Demographic, medical history, and alaryngeal communication information were summarized using descriptive statistics. For ordinal and nominal variables, frequencies and percentages were calculated. For scaled and ratio data, means, standard deviations, and ranges are presented.

To address the first research question, it was necessary to calculate FFWEL scores (*Total Wellness*, second order scores, and third order scores). Scoring consisted of adding up each participants' raw score from the 91 items, resulting in an overall *Total Wellness* score. Additionally, second and third order factor scores were calculated based on participant responses

from specific subsets of questions (Myers & Sweeney, 2014b). The second and third order factor scores are normalized because each consists of a different total number of items, and therefore, the range of summed scores for the subscales differ. The FFWEL instructions require that all the sub-factor scores be scaled on a common metric ranging from 25 to 100 by diving the mean score for each scale by the number of items for that factor and multiplying by 25. In order for a scale to be scored, a minimum of three item responses per scale was required as specified in the FFWEL manual. To minimize human error in calculating FFWEL scores, an Excel worksheet was created to automate calculation of first, second, and third order factors. In some instances, participants did skip a question, in which case the automatic calculations had to be adjusted by the investigator to achieve the proper scaled score.

For RQ1, a series of two sample z-tests were computed to test whether or not the mean FFWEL factor scores from the younger laryngectomy group were equal to the mean FFWEL factor scores reported from the normative data in the FFWEL manual. This test was run using an online calculator (https://mathcracker.com/z-test-for-two-means) utilizing the means and standard deviations from the experimental data and the corresponding means and standard deviations for each FFWEL factor. To control for Type 1 errors, the Holm-Bonferroni method was applied using a family-wise error rate of alpha = .05 In this case, the family of tests consisted of the 23 two-sample z-tests comparing the experimental to the normative means for the first (n = 1), second (n = 5), and third (n = 17) order FFWEL factors.

The second research question required a comparison of the FFWEL scores of the younger TL (<55 years) and older TL (≥65 years) groups. A series of 23 independent sample t-tests, one each for the first, second, and third order factors, were completed using IBM SPSS Statistics 28.0.0.0. Again, the Holm-Bonferroni approach for controlling Type I errors was applied with a

family-wise alpha of .05. Cohen's *d* was calculated as an effect size measure for each t-test and interpretation of *d* was based on Cohen's original suggestion of 0.2 as "small," 0.5 as "medium," and 0.8 as "large" (Cohen, 1988).

The third research question addressed the strength of the relationship between the CPIB score and all first, second, and third order factors of the FFWEL for the younger TL. The CPIB was scored according to the test instructions by adding up each participant's cumulative rating point total of all ten questions to obtain a summary score which ranged from 0 to 30 (Myers & Sweeney, 2014c). Higher scores indicated better communication participation and less limitations to participation. A Pearson correlation coefficient was calculated to assess the strength and direction of the relationship between the *Total Wellness* score, as well as all second and third order factors for the FFWEL, and the CPIB score. An alpha level of .05 or smaller was considered statistically significant. Following Cohen's suggestion (1992), the strength of the association was considered to be small for *r* values between +/- 0.1 to 0.3, medium for values between +/- 0.3 to 0.5, and large for values between +/- 0.5 to 1.0.

CHAPTER 3: RESULTS

Participant Demographics, Medical History, and Alaryngeal Communication

A total of 55 individuals met the inclusion criteria for the study, with 26 individuals under the age of 55 years (mean (M) = 50.5 years (yrs); standard deviation (SD) = 2.9 yrs; range (R) = 44 – 54 yrs) and 29 individuals 65 years or older (M = 71.7 yrs; SD = 4.6 yrs; R = 65 – 81 yrs). The younger group was 58% male and 42% female compared to 97% male and 3% female in the older TL group. Both groups self-identified predominantly as White (81% of younger and 72% of older TL participants) and non-Hispanic (100% younger; 93% older participants). Additional details about gender, race, ethnicity, marital status, employment status, education level, hearing loss, cognitive impairment, mental health diagnoses, and physical impairment are included in Appendix C. These variables are not analyzed as part of this study but are available for secondary analyses and for contextualizing the current results.

As anticipated, the majority of TL participants had Stage 3 or Stage 4 cancer (Table 1) and most had some other head and neck surgery in addition to the TL such as a neck dissection, partial glossectomy, pharyngectomy, etc. A majority of both the younger and older TL groups had received radiation therapy (81% and 69%, respectively). Relatively few of the older TL participants reported chemotherapy treatment (10%) compared to the younger TL patients (46%). The distribution of alaryngeal communication method for the younger TL group was as follows: ES – 8%, TES – 58%, ELS – 31%; Other – 4%. For the older TL group, the distribution was: ES – 17%; TES – 66%, ELS – 17%. None of the participants selected PAL or AAC as their primary method of communication. Additional information about HME use and SLP therapy are provided in Table 2.

Table 1

Cancer stage, head and neck surgical history besides total laryngectomy, radiation therapy, and chemotherapy descriptive statistics

Statistics		**Age Groups**			
		<55 years		**≥ 65 years**	
Cancer Stage		**N**	**%**	**N**	**%**
	Stage 1	0	0%	1	3%
	Stage 2	0	0%	0	0%
	Stage 3	15	58%	4	14%
	Stage 4	9	35%	11	38%
	Unsure	2	8%	13	45%
Received Other Head/Neck Surgery					
	Yes	17	65%	20	69%
	No	9	35%	9	31%
Radiation					
	Yes	21	81%	20	69%
	No	5	19%	9	31%
Chemotherapy					
	Yes	12	46%	3	10%
	No	14	54%	26	90%

Table 2

Descriptive statistics regarding primary communication method, heat-moisture exchange use (HME), and speech-language pathology (SLP) services. AAC = augmentative and alternative communication

Statistic	**Age Groups**			
	< 55 years		**≥ 65 years**	
	N	**%**	**N**	**%**
Primary Communication Method				
Esophageal Speech	2	8%	5	17%
Tracheoesophageal Speech	15	58%	19	66%
Electrolarynx Speech	8	31%	5	17%
Pneumatic Artificial Larynx	0	0%	0	0%
AAC	0	0%	0	0%
Other	1	4%	0	0%
Use of HME				
Never	0	0%	6	21%
Sometimes	3	12%	7	24%
Half the Time	3	12%	4	14%
Most of the Time	14	54%	5	17%
Always	6	23%	7	24%
SLP Services				
Yes	26	100%	29	100%
No	0	0%	0	0%
Number of SLP Sessions				
1 - 5 Sessions	10	38%	11	38%
6 – 10 Sessions	12	46%	5	17%
10+ Sessions	4	15%	13	45%
SLP Focus				
Electrolarynx Training	9	35%	3	10%
Esophageal Speech Training	2	8%	5	17%
Tracheoesophageal Speech Training	14	54%	16	55%
HME Use and Training	1	4%	2	7%
Swallowing	0	0%	2	7%
Speech Production	0	0%	0	0%
Voice Rehabilitation	0	0%	0	0%
Other	0	0%	1	3%

Younger Laryngectomees' Wellness versus Normative Data (RQ1)

Groups means and SDs for the younger laryngectomees and FFWEL norms are reported in Table 3 along with the adjusted *p* value outcomes after applying the Holm-Bonferroni method. The younger laryngectomee group had significantly lower scores than the normative FFWEL scores for the majority of FFWEL factors (Table 3). Exceptions to this pattern in which the two groups did not differ significantly were for the following third order factors: *realistic beliefs, exercise, stress management,* and *work.*

Younger versus Older Laryngectomees' Wellness (RQ2)

Total Wellness

A boxplot showing the median, mean, interquartile range, and minimum and maximum values of the FFWEL *Total Wellness Score* for the younger and the older TL groups is depicted in Figure 3. The older TL participants *Total Wellness* (M 53.14, SD 7.17) compared to the younger TL participants (M 61.84, SD 4.93) demonstrated a significantly lower overall wellness score (t[49.79] = 5.29, adjusted p = .0003). The Cohen's d was 1.4 indicating a large effect size. See Appendix D for the full set of statistical values including the mean, SD, minimum and maximum values for each group for the *Total Wellness* score (and all second and third order factors).

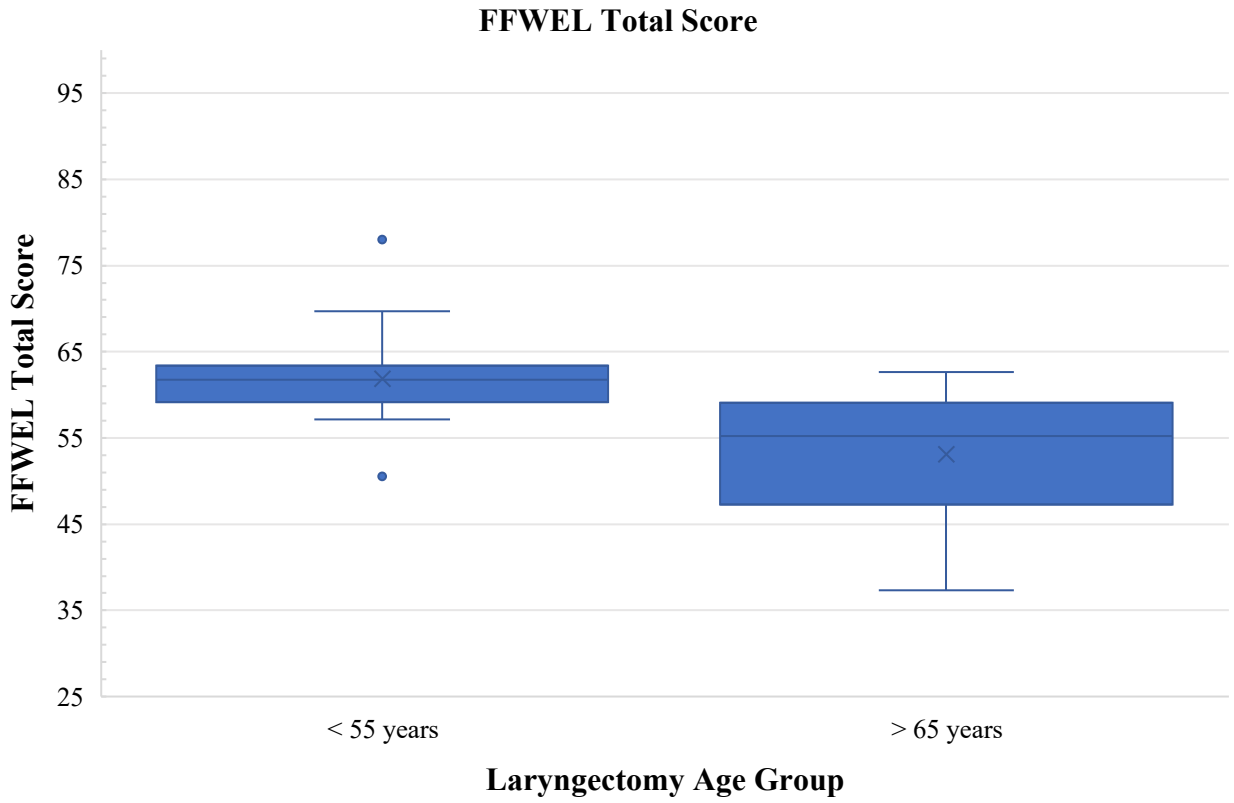
Table 3

Statistical results from two-sample z-tests comparing means of younger laryngectomees and Five Factor Wellness Inventory (FFWEL) norms. SD= standard deviation, adjusted p = one-sided probability after Holm-Bonferroni adjustment

	Younger Laryngectomee Group		**FFWEL Norms**		
	Mean	**SD**	**Mean**	**SD**	**Adjusted *p* Value**
Total Wellness	**61.84**	**4.93**	**71.63**	**15.87**	0.0021
Creative Self	**61.25**	**5.23**	**73.18**	**16.15**	0.0020
Thinking	56.54	5.79	73.46	17.75	0.0019
Emotions	56.01	7.60	73.03	17.67	0.0018
Control	56.41	9.52	73.69	18.36	0.0017
Work	71.92	9.17	71.86	16.35	0.5010
Positive Humor	62.74	10.68	74	19.74	0.0016
Coping Self	**63.87**	**5.23**	**68.73**	**12.73**	0.0015
Leisure	64.90	8.59	71.58	18.59	0.0014
Stress Management	67.55	8.30	69.01	16.61	0.5010
Self-Worth	63.46	7.84	74.62	21.31	0.0013
Realistic Beliefs	65.96	7.49	60.71	12.35	0.5010
Social Self	**48.32**	**7.67**	**77.35**	**23.56**	0.0012
Friendship	49.76	7.60	76.21	22.88	0.0011
Love	46.88	9.56	78.58	25.61	0.0010
Essential Self	**56.84**	**3.79**	**73.38**	**20.07**	0.0009
Spirituality	60.34	8.06	71.69	23.62	0.0008
Gender Identity	58.17	5.23	73.58	20.21	0.0007
Cultural Identity	61.06	6.12	70.71	20.65	0.0006
Self-Care	48.08	9.96	83.62	14.01	0.0005
Physical Self	**56.92**	**8.87**	**66.56**	**18.13**	0.0004
Exercise	65.77	10.36	68.14	21.2	0.5010
Nutrition	48.08	11.32	64.98	19.67	0.0012

Figure 3

Total Wellness boxplot for younger and older total laryngectomy groups



Creative Self and Associated Third Order Factors

A boxplot showing the median, mean, interquartile range, and minimum and maximum values of the FFWEL *Creative Self* second order factor and the associated third order factors for the younger and older TL groups is depicted in Figure 4. The older TL group had a significantly lower *Creative Self* score (M 49.92, SD 9.41) compared to the younger laryngectomee group (M 61.25, SD 5.23) based on the t-test results (t[44.71] = 5.59, adjusted $p < .0001$). The older group also had significantly lower third order factor scores in the domains of *control, work,* and *positive humor* (see Table 4 for t-test results). *Control* relates to a person's beliefs about their competence, ability to achieve goals, and exercising individual choice. *Work* refers to satisfaction with work, feelings of financial security, perception that skills are being used, feeling

appreciated and accepted in the workplace, and coping with workplace stress. *Positive humor* reflects an ability to laugh at a person's own mistakes, seeing contradictions in life objectively and gaining new perspective, and use of humor to complete tasks that might be serious. There was a large effect size for the factors of *Creative Self, control*, *work*, and *positive humor* (Table 4). Finally, there was not a significant difference between the two age groups for the third order factors of *thinking* (relates to being open-minded and mentally active), or *emotions* (pertains to being aware of one's own feelings), which both had medium effect sizes.

Figure 4

Creative Self and associated third order factor boxplots for younger and older total laryngectomy groups (red star indicates statistically significant group difference)

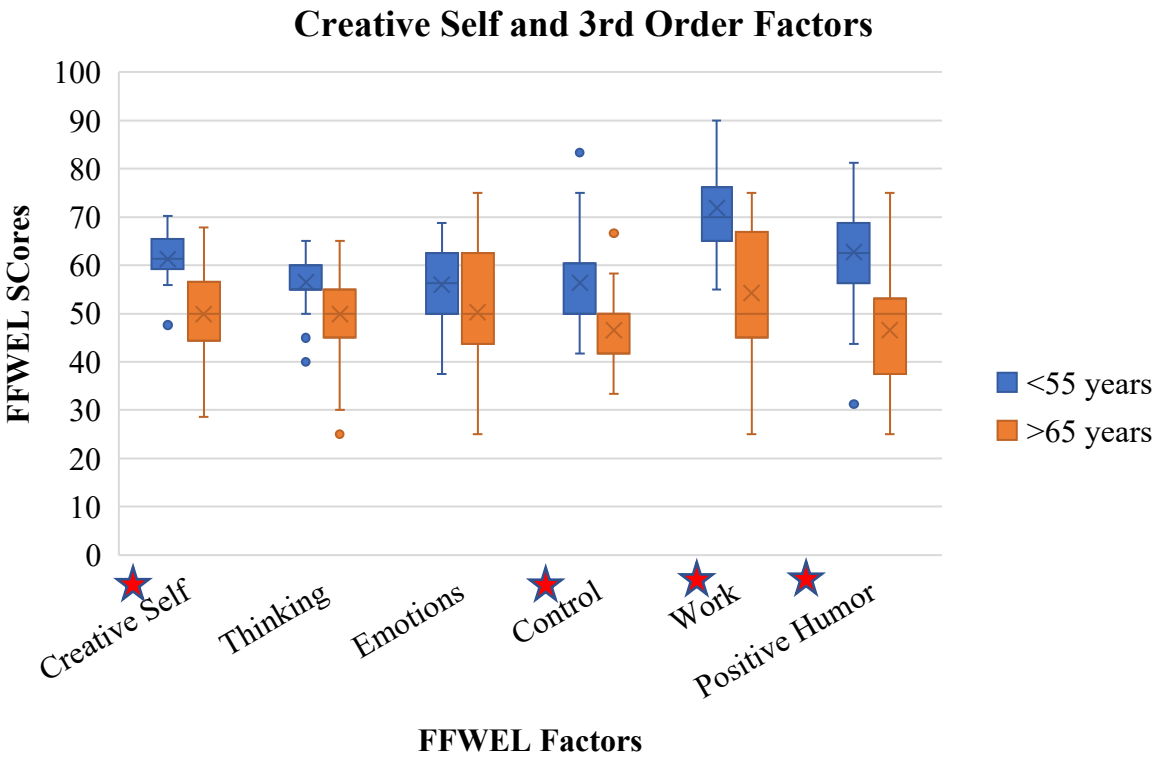


Table 4

Statistical results from t-tests comparing younger and older total laryngectomy groups for the second order factor of Creative Self and associated third order factors. t = t-value, df = degrees of freedom (non-whole numbers indicate equal variances not assumed), adjusted p = one-sided probability after Holm-Bonferroni adjustment

First Order Factor	Third Order Factors	*t*	*df*	Adjusted *p* value	Cohen's *d*
Creative Self		5.59	44.71	<.0001	1.47
	Thinking	2.76	53.00	.0514	0.75
	Emotions	2.09	46.81	.1876	0.55
	Control	3.82	53.00	.0026	1.03
	Work	5.77	49.89	<.0001	1.53
	Positive Humor	5.20	53.00	<.0001	1.40

Coping Self and Associated Third Order Factors

A boxplot showing the median, mean, interquartile range, and minimum and maximum values of the FFWEL *Coping Self* second order factor and the associated third order factors for the younger and the older TL groups is depicted in Figure 5. There was a significant difference between the groups for the second order factor of *Coping Self* with the older group having a lower score (M 53.13, SD 6.79) than the younger group (M 63.87, SD 5.23) based on the t-test results ($t[53] = 5.59$, adjusted $p < .0001$) and a large Cohen's *d* value. The older group also had significantly lower third order factor scores in the domains of *leisure, stress management,* and *self-worth* compared to the younger group with large effect sizes for each (see Table 5 for t-test results and effect sizes). *Leisure* refers to concepts such as satisfaction with, importance of, and balance between work and free-time activities. *Stress management* relates to perceptions of one's ability to self-regulate, view changes as growth opportunities, and management of coping

resources. *Self-worth* pertains to acceptance of self, including imperfections as well as positive attributes, and affirming one's existence as valuable. No significant difference and a small effect size was found for the groups for the third order factor of *realistic beliefs*, which relates to one's understanding of possible goals and avoidance of unrealistic expectations of self and reality.

Figure 5

Coping Self and associated third order factor boxplots for the younger and older total laryngectomy groups (red star indicates statistically significant group difference)

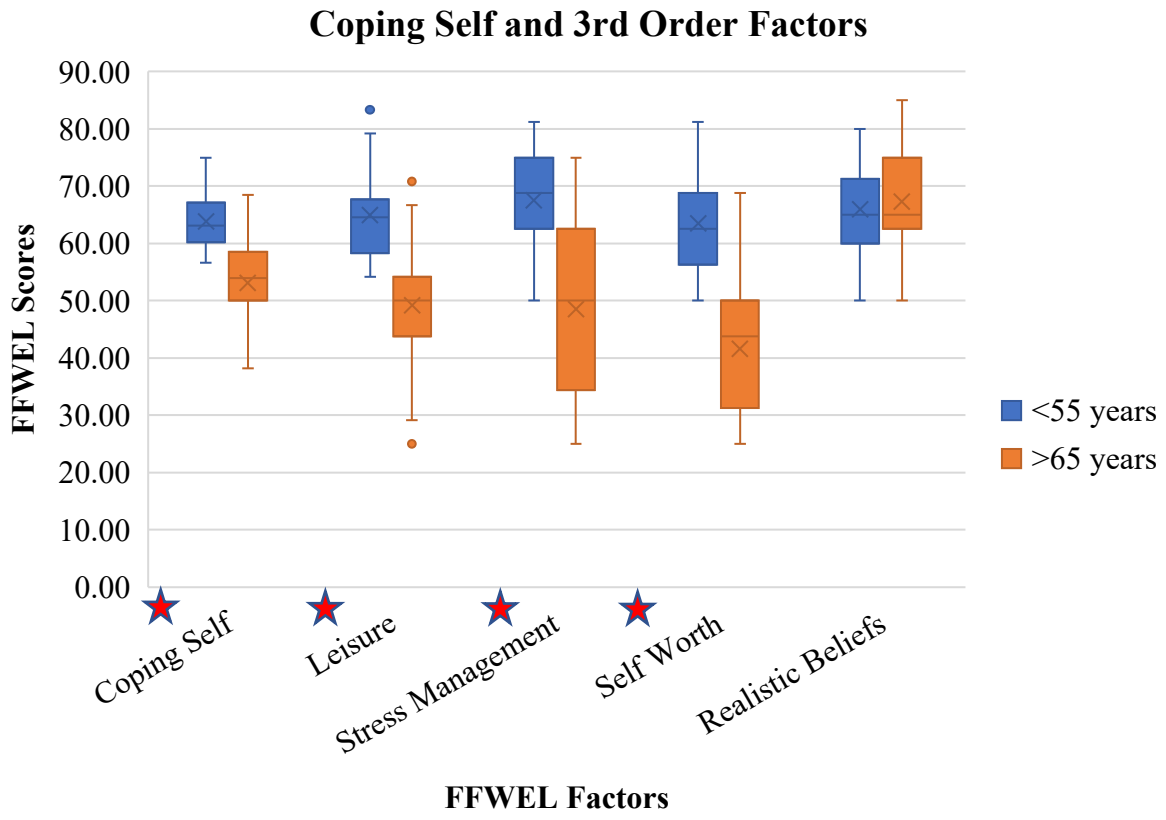


Table 5

Statistical results from t-tests comparing younger and older total laryngectomy groups for the second order factor Coping Self and associated third order factor. T = t-value, df = degrees of freedom (non-whole numbers indicate equal variances not assumed), adjusted p = one-sided probability after Holm-Bonferroni adjustment

First Order Factor	Third Order Factors	*t*	*df*	Adjusted *p* value	Cohen's *d*
Coping Self		6.52	53.00	<0.0001	1.76
	Leisure	5.71	53.00	<0.0001	1.54
	Stress Management	5.88	44.40	<0.0001	1.54
	Self-Worth	8.26	49.43	<0.0001	2.18
	Realistic Beliefs	-0.59	52.91	1.0000	-0.16

Social Self and Associated Third Order Factor

A boxplot showing the median, mean, interquartile range, and minimum and maximum values of the FFWEL *Social Self* second order factor and the associated third order factors for the younger and older groups is depicted in Figure 6. There was not a statistical difference between the older (M 41.70, SD 12.31) and younger TL groups (M 48.32, SD 7.67) for the second order factor, *Social Self* (t [47.51], p =0.1171) which had a medium effect size (Table 6). Similarly, no significant difference between the two groups was found based on the t-test results for the third order factors of *friendship* and *love,* which both are measures of social connections and relationships (Table 6). Both third order factors had a medium sized Cohen's *d* value.

Figure 6

Social Self and associated third order factor boxplots for the younger and older total laryngectomy groups

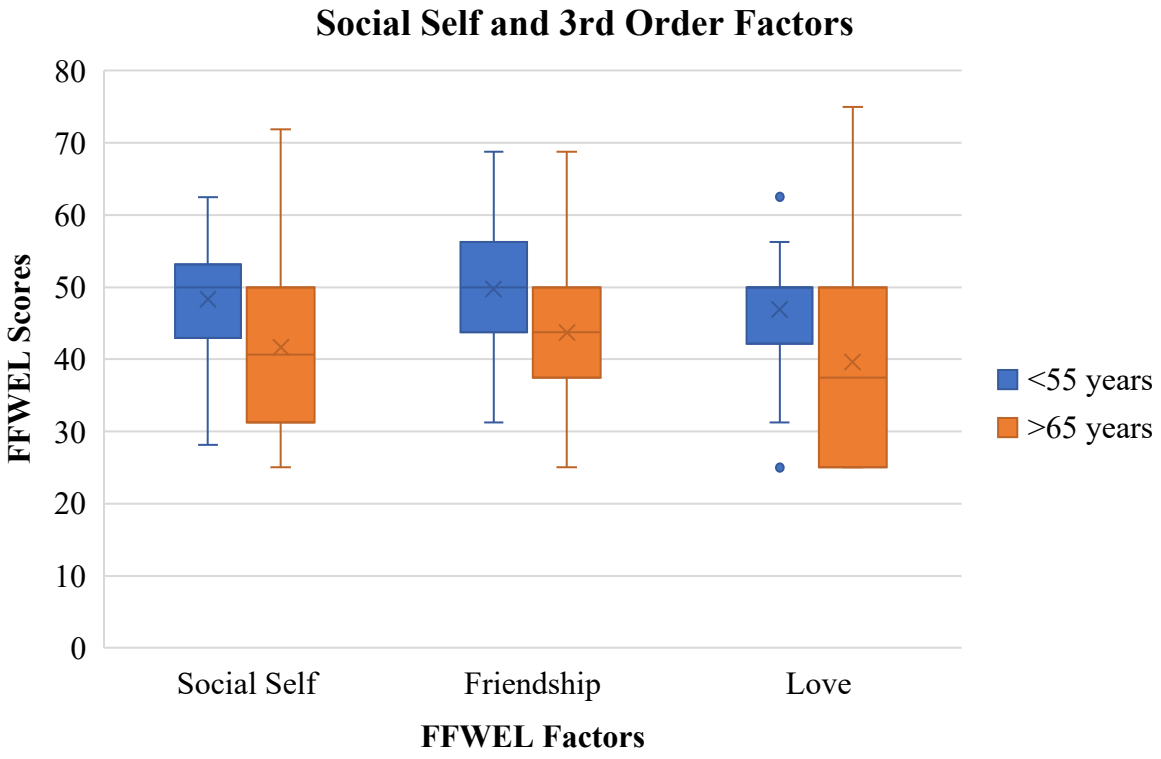


Table 6

Statistical results from t-tests comparing younger and older total laryngectomy groups for the second order factor Social Self and associated third order factor. T = t-value, df = degrees of freedom (non-whole numbers indicate equal variances not assumed), adjusted p = one-sided probability after Holm-Bonferroni adjustment

First Order Factor	Third Order Factors	*t*	*df*	Adjusted *p* value	Cohen's *d*
Social Self		2.42	47.51	0.1171	0.64
	Friendship	2.21	47.36	0.1704	0.58
	Love	2.22	49.19	0.1704	0.59

Essential Self and Associated Third Order Factors

A boxplot showing the median, mean, interquartile range, and minimum and maximum values of the FFWEL *Essential Self* second order factor and the associated third order factors for the younger and the older TL groups is depicted in Figure 7. There was not a statistical difference between the older (M 53.10, SD 9.83) and younger TL groups (M 56.84, SD 3.79) for the second order factor, *Essential Self* (t [36.90], p =0.2295) which did have a medium effect size (Table 7). A significant difference between the groups was found for the third order factor of *cultural identity*, with the older group reporting significantly lower scores. *Cultural identity* relates to satisfaction with and feeling supported by one's cultural identity. A large Cohen's *d* value was reported for this factor. The remaining third order factors of *gender identity* (satisfaction with and feeling supported by one's gender), *self-care* (taking responsibility for one's own wellness), and *spirituality* (beliefs and behaviors practiced in recognition that one is more than the material aspect of mind and body) did not differ significantly between the groups and effect sizes ranged from small to medium (Table 7).

Figure 7

Essential Self and associated third order factor boxplots for the younger and older total laryngectomy groups (red star indicates statistically significant group difference)

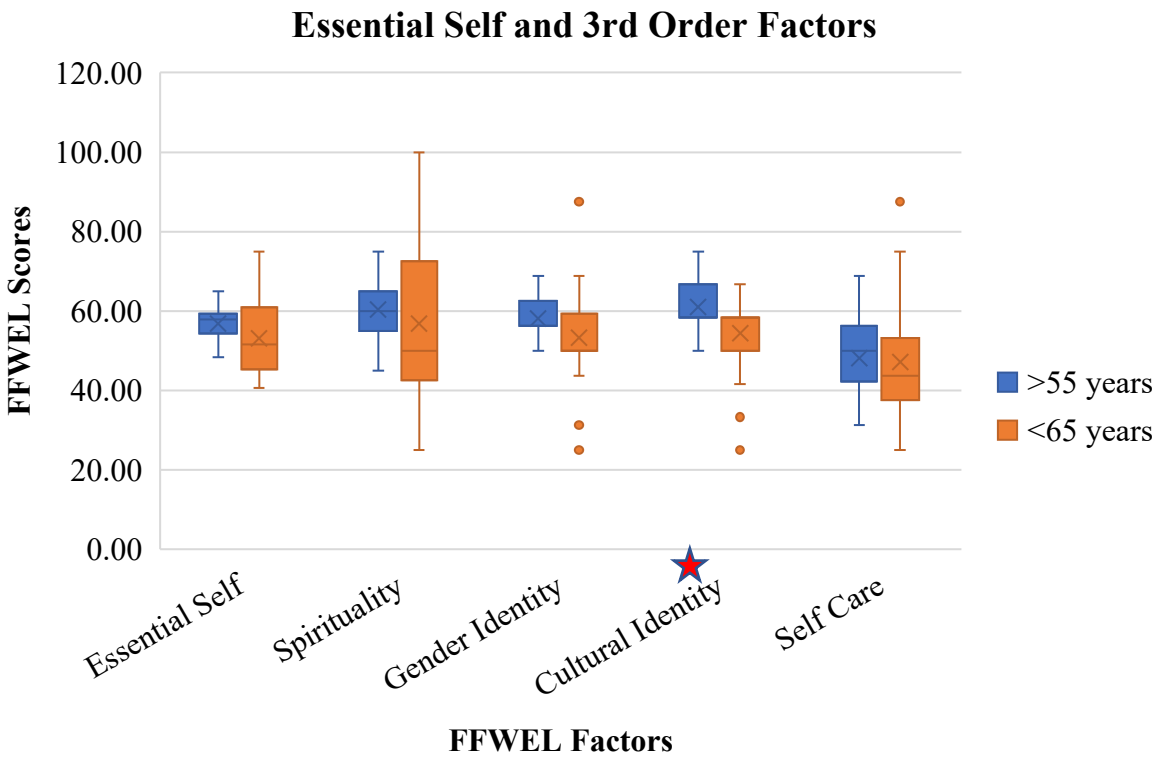


Table 7

Statistical results from t-tests comparing younger and older total laryngectomy groups for the second order factor Essential Self and associated third order factor. T = t-value, df = degrees of freedom (non-whole numbers indicate equal variances not assumed), adjusted p = one-sided probability after Holm-Bonferroni adjustment

First Order Factor	Third Order Factors	*t*	*df*	Adjusted *p* value	Cohen's *d*
Essential self		1.90	36.90	0.2295	0.49
	Spirituality	0.77	35.67	1.0000	0.20
	Gender Identity	2.05	39.57	0.1900	0.53
	Cultural Identity	2.94	46.57	0.0352	0.77
	Self-care	0.26	53.00	1.0000	0.07

Physical Self and Associated Third Order Factors

A boxplot showing the median, mean, interquartile range, and minimum and maximum values of the FFWEL *Physical Self* second order factor and the associated third order factors for the younger and the older TL groups is depicted in Figure 8. There was not a statistical difference between the older (M 55.46, SD 10.11) and younger TL groups (M 56.92, SD 8.87) for the second order factor, *Physical Self* (t [53], p =1.00) which did have a small effect size (Table 8). There was no significant difference found between the two groups based on the t-test results for the third order factors of *exercise* (sufficient physical activity, staying flexible through exercise, work, and leisure activities) and *nutrition* (consuming balanced diet and avoiding overeating) (Table 8). Both third order factors also had a small effect size.

Figure 8

Physical Self and associated third order factor boxplots for the younger and older total laryngectomy groups

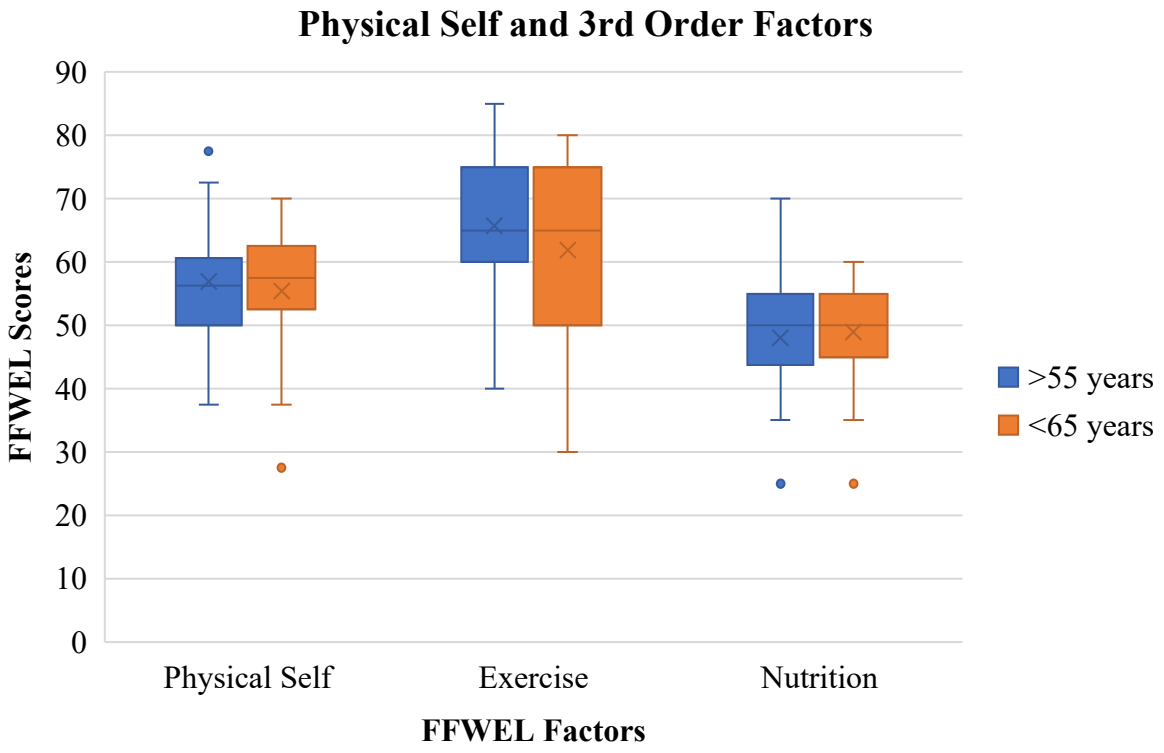


Table 8

Statistical results from t-tests comparing younger and older total laryngectomy groups for the second order factor Physical Self and associated third order factor. T = t-value, df = degrees of freedom equal variances not assumed, adjusted p = one-sided probability after Holm-Bonferroni adjustment

First Order Factor	Third Order Factors	*t*	*df*	Adjusted *p* value	Cohen's *d*
Physical Self		0.58	53.00	1.0000	0.16
	Exercise	1.12	53.00	0.8048	0.30
	Nutrition	-0.32	53.00	1.0000	-0.09

Relationship Between Wellness and Communication Participation (RQ3)

Total Wellness

A Pearson correlation coefficient was calculated to determine the strength and direction of the relationship between younger laryngectomees' *Total Wellness* score and CPIB score. For full details regarding CPIB results and statistical values, see Appendix E. No significant correlation was found between *Total Wellness* score and CPIB score (r = -0.120, p = 0.56).

Creative Self and Associated Third Order Factors

There was no significant correlation found between CPIB score and the second order factor of *Creative Self* or its third order factors of *thinking, emotions,* and *positive humor* (Table 9). In contrast, a significant correlation was found between CPIB score and the third order factors of *control* and *work.* A medium, negative correlation with CPIB scores was found for both factors.

Coping Self and Associated Third Order Factors

No significant correlation was found between CPIB score and the second order factor of *Coping Self* or its associated third order factors based on the Pearson correlation analysis (Table 9).

Social Self and Associated Third Order Factors

Results from the Pearson correlation analysis indicated a significant correlation between CPIB scores and the second order factor of *Social Self* and its associated third order factor of *love* (Table 9). Both factors have a medium, positive correlation with CPIB scores. In contrast, no significant correlation was found between CPIB score and the third order factor of *friendship.*

Table 9

Pearson Correlation and probability (p) of second and third order factors from the Five Factor Wellness Inventory

Second Order Factor	Third Order Factor	Pearson Correlation	Two-Sided *p* Value
Creative Self		**-0.38**	**0.0589**
	Thinking	-0.08	0.6993
	Emotions	-0.20	0.3321
	Control	-0.47	0.0158
	Work	-0.49	0.0136
	Positive Humor	0.06	0.7826
Coping Self		**-0.23**	**0.2518**
	Leisure	-0.31	0.1204
	Stress Mgmt.	-0.11	0.5992
	Self-Worth	-0.32	0.1076
	Realistic Beliefs	-0.07	0.7232
Social Self		**0.47**	**0.0148**
	Friendship	0.28	0.1654
	Love	0.54	0.0049
Essential Self		**0.47**	**0.5556**
	Spirituality	0.15	0.4741
	Gender Identity	-0.13	0.5124
	Cultural Identity	-0.26	0.2084
	Self-Care	0.23	0.2687
Physical Self		**0.10**	**0.6202**
	Exercise	-0.12	0.5714
	Nutrition	0.27	0.1886

Essential Self and Associated Third Order Factors

No significant correlation was found between CPIB score and the second order factor of *Essential Self* or any of the third order factors (Table 9).

Physical Self and Associated Third Order Factors

There was no significant correlation found between CPIB score and the second order factor of *Physical Self* or any of the associated third order factors (Table 9).

CHAPTER 4: DISCUSSION

This study had three purposes. The first was to determine if younger adults who have had a TL because of cancer report wellness characteristics that differ from the FFWEL normative data set. The second was to determine if younger and older adults who have had a TL because of cancer differ in terms of wellness. Finally, the study assessed the strength of the relationship between wellness and communication participation for younger adults with a TL.

The results of this study indicated that younger laryngectomees reported lower wellness scores than the normative population for the majority of wellness characteristics assessed by the FFWEL. Additionally, it was found that most wellness factor scores were statistically lower among older compared to younger laryngectomees. Lastly, communication participation was not significantly correlated with *Total Wellness*, but there were significant correlations for some second and third order factors on the FFWEL. Details of these results are discussed below.

Younger Laryngectomees' Wellness versus Normative Data (RQ1)

The hypothesis that younger aged laryngectomees would have lower wellness than people without a laryngectomy was generally supported by the study results. Of the 23 first, second, and third order factors assessed by the FFWEL, 19 were lower in the laryngectomee group, including the *Total Wellness* score. The finding that laryngectomees reported lower wellness across multiple factors is not surprising considering that laryngectomees often report substantial social, physical, mental, and occupational challenges post TL (e.g., Costa et al., 2018; Ferrer Ramirez et al., 2003; Palmer & Graham, 2004). However, the current study adds to the understanding of the impact of TL on a person by providing evidence across a broad range of wellness parameters, many of which have not previously been directly assessed. This includes unstudied or understudied areas of wellbeing that were negatively impacted in the younger TL

group, such as *spirituality* which measures one's belief in a higher power and purpose, *control* which measures competence, confidence, and mastery, *positive humor* which measures one's ability to laugh at self and mistakes, and *cultural identity* which measures one's satisfaction with, and feeling supported by, a person's cultural identity. Overall, this study provides support that one's comprehensive *Total Wellness* is significantly lower after having a TL.

There were four FFWEL third order factors that did not differ between the younger TL group and the normative data. These were *work, realistic beliefs, stress management,* and *exercise*. It was a positive, but unexpected, outcome that work related wellbeing was not significantly lower for the younger TL group. Prior investigation of occupational outcomes in laryngectomees has focused primarily on return to work and availability of job opportunities (Costa et al. (2018); Osazuwa-Peters et al. (2018)). Those studies included a majority of older laryngectomees. In contrast, the present study specifically considered younger-aged laryngectomees, below the usual retirement age, who may need to continue work for economic stability, despite their condition. Additionally, the current study was not focused on availability of work options, but rather on wellbeing associated with working. The FFWEL items that are used to calculate the *work* score focus on issues such as control over working conditions, application of skills to the job, appreciation by co-workers, and positive anticipation about going to work. The results of the study indicate that younger laryngectomees scored comparably to the normative data set in this regard.

The remaining three FFWEL factors that did not differ between the younger TL and normative sample are less readily explained. As previously mentioned, no prior literature has directly addressed how *realistic beliefs* are impacted following a TL. This factor measures how an individual perceives themselves, their roles and responsibilities, and their place in

relationships. The FFWEL questions that pertain to *realistic beliefs* address topics such as feeling the need to keep others happy, tending to jump to incorrect conclusions, and placing importance on being liked by all. Although the hypothesis was that all wellness factors would be lower for the TL group, lack of a significant difference versus the norms is a positive outcome. The reason(s) why the TL patients did not differ on the *realistic beliefs* factor is not discernible from the study. Potential supports, such as pre- and post-operation counseling, for example, could conceivably impact such a factor but that information was not part of the data collected. It may also be that younger TL patients, faced with the seriousness of a cancer diagnosis and its treatment, may have simply established a set of life outcomes and goals that align with where they are at in their own recovery, and issues such as trying to be liked by all people may become low priority Future work involving collection of more detailed information from structured interviews could be helpful.

In terms of *stress management*, Yang et al (2021) reported that laryngectomees typically have less capability to do so than those who have not had to go through the experience of a TL. It may be that reduced *stress management* on the FFWEL did not emerge in this study because younger TLs were specifically targeted. It is possible that the younger TL group included in the study was relatively high functioning as evidenced by the large percentage still working. Additionally, recall that a primary route of participant recruitment was through social media groups catering to the support needs of people with a TL. In this case, it may be that the participants were either inclined to seek supports, which might in turn help them manage stress, or they may be inclined to offer support to others which might provide a sense of self-worth or contribution to other's wellbeing. These speculative comments require more direct and systematic inquiry to confirm or refute.

The last factor that did not differ between the younger TL and normative data set was *exercise*. This finding is in contrast to three prior studies that each indicated a reduction in physical fitness post TL (Hlozek & Hledíková, 1989; Marszałek et al., 2005; Büntzel et al., 2016). Again, the specific focus on younger TLs in the current study may offer one explanation for this contrasting finding. As noted above, younger adults tend to lead more active lives, including physical activity, than older adults in the general population (Whitaker & Bokemeier, 2018) and this same trend may hold for younger TL patients. The current participants also were all working, as noted above, which may indirectly indicate a relatively healthy and physically capable set of people. More recently, Yang et al. (2021) reported that some TL patients adapted well to the significant life changes following the surgery with exercise and positive motivation as influential in this process.

Younger versus Older Laryngectomees' Wellness (RQ2)

The hypothesis that younger laryngectomees would have lower wellness scores than older laryngectomees was not supported by the results of the study. In direct contrast with the hypothesized outcome, older laryngectomees scored statistically lower than younger laryngectomees for the majority of wellness factors that comprise the FFWEL. This included the *Total Wellness* score which was significantly lower for those over age 65 years compared to those younger than 55 years of age.

The hypothesis that having the TL surgery at a younger age would result in lower wellbeing compared to those who were older was based on a few lines of reasoning. One was projecting that there might be a substantial impact on one's sense of worth related to altered roles in the workplace. However, in this study, the younger laryngectomees were employed at a high rate and generally felt valued, had agency, and looked forward to work. The fact that this group of

younger TLs was working indicates that they also had a continued source of income which might mitigate stressors such as being worried about supporting themselves or their family. Additional reasons that contributed to the hypothesis of lower wellbeing for younger laryngectomees was projecting serious alterations to other life roles (e.g., parent, spouse) and the potentially weighty prospect of living for many years as a laryngectomee. These projections may simply have been unfounded or outweighed by other factors that ultimately resulted in lower wellbeing for older laryngectomees.

The simplest, and perhaps most reasonable, explanation for lower wellbeing among older compared to younger laryngectomees is the impact of age itself. Older adults have a higher number of health conditions than younger populations. As reported by the World Health Organization, (2022), the emergence of multiple complex health states, commonly called geriatric syndromes, increases as individuals age. Additionally, research has shown that older adults may experience greater hopelessness and a lack of enthusiasm for life. A study by the Pew Research Center, (2013) found that of the general population, older adults are considerably less optimistic about the future than younger generations.

The self-reported history gathered in the current study is generally supportive of the literature indicating presence of variables that might negatively impact older adults. The older TL group reported a higher number of co-morbidities overall. In particular, hearing loss was reported by 55% of the older laryngectomees, whereas none of the younger group reported hearing loss. Likewise, physical disability was reported by nearly half of the older group compared to 15% of the younger group. Social factors, such as marital status, may also have impacted the wellbeing of the study participants. The older group had 41% reporting that they were divorced or widowed compared to 4% of the younger TL group. Psychological wellbeing has been shown to be higher

in adults who are married (Kim & McKenry, 2002). One additional difference between the two age groups deserves mention as a possible influence on the measure of wellbeing. The use of an HME was notably higher in the younger age group with 71% reporting wearing one "Always" or "Most of the Time" compared to 41% reporting the same in the older laryngectomee group. Wearing an HME is associated with higher quality of life among laryngectomees (Brook et al., 2013), which might contribute to the higher wellbeing in the younger TL group in the current study. Thus, the current findings may reflect a combination of factors that ultimately resulted in lower wellbeing in the older age group.

Relationship Between Wellness and Communication Participation (RQ3)

The hypothesis that communication participation scores would be significantly associated with wellness as partially supported. Four of the twenty three FFWEL factors had significant correlations: *Social Self, love, control,* and *work*. The *Social Self* is a measure of how one can connect with others and build mutual relationships. *Love*, a third order factor under *Social Self*, represents one's ability to be intimate, trusting, and self-disclosing with another person. Communication with others in some fashion seems logically linked to both of these concepts and as such, an association with communication participation scores is logical. Those with lower CPIB scores tended to have lower *Social Self* and *love* wellness scores. These finding are consistent with previous findings indicating that a substantial percentage of people with a TL experience social isolation (Summers, 2017) and a reduction in social relationships (Perry et al., 2015). Specific to the factor of *love*, Offerman et al. (2015) reported that 35% and 31% of spouses reported changes to their social life and sexual relationships, respectively, after their partners had a laryngectomy (Offerman et al., 2015).

The two other wellness factors that significantly correlated to communication participation were *control* and *work*, which are both third order factors under *Creative Self*. Within the FFWEL framework, *control* is "a matter of perceived capacity to influence events in one's life" (FFWEL manual, p. 7). The FFWEL further notes that *work* is a common element in a person's life that has the potential to enhance their ability to live a full life. What is challenging to explain is that the correlations between CPIB and these two wellness factors are negative. This indicated that as communication participation scores increased (i.e., "better" communication participation), wellness scores on *control* and *work* decreased. Specific to *work*, previous research has found that changes to communication abilities after a TL impacts workplace success (Osazuwa-Peters et al., 2018) and so one would anticipate CPIB and *work* wellness to increase (or decrease) in tandem. Similarly, past studies have found that reduced ability to communicate after a TL is associated with a feeling of lack of control over one's life and negative mental health implications (Ferrer Ramírez et al., 2003), which would also lead to the expectation of a postive correlation. At the moment, this set of findings for *control* and *work* remain to be explained. One consideration is to recognize that measuring participation in communication is not the same as measuring actual communication abilities. It seems logical that better communication abilities as an alaryngeal communicator would be associated with greater communication participation in daily activities. However, closer investigation of this issue for people with a TL seems warranted.

In contrast to the four wellness factors above, the remaining wellness factors were not significantly correlated with communication participation. Significant correlations were hypothesized based on previous research that found laryngectomees reported communication limitations that reduced their ability to participate in daily events with a subsequent negative

impact on QoL and social wellbeing (Dahl et al., 2022; Eadie et al., 2016; Sharpe et al., 2019). One potential explanation for a lack of significant correlations may be that the CPIB did not adequately measure the relevant environments and life situations that are important for younger laryngectomees. The ten questions presented in the CPIB short form include scenarios that may be applicable to various communication partners, but none that specifically address the unique challenges laryngectomees face. For example, questions that ask how lack of hands-free speech or use of unnatural sounding voice impact communication are not part of the CPIB. Likewise, the CPIB does not include questions specifically about communicating at work. Future work may need to consider using a mixed methods approach that uses the CPIB with subsequent qualitative interviewing to learn more specifically about the types of communication limitations that a person with a TL is experiencing and how this does or does not impact their wellness.

At face value, the set of correlation results indicated that for this group of younger laryngectomees, a measure of communication participation did not strongly predict most aspects of wellness as reflected by the FFWEL. The group had relatively low CPIB scores, with a mean of 16.81 out of a potential 30 points. Dahl et al. (2022) assessed a number of individual characteristics associated with communication participation as measured by the CPIB after TL. In that study, they did find that reduced CPIB scores were associated with younger age of the person with a TL. They further noted that lower CPIB scores were associated with more reported depression symptoms. Of note in the current study is that 50% of the younger TL group reported some type of mental health condition. Ultimately, Dahl et al. concluded that a range of factors related to a person's communication abilities, demographics, and health may affect communication participation. In the current study, the resulting CPIB scores simply did not

associate strongly with most of the wellness scores and a satisfying explanation for this is not readily apparent.

Limitations

Several limitations of the present study deserve mention. First, results are based on a relatively small sample of younger laryngectomees. The findings point to some potentially complex relationships between wellness and communication that may relate to characteristics of the individual TL participant. As such, much larger study samples will be needed to fully capture phenomenon of interest. Second, the anonymous online survey method does not allow the researcher to verify potentially important characteristics of the respondents (demographics, medical-surgical, etc.) that might potentially be useful in understanding the wellness and communication participation scores.

Another consideration is that the majority of participants included in this analysis are from Facebook HNC support groups. These may represent a unique subset of people with a TL, namely those inclined to join and perhaps need such groups for support. If the participants are more inclined to need support from such groups, they might conceivably be those with greater issues of any variety which might be associated with lowered wellness and communication scores. As such, they would not provide an accurate reflection of the variation in wellness and communication scores for the larger TL population. Alternatively, those who join such social support groups may be more inclined to value their wellness and have access to an increased number of self-health resources than the average laryngectomee. In that case, the FFWEL and CPIB scores in the present study may be higher compared to broader sample of laryngectomees. Additionally, the online survey approach requires internet access. Socioeconomic status is known to be associated with internet access and the ‘digital divide’ continues with nearly one in

four households with incomes below $30,000 reporting they do not own a smartphone, 43% without home broadband, and 41% without a computer (Pew Research Center, 2021). Given this, the sample reported here may be underrepresenting those with lower socioeconomic status, which may also impact overall wellness (J. Wang & Geng, 2019). Finally, for research question 1, the normative sample from the FFWEL were used for comparison. That normative sample consisted of 3,343 adult (Myers & Sweeney, 2014a). However, the way that the normative sample are reported, it was not possible to extract just the age ranges of interest to match the study participants. Thus, the normative group did include participants who were both younger and older than the laryngectomees who participated. Future work could gather data from participants without a TL to more closely match the laryngectomee group of interest.

Conclusion & Future Directions

This study examined wellness and communication participation among people having a total laryngectomy before the age of 55 years. The results indicated that younger laryngectomees did have significantly lower wellness characteristics for the majority of the 23 factors assessed by the FFWEL, compared to the normative population sample. Additionally, older laryngectomees (i.e., $\geq$ 65 years of age) had significantly lower wellness outcomes for most FFWEL factors compared to the younger laryngectomees. Finally, only a few significant correlations were found between wellness and communication participation for the younger laryngectomees, and some of the significant correlations were in the opposite direction of what was expected.

This was the first attempt (of which the author is aware) to comprehensively assess overall wellness of laryngectomees who are at an earlier stage of life than the typical person who undergoes the procedure. The fact that several previously unstudied, comprehensive wellness characteristics are significantly reduced among this population should focus attention and action

on the unique needs of this population. This may include increasing resources that address wellness factors such as spirituality, self-care, emotions, and love. A team approach is likely necessary to comprehensively address such wellness needs, including counselors, SLPs, spiritual advisors, and others. The goal of this treatment would be to holistically treat the person so they can achieve their fullest life. Another meaningful take away worth acknowledging are the extensive and comprehensive wellness care needs among older laryngectomees as well. Total wellness outcomes were worse among older laryngectomees for potentially numerous reasons. However, SLPs can play a critical role in working to improve many of these outcomes, such as social, creative, and essential self-characteristics.

The role of communication, and specifically communication participation, as a contributor to a laryngectomee's wellness will require further investigation. Among this younger group of laryngectomees, communication participation was not strongly associated with most aspects of wellness. That simply may be the situation. However, repeating this study with a larger participant pool and modifying the approach to gather additional information from participants would be helpful. Of particular interest might be collection of voice and speech samples that could be used to evaluate characteristics of the communication itself and not just the person's judgment of communication participation. Additionally, a mixed methods approach with participant interviews and assessment of voice and speech would allow learning directly from the laryngectomee what their unique experiences have been and how they relate to are wellness.

This study focused specifically on younger larynectomees. However, the survey that was launched was open to laryngectomees of all ages as well as to people with other types of head and neck cancer. From the full set of laryngectomees who have completed the survey to date, it

will be possible to revisit some aspects of this study with a larger, more complete data set. For example, the survey now has a relatively large respondent pool somewhat equally distributed across age decades from the 40's through the 80's. This will provide a more complete data set for the consideration of the impact of age among laryngectomees on communication participation and wellness. Analyses that examine and contrast total wellness and communication participation outcomes across different head and neck cancer populations is also of interest in order to better inform clinicians of the unique and the overlapping concerns that are present for patients with labial, lingual, base of tongue, pharyngeal, and laryngeal cancers. Lastly, it will be important in future work to learn whether there are meaningful differences in the wellness and the communication participation experiences of men and women who have had a TL. There are indications that this is so (e.g., Cox et al., 2015), but only limited attention has been given to this issue in the peer reviewed literature.

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APPENDIX A: MEDICAL HISTORY AND COMMUNICATION MODALITY SURVEY

1. What year were you born?
2. Do you have a diagnosed hearing loss?
3. Do you have a diagnosed cognitive impairment? (i.e., dementia, traumatic brain injury, etc.).
4. Do you have a diagnosed mental health condition? (i.e., depression, anxiety, etc.)
5. Do you have any physical or mobility limitations?
6. Where was the cancer in your head and neck located? Check all that apply. [lips, tongue, base of tongue, floor of mouth, roof of mouth, throat, voice box, other].
7. What was the stage of your cancer at the time of diagnosis? [stage 1, stage 2, stage 3, stage 4, unsure].
8. Have you had any type of surgery to remove your head and neck cancer?
9. Have you had a total laryngectomy (complete removal of the voice box)?
10. Besides the laryngectomy surgery, have you received any other surgeries to your head or neck? If so, please list below.
11. What year did you receive a total laryngectomy?
12. What is your primary method of communication? [esophageal speech, tracheoesophageal speech, electrolarynx speech, pneumatic artificial larynx, AAC, other].
13. How often do you wear a Heat - Moisture Exchange (HME) device? [never, sometimes, about half the time, most of the time, always].
14. Have you ever received chemotherapy?
15. Have you ever received radiation?
16. Have you ever received Speech-Language Pathology services?

17. Approximately how many Speech-Language Pathology therapy sessions have you had? [1-5 sessions, 6-10 sessions, 10+ sessions].
18. What has been the main focus of your Speech-Language Pathology services? [electrolarynx training, esophageal speech training, tracheoesophageal speech training, heat-moisture exchange use and training, swallowing, speech production, voice rehabilitation, other].

APPENDIX B: COMMUNICATION PARTICIPATION ITEM BANK – GENERAL SHORT FORM

The Communicative Participation Item Bank – General Short Form

Instructions:
The following questions describe a variety of situations in which you might need to speak to others. For each question, please mark how much your condition interferes with your participation in that situation. By "condition" we mean ALL issues that may affect how you communicate in these situations including speech conditions, any other health conditions, or features of the environment. If your speech varies, think about an AVERAGE day for your speech – not your best or your worst days.

	Not at all (3)	A little (2)	Quite a bit (1)	Very much (0)
1. Does your condition interfere with... **…talking with people you know?**	○	○	○	○
2. Does your condition interfere with... **…communicating when you need to say something quickly?**	○	○	○	○
3. Does your condition interfere with... **…talking with people you do NOT know?**	○	○	○	○
4. Does your condition interfere with... **…communicating when you are out in your community (e.g. errands; appointments)?**	○	○	○	○
5. Does your condition interfere with... **…asking questions in a conversation?**	○	○	○	○
6. Does your condition interfere with... **…communicating in a small group of people?**	○	○	○	○
7. Does your condition interfere with... **…having a long conversation with someone you know about a book, movie, show or sports event?**	○	○	○	○
8. Does your condition interfere with... **… giving someone DETAILED information?**	○	○	○	○
9. Does your condition interfere with... **…getting your turn in a fast-moving conversation?**	○	○	○	○
10. Does your condition interfere with... **…trying to persuade a friend or family member to see a different point of view?**	○	○	○	○

APPENDIX C: DESCRIPTIVE STATISTICS REGARDING PARTICIPANT DEMOGRAPHICS AND MEDICAL HISTORY

Table 14

Gender, race, and ethnicity frequency counts and distributions for each age group

Statistic		Age Groups			
		<55 years (n=26)		**≥ 65 years** (n=29)	
Gender					
	Male	15	58%	28	97%
	Female	11	42%	1	3%
Race					
	White	21	81%	21	72%
	Black	1	4%	4	14%
	Indian	2	8%	0	0%
	Asian	1	4%	3	10%
	Islander	0	0%	1	3%
	Other	1	4%	0	0%
Ethnicity					
	Hispanic	0	0%	2	7%
	White alone	21	81%	19	66%
	Black non-Hispanic	1	4%	4	14%
	American Indian non-Hispanic	1	4%	0	0%
	Asian Hispanic	1	4%	3	10%
	Islander Non-Hispanic	1	4%	1	3%
	Other non-Hispanic	1	4%	0	0%
	Multiracial	0	0%	0	0%

Table 15

Descriptive statistics regarding marital, employment, and educational status

Statistic	**Age Groups**			
	< 55 years		**≥ 65 years**	
Marital Status	**N**	**%**	**N**	**%**
Married	21	81%	15	52%
Single	1	4%	2	7%
Separated	3	12%	0	0%
Divorced	1	4%	3	10%
Widowed	0	0%	9	31%
Employment Status				
Full Time	16	62%	2	7%
Part Time	10	38%	4	14%
Retired	0	0%	21	72%
Retired, Part Time	0	0%	2	7%
Not Working	0	0%	0	0%
Highest Degree				
Less than High School	0	0%	0	0%
High School Graduate	0	0%	9	31%
Trade School	11	42%	6	21%
Bachelor's Degree	14	54%	9	31%
Advanced Degree	1	4%	5	17%

Table 16

Descriptive statistics regarding physical and mental health conditions

Statistic		**Age Groups**			
		<55		**≥ 65**	
Hearing Loss		**N**	**%**	**N**	**%**
	Yes	0	0%	13	55%
	No	26	100%	16	45%
Cognitive Impairment					
	Yes	0	0%	0	0%
	No	26	100%	29	100%
Mental Health					
	Yes	13	50%	2	7%
	No	13	50%	27	93%
Physical Health Condition					
	Yes	4	15%	14	48%
	No	22	85%	15	52%

APPENDIX D: FIVE FACTOR WELLNESS INVENTORY (FFWEL) STATISTICAL RESULTS FOR YOUNGER AND OLDER ADULTS WITH A TOTAL LARYNGECTOMY

Table 17

SD = standard deviation, min = minimum, max = maximum.

	Younger Adult (<55 Years)				Older Adult (≥ 65 Years)			
	Mean	**SD**	**Min**	**Max**	**Mean**	**SD**	**Min**	**Max**
Total Wellness Score	**61.84**	**4.93**	**50.55**	**78.03**	**53.14**	**7.17**	**37.36**	**62.64**
Creative Self	**61.25**	**5.23**	**47.62**	**70.24**	**49.92**	**9.41**	**28.57**	**67.86**
Thinking	56.54	5.79	40.00	65.00	50.52	9.67	25.00	65.00
Emotions	56.01	7.60	37.50	68.75	50.22	12.55	25.00	75.00
Control	56.41	9.52	41.67	83.33	46.55	9.58	25.00	66.67
Work	71.92	9.17	55.00	90.00	54.31	13.29	25.00	75.00
Positive Humor	62.74	10.68	31.25	81.25	46.55	12.23	25.00	75.00
Coping Self	**63.87**	**5.23**	**56.58**	**75.00**	**53.13**	**6.79**	**38.16**	**68.42**
Leisure	64.90	8.59	54.17	83.33	49.14	11.49	25.00	70.83
Stress Management	67.55	8.30	50.00	81.25	48.49	15.09	25.00	75.00
Self-Worth	63.46	7.84	50.00	81.25	41.59	11.61	25.00	68.75
Realistic Beliefs	65.96	7.49	50.00	80.00	67.24	8.72	50.00	85.00
Social Self	**48.32**	**7.67**	**28.13**	**62.50**	**41.70**	**12.31**	**25.00**	**71.88**
Friendship	49.76	7.60	31.25	68.75	43.75	12.27	25.00	68.75
Love	46.88	9.56	25.00	62.50	39.66	14.30	25.00	75.00
Essential Self	**56.84**	**3.79**	**48.44**	**65.00**	**53.10**	**9.83**	**40.63**	**75.00**
Spirituality	60.34	8.06	45.00	75.00	56.90	22.65	25.00	100.00
Gender Identity	58.17	5.23	50.00	68.75	53.23	11.77	25.00	87.50
Cultural Identity	61.06	6.12	50.00	75.00	54.45	10.20	25.00	66.67
Self-Care	48.08	9.96	31.25	68.75	47.20	14.13	25.00	87.50
Physical Self	**56.92**	**8.87**	**37.50**	**77.50**	**55.43**	**10.11**	**27.50**	**70.00**
Exercise	65.77	10.36	40.00	85.00	61.90	14.66	30.00	80.00
Nutrition	48.08	11.32	25.00	70.00	48.97	9.39	25.00	60.00

APPENDIX E: COMMUNICATION PARTICIPATION ITEM BANK (CPIB) STATISTICAL RESULTS FOR YOUNGER ADULTS

Table 18

SD = standard deviation, min = minimum, max = maximum.

Statistic	Age Group
	<55 years
Mean	16.81
SD	5.84
Min	0
Max	25
Range	25