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Translating the Evidence: Comprehensive Approaches for Head and Neck Cancer Prehabilitation

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Translating the Evidence: Comprehensive Approaches for Head and Neck Cancer Prehabilitation

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A doctoral project submitted in partial fulfillment of the requirements for

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Abstract

Head and neck cancer survivors experience significant changes to their health, well-being, and ability to participate in daily life activities as a result of cancer treatment. Oftentimes, these patients are left to their own devices without concrete instructions or strategies to mitigate, much less prevent, the sequelae they experience. Likewise, interdisciplinary teams lack an evidence-based framework in which to provide comprehensive supportive care for patients with head and neck cancer. Despite acknowledgement within the occupational therapy profession of the chronic nature of survivorship (Baxter et al., 2017) and the national public health initiatives to prevent and reduce the impact of secondary chronic disease burden (American Occupational Therapy foundation, n.d.; National Center for Chronic Disease Prevention and Health Promotion (U.S.) et al., 2004), there remains a critical gap in preventative services in head and neck cancer populations regarding known side effects of cancer treatment (Berkowitz et al., 2018; Fang & Heckman, 2016; Rogers et al., 2011). Therefore, a review and critical appraisal of the existing evidence surrounding prehabilitation as a model of care and the role of occupational therapy with head and neck cancer survivors was indicated. The evidence review and critical appraisal, which took place in the fall of 2021, provided the underpinning for three knowledge translation projects.

The aims of this doctoral project are to increase awareness of head and neck cancer survivors’ needs and to share knowledge concerning evidence-based interventions and approaches to meet these needs. To accomplish these aims, I selected three different methods to translate knowledge. In the first project I sought to educate generalist practitioners and students in the context of a collaborative synchronous webinar series with the Minnesota Occupational Therapy Association about implications for practice. The second project involved a live webinar embedded within a semi-annual meeting of the Michigan Occupational Therapy Association Oncology Special Interest Section. Attendees in this project were assumed to have had at least minimal training or experience in oncology practice and included a
range of practitioners and students. Attendees also participated in discussion pertaining to implementation. The third project was a scoping review article submitted to the interdisciplinary journal *Archives of Physical Medicine and Rehabilitation*. This article serves as a method to reach a wide audience in terms of discipline as well as geographic location.

Together, these three projects provided a variety of opportunities to increase knowledge about prehabilitation and occupational therapy approaches in the supportive care of head and neck cancer survivors. In light of the vast scope of this project, future refinements of the recommended model are expected. Additional information and input from other disciplines would serve the usability of the model well. Future planned projects include a poster presentation at the American Congress of Rehabilitative Medicine Annual Conference in the fall of 2022, in addition to a critical issues article in the *American Journal of Occupational Therapy* to provide a call to action for occupational therapy practitioners to take their place on the interdisciplinary team.
Chapter 1. Introduction and Background

Student and Project Background

I became an occupational therapist because, like many entering a health profession, I wanted to help people and make a difference in others’ lives. I “happened upon” occupational therapy (OT) in my senior year of high school, uncertain what I wanted to do next, by looking through a course catalog for my local community college. My mom read off the description and the two pieces that stood out to me were essentially the science and the art, the mind and the heart that I now live and breathe as an occupational therapist. I am driven by both the need to understand the processes or reasons behind the human experience and the lived experience itself. There is no greater honor to me than hearing a person’s story, hearing daily struggles, celebrating big and small victories, and being able to offer them hope. As a neutral party, I have the luxury of listening and caring without expectations or limitations brought on by family roles.

As an occupational therapist, my ultimate goal is to help people live their lives to the fullest, to reach their potential regardless of diagnosis or prognosis. Since I began specializing in oncology and lymphedema in 2015, I have witnessed first-hand the severe impact of cancer treatment on daily life and the need for OT in oncology. Cancer is unkind. Its onset and threat of return are life changing. It affects every system of the body and every part of one’s life. The beauty in it all is that life is inherently meaningful, no matter the stage of disease. One group of patients that stands out to me with particular needs is comprised of those with head and neck cancer (HNC).

The first time I ever treated a patient with head and neck lymphedema I was astounded by how seemingly barbaric the surgery was, the patient having had his tongue removed and replaced with flesh (complete with hair!) from his forearm. He had more than 50 lymph nodes removed. His mouth was constantly dry and plagued with thrush. He still had a feeding tube and would likely never eat normally again. And despite his best efforts, his speech was intelligible but would never sound normal either. The
pain he described and the neck and shoulder dysfunction he displayed were profound. He had been hospitalized for dehydration, infections, and problems with his feeding tube. He was terrified he would never be able to return to work because he was not financially in a position to retire, and more significantly to him, he found deep meaning, purpose, and connection through work. He described to me that the hardest part was that he felt scared and “in the dark” about each step of his treatment, that he really had no idea how to prepare himself or what to expect. I naively thought this gentleman’s experiences must be unique: surely not all HNC patients have such invasive medical intervention; surely they do not all have such severe problems afterwards; surely they do not go into their treatment without proper education, support, or resources. I was sorely mistaken in my thinking.

Over the last 7 years, I have seen this gentleman’s story play out time and time again. Patients with HNC are often recommended to receive invasive treatment and surgeries. Their problems during and after treatment affect their lives greatly. Unlike other cancer populations with whom I have worked, it seems that nearly 100% of patients with HNC experience some degree of fatigue, weight loss or malnutrition, lymphedema, dysphagia, speech impairments, and pain, among others. And each time, the patient asks me, “Why didn’t anyone tell me this could happen? Why didn’t anyone help me through it?” At the same time, a major growing initiative in my clinic was prehabilitation with the breast cancer population. We had instituted a very successful prospective lymphedema surveillance protocol and OT is involved with every patient diagnosed with breast cancer in our hospital system at least once. The physicians are very supportive of this model of care, and we repeatedly receive high praise from various stakeholders, including our patients and hospital administrators alike. Despite the program’s success, it has never seemed right or fair that patients with breast cancer receive such excellent proactive care, while patients with HNC do not. Would they not benefit from education ahead of time? Would they not benefit from identifying problems early? As a result of these two burdensome questions, I chose to
focus my doctoral studies on OT intervention for patients with HNC using a prehabilitative model of care.

**Qualifications and Expertise**

As a registered and licensed occupational therapist, I completed my lymphedema certification training in 2016 and sat for my board examination in 2017. I have completed much additional coursework in breast cancer rehabilitation, general oncology rehabilitation, and ongoing lymphedema-related topics (i.e. lipedema, surgery, venous disease, management topics). As an adjunct instructor in an entry-level master’s program, I teach content pertaining to cancer, end of life, lymphedema, chronic swelling, and wound care. I provide multiple in-services per year in various departments of our hospital regarding oncology and lymphedema topics, such as the generalist’s role in lymphedema management in home health, long term functional needs of patients with a cancer history in a meeting of primary care physicians, or advanced toe bandaging strategies in the wound clinic. Additionally, as a level II fieldwork educator, I work hard to incorporate current evidence and focus on occupation. Research in oncology and lymphology is evolving rapidly, and consuming research is a habit in my practice. I believe my advanced certification, training, teaching and presenting experience, and ongoing learning in these areas support my qualifications for this project.

**Background Information on Head and Neck Cancer and Related Intervention**

More than 54,000 people in the US were diagnosed with HNC in 2021 (National Cancer Institute, n.d.). Often its survivors undergo intensive, numerous, and medically complex procedures and treatments, which can result in significant changes to one’s quality of life (QOL) and daily occupational performance (Amin et al., 2017; Barnard et al., 2016; Hortense et al., 2020; Llewellyn et al., 2006; Molassiotis & Rogers, 2012; Nixon, Pigott, et al., 2018; Yueh-Hsia et al., 2018). To address these long term changes and issues, occupational therapy is a logical match (Amanat & Morikawa, 2020). However, to date, there has been no critical appraisal of the evidence surrounding occupational therapy
interventions and models of care (including prehabilitation) for clients with HNC. Prior to critical appraisal of the evidence, a background search was performed to better understand the population, the existing interventions and models of care, and interdisciplinary team member contributions.

**About Head and Neck Cancer**

*Head and neck cancer* refers to a collection of cancers arising from the tissues and structures in the larynx, lips, oral cavity, and pharynx (Stoyanov et al., 2017). The most common histopathological groups include squamous cell carcinoma (SCC) and adenocarcinoma. Primary tonsillar, epithelial, lymphoid, and connective tissue malignancies occur in the head and neck region as well (Stoyanov et al., 2017). There are several known contributing lifestyle and genetic factors related to HNC. High alcohol consumption, tobacco use, or especially when the two are combined increase an individual’s risk for cancers involving the oral cavity, hypopharynx, oropharynx, and larynx (Islami et al., 2021). Another contributing factor is the type 16 variant of the human papilloma virus (HPV-16), accounting for an increasing number of tumors affecting the oral cavity and pharynx (Islami et al., 2021; Lawrence et al., 2015; National Cancer Institute, 2021d). This increase is theorized to be the result of changes in sexual practices in recent decades (increased number of average partners, etc.) and its contribution to increasing rates of sexually transmitted diseases, including HPV (Islami et al., 2021). Therefore, HPV-associated SCCs of the oropharynx continue to rise. As mentioned above, tobacco use is a main contributing lifestyle or environmental factor associated with laryngeal cancers. Tobacco use has been steadily declining in the U.S. since the early 2000s, and as a result, laryngeal cancer rates have also declined (Islami et al., 2021).

**Demographics, Incidence, and Prevalence**

Oropharyngeal cancer is most common among men (17.3 per 100,000 men versus 6.5 per 100,000 women), and although it is found in people of all races, it is most prevalent among white individuals (National Cancer Institute, n.d.). There were approximately 54,000 new cases of and 11,000
deaths due to HNC in 2021. Median age at diagnosis was 64 years, and the 5-year survival rate overall is 66.9% (National Cancer Institute, n.d.). If diagnosed in early stage disease (local invasion only), the 5-year survival rate is above 85%; however, at the time of diagnosis, nearly 70% of individuals have at least regional advancement of disease (National Cancer Institute, n.d.).

**Typical Course of HNC Treatment**

Medical treatment for HNC encompasses preventative, curative, and palliative approaches (National Cancer Institute, 2021b, 2021d). In addition to broad public health efforts to address tobacco and alcohol abuse, national public health initiatives related to HNC have centered on the HPV vaccine in recent decades (National Cancer Institute, 2021d). As a greater number of people are immune to HPV, there is less opportunity to transmit/contract HPV. In turn, by not contracting HPV, the risk of developing HPV-associated SCC is mitigated. At this time screening for HNC is limited to routine visual and physical examination (National Cancer Institute, 2021d).

Individuals with HNC are often symptomatic at the time of diagnosis; symptoms vary and depend on the tissue and structures involved. Commonly, patients present with complaints of palpable lumps, changes in voice quality, pain, or visible changes in tissue appearance (National Cancer Institute, 2021b). The diagnosis of HNC involves a physical examination, tissue biopsies, and imaging, such as CT, MRI, or PET scans (National Cancer Institute, 2021b). Patients enter the medical pathway via primary care physicians; ear, nose, and throat specialists; dentists; or oral surgeons. Surgery is utilized to remove or debulk tumors and stop the spread of invasion (Bulsara et al., 2018). It is not uncommon for more than 20 lymph nodes to be removed from one or both sides of the neck. Other surgeries include partial or total removal of the tongue, jaw, or cheek which may be reconstructed using bone from the hip and/or titanium, nerve grafts from the lower leg, and tissue flaps from the leg, forearm, or lateral chest wall (Bulsara et al., 2018). Occasionally, patients require a total laryngectomy, resulting in loss of voice function. Depending on the specific procedure, these patients can either utilize an external artificial
larynx device, which is held to the throat to recreate sound, or they may opt for an internal prosthesis, created at the site of their laryngectomy stoma (Bulsara et al., 2018). When the stoma is covered with the patient’s hand, airflow is rerouted in such a way that allows the patient to produce a more natural voice sound than with an external device. Complications, however, include stoma infection or prosthetic failure (Jacobson, 2018; Singer et al., 2014). For any patient undergoing radiation, the medical team may recommend a feeding tube, which could be permanent if the patient is unable to regain sufficient and safe swallowing function after treatment (Falchook et al., 2016; Glenny et al., 2010). Radiation and chemotherapy are both commonly utilized to treat HNC. Due to the effects on dentition, if there are any teeth that will likely die during radiation, they must be surgically extracted prior to beginning radiotherapy (Eliyas et al., 2013; National Cancer Institute, 2021b).

**Effects of HNC Treatment on Daily Life**

Due to the invasiveness of the treatment and the nature and locations of the structures involved, the long term effects of HNC treatment can cause significant limitations on QOL, performance of valued routines, role fulfillment, and participation in meaningful tasks and activities (Berkowitz et al., 2018; Giuliani et al., 2019a; Isaksson, Salander, et al., 2016; National Cancer Institute, 2021c). More specifically, radiation causes fibrosis and decreases soft tissue extensibility, halts saliva production and alters sensation. Radiation can also contribute to hearing loss and vestibular dysfunction. Typical side effects of chemotherapy include changes in taste, cognitive impairments (temporary or permanent, mild “fogginess” to moderate), and cardiomyopathy (National Cancer Institute, 2021c; Potter & Gentry, 2018; Verma et al., 2019). These side effects altogether create chronic dry mouth and increase the risk of fungal and bacterial infections. Constitutionally, patients complain of deconditioning and fatigue that does not match the level of exertion or amount of sleep obtained. Soft tissue quality changes, scar tissue, and removal of tissue result in decreased mobility of the neck, jaw, and shoulders. Most patients after radiation experience some level of dysphagia, and for more involved cases, malnutrition remains a
long term concern (Fang & Heckman, 2016). Lymphedema caused by direct injury to lymphatic vessels and lymph node removal in surgery and/or radiation as well as surgery itself can result in facial disfigurement and related psychosocial effects (Davidson & Williams, 2019). Other complications include trismus (commonly referred to as “lockjaw,” or chronic loss of jaw ROM), chronic oral pain, and necrosis.

Occupational therapists are chiefly concerned about the client’s overall ability to participate in meaningful living and are experts in the things that comprise daily life. For patients with HNC, the combined interaction of multiple dysfunctions and stressors (i.e. dysphagia, pain, and financial stress) has a substantial impact on one’s daily life (Amanat & Morikawa, 2020; Isaksson et al., 2016). For example, people with HNC have difficulty eating to meet health/nutritional needs and participate in meal-centered social events (Amanat & Morikawa, 2020; Checklin et al., 2020). Moreover, the interplay of fatigue, neck and shoulder dysfunction, communication deficits, and depression can negatively affect returning to driving (Yuen et al., 2007) and work (Giuliani et al., 2019a; Isaksson, Wilms, et al., 2016).

Depression is highly prevalent among HNC survivors, and they are more likely to commit suicide than survivors of other types of cancer (Anguiano et al., 2012). In one retrospective survey of 350,413 HNC patients from the Surveillance, Epidemiology, and End Results (SEER) registry from 1973 to 2011, HNC survivors were at a 3 times greater risk of suicide than the general U.S. population (Kam et al., 2015). HNC survivors are less likely to return to work (RTW) and experience financial hardship, loss of social connections, and diminished self-efficacy as a result (Giuliani et al., 2019a). Navigating life activities amidst and after medical treatment requires specific knowledge and strategies – whether compensating for a loss of function or in attempts to restore the patient to their prior level of function, in their preferred manner of performance (McEwen et al., 2016).

**Intervention Approaches**

The dominant approach to intervention noted in the literature is the traditional post-treatment rehabilitative model. Intervention consisting of speech therapy, physical therapy, and/or occupational
therapy is initiated upon identification of any functional limitation (Cohen et al., 2016; Guru et al., 2012; Roy et al., 2021). In other areas of oncology, particularly breast cancer, prehabilitation is gaining increasing recognition (Harcrow et al., 2020). Prehabilitation aims to prevent or minimize treatment side effects on daily living and overall health through education, exercise programs (if applicable), and baseline testing completed prior to treatment (Silver & Baima, 2013). This may be followed by prospective monitoring.

Authors have argued for the role of occupational therapy in the post-treatment setting, and interestingly, in the pre-treatment setting beginning more than 40 years ago (Amanat & Morikawa, 2020; Dudgeon et al., 1980; Park & Hashmi, 2018). Contemporary approaches to OT intervention for HNC are delineated by stage of medical treatment and setting: prehabilitation, acute care/inpatient rehabilitation, and outpatient/long term rehabilitation (Park & Hashmi, 2018). In each stage and setting, occupational therapists provide interventions for physical, functional, cognitive, and psychosocial limitations.

**Review of Evidence on Head and Neck Cancer and Related Intervention**

**Theme 1: Effective Educational Intervention**

HNC survivors experience significant changes to their life roles, routines, and health. According to the literature, education is a key intervention for achieving optimal physical, financial, and mental health (Llewellyn et al., 2006). In a cross-sectional survey of 68 HNC survivors, the majority of patients (69%) after treatment indicated they were not satisfied with the information they received prior to treatment (Llewellyn et al., 2006). There is strong level I evidence that HNC survivors need and desire education concerning changes to daily routines (i.e. effect of cancer treatment on activity tolerance) and cancer treatment-related side effects (Faithfull et al., 2019; Lang et al., 2013; Lukez & Baima, 2020). Additionally, several level II studies have demonstrated that patients desire to have more information on sleep disturbance and fatigue, speech and eating, length of recovery, attaining/maintaining a healthy
lifestyle, severity of surgery, and HPV (Fang & Heckman, 2016; Rogers et al., 2011). Furthermore, patient satisfaction with information provided is associated with better mental health (Llewellyn et al., 2006).

Although lymphedema affects at least 75% (Deng et al., 2012) and up to 98% of HNC survivors by 3 years posttreatment (Jeans et al., 2020b), patients frequently identify lymphedema as a topic on which they receive insufficient information (Deng & Murphy, 2016; Jeans et al., 2019; Nixon, Pigott, et al., 2018). Appropriate and timely lymphedema education and intervention can reduce the risk of physical and functional problems, and it can also reduce distress associated with head and neck lymphedema (Nixon, Pigott, et al., 2018).

Furthermore, several researchers have identified important considerations relating to the context in which these educational interactions take place. Lang et al. (2013) argue in their systematic review that through effective therapeutic alliance healthcare professionals can foster an environment in which patients can voice the nature and extent of their needs. Moreover, patients often downplay the severity of their symptoms (such as effect of dysphagia on social engagement), and the responsibility of raising topics related to common issues rests on the healthcare team. There is also consistently favorable, strong evidence regarding how education should be provided. Educational strategies built on self-management principles have been found to be effective for improving QOL and reducing anxiety and depression in patients with HNC (Hortense et al., 2020). A self-management approach focuses on equipping patients with knowledge of their disease and sequelae and empowering them with the language and strategies to successfully manage their health.

Cancer sequelae education is most effectively provided near the time of diagnosis and reinforced in subsequent encounters (Lukez & Baima, 2020), and it is important to provide handouts or other media for the patient to reference later (Verma et al., 2019). By the same token, researchers of one randomized control trial demonstrated that cancer patients enjoy multi-media education methods (i.e. education provided via tablet application, video, or computer module) for preoperative education,
but the end result was the same between groups: anxiety, compliance, and knowledge acquisition outcomes were not significantly different whether education was provided via multi-media methods or traditional methods (Steves & Scafide, 2021).

In whole, there is strong evidence that education is an essential focus of intervention with the HNC population. The research demonstrates the need for specialized and tailored education early on in the cancer treatment process. By meeting educational needs effectively, physical, psychological, and functional issues can be prevented altogether or identified and addressed right away.

**Theme 2: Evidence-Based Intervention**

**Psychological Intervention.** To understand the rich complexities of the psychosocial experience of HNC survivors, much of the existing research is qualitative in nature and provides insight into the psychosocial needs of this population. In a systematic review of qualitative literature, Lang et al. (2013) states that supporting HNC patients “requires a detailed understanding of the ways in which an individual’s sense of self and daily life are disrupted, and a recognition that uncertainty is likely to pervade both the individual’s present and future” (p. 2661). The interdisciplinary healthcare team can best meet the needs of their patients when they employ a holistic approach and engage in a therapeutic alliance (Lang et al., 2013; Semple et al., 2013). Patients are not always comfortable bringing up functional issues because they may think functional issues are insignificant when compared with successful curative treatment. With this idea in view, it is necessary for the clinician to take on the responsibility of bringing up uncomfortable topics, such as dissatisfaction with appearance after surgery. Furthermore, multiple level I studies identified the need for and efficacy of coping strategies for anxiety and depression (Gillis et al., 2014; Hunter et al., 2017a; Yun-Jen Chou et al., 2018).

Healthcare providers also need to be mindful of both the resilience and the contextual stressors present in HNC patients’ lives. Coping with changes as a cancer survivor is a “transformational journey” (Barnard et al., 2016, p. 1). Individuals with cancer need to and often do adapt to many new realities
that affect one’s future and day-to-day life. Financial freedom, roles within relationships, and self-efficacy may be threatened and strained throughout cancer treatment and recovery. Yet, Barnard and colleagues (2016) highlight the resilience and hope people find through a processing approach to the realities of cancer: “Ultimately, adjustment and coping become most constructive when cancer survivors resolve to re-assess life and self through meaning-making, resulting in renewed appreciation of life, appropriate life style changes, and regained confidence in their relational role” (p. 1). Some contextual stressors may be less obvious to healthcare professionals. There is moderate strength evidence to suggest that cancer survivors tend to attribute greater life disruption due to daily stressors, although they experience similar numbers and types of stressors compared to the control group without cancer (Costanzo et al., 2012). Howren et al. (2010) demonstrated that the presence of depression in HNC patients prior to treatment is predictive of presence and greater severity of posttreatment depression. As a result, Howren et al argue that screening and subsequent intervention should be employed prior to cancer treatment as well as regularly after treatment.

A unique topic in the literature relating to the lived experience and psychosocial well-being of HNC survivors is the concept of mask anxiety. This anxiety occurs when patients are undergoing radiotherapy and the head, neck, and shoulders are held in place with a thermoplastic formed mask for the duration of the radiation treatment. For those whom radiation is indicated, they typically receive treatment 5 days per week for up to about 6 weeks. In cohort and qualitative studies, patients describe themselves as unprepared for the psychological experience of the radiotherapy mask (Effeney et al., 2021; Molassiotis & Rogers, 2012; Nixon, Cartmill, et al., 2018). There is limited but promising evidence that occupational therapists can successfully and feasibly prepare patients for this aspect of curative treatment (Effeney et al., 2021), and reduce the “distress, fear, and panic” (Molassiotis & Rogers, 2012, p. 203) induced by the experience. Guided by the Canadian Model of Occupational Performance and Engagement (Townsend et al., 2013), Effeney et al. (2021) provided successful intervention using 1)
internal strategies, such as shifting one’s thinking toward positive topics or aspects of treatment, mindfulness, or prayer; and 2) external strategies, such as distraction with music or external cuing for breathing.

**Physical Health Intervention.** The most prevalent data regarding prehabilitation in head and neck cancer pertains to physical function. The majority of studies in this review were descriptive in nature and identified the prevalence and severity of various sequelae, such as dysphagia, trismus, HNC-related lymphedema, pain, neck and shoulder range of motion (ROM) impairments, and fatigue. Regarding intervention, there is strong evidence that supports the safety and efficacy of exercise programs to prevent or minimize cancer-related fatigue. To successfully do so, it is necessary to design and implement *supervised* exercise programs which are tailored to meet the individual needs of each patient. It is insufficient to instruct patients to “stay active” or to prescribe an exercise program without follow up (D’souza et al., 2020; Meneses-Echávez et al., 2015; Samuel et al., 2013). Based on several systematic reviews and RCTs, there is consistent strong evidence that moderate perceived rate of exertion aerobic exercise combined with resistive exercise that incorporates the whole body is beneficial for maintaining endurance throughout treatment and after treatment (Gillis et al., 2014; Michael et al., 2021; Piraux et al., 2018; Rodriguez et al., 2019). Additionally, there is moderate strength but consistently favorable evidence to support yoga and mindfulness to address pain, QOL, fatigue, and psychosocial sequelae related to cancer (Hunter et al., 2017a; Rodriguez et al., 2019).

Patients with HNC commonly experience dysphagia, xerostomia (dry mouth), and trismus – all of which can contribute to unwanted or critical weight loss and malnourishment, communication deficits, and decreased QOL. Additionally, malnutrition can delay healing time and xerostomia places the patient at an increased risk of bacterial infection (Molassiotis & Rogers, 2012). There is moderate strength evidence to support prehabilitative exercises for preventing or reducing severity of cancer treatment-related dysphagia for HNC survivors (Loewen et al., 2021). The greatest challenge in review of the
literature regarding dysphagia is the lack of consensus on dosage or protocol. However, the common favorable finding is that providing intervention as close to the time of diagnosis as possible affords the most optimal outcomes (Loewen et al., 2021). There is limited evidence available regarding physical interventions for trismus. According to one systematic review of 11 RCTs, there was no significant improvement in trismus whether intervention was provided before, during, or after treatment, or if the intervention consisted of exercise alone, utilized a jaw mobilization device along with exercise, gum chewing, or no exercise (Chee et al., 2021). The authors did, however, identify one RCT that had superior results with low-level laser therapy and exercise versus exercise alone in improving trismus after radiation to the neck (Elgohary, et al., 2015, as cited in Chee et al., 2021).

Lymphedema has long been established as a distressing and complicated sequel to cancer treatment, and this is especially true within the HNC population due to its physical and emotional effects (Nixon, Pigott, et al., 2018). Head and neck lymphedema is not currently preventable or curable but is very common for survivors to develop it within 2-3 years of treatment (Deng et al., 2012; Jeans et al., 2020b). Head and neck lymphedema is frequently overlooked by the interdisciplinary team and the best available evidence for addressing it is to provide education about lymphedema near the time of cancer diagnosis and provide routine prospective screening in all HNC patients. Subsequent early management efforts with traditional lymphedema therapy principles have proven successful in improving swallow function and QOL (Deng & Murphy, 2016; Nixon, Pigott, et al., 2018).

**Special Population Needs.** According to a number of high quality, moderate strength studies (primarily cross-sectional surveys, qualitative studies, and mixed methods studies), there are several HNC subpopulations that present with unique challenges. HNC patients who are younger tend to have lower QOL and greater care needs overall compared to older counterparts (Deng et al., 2013; Schorn et al., 2020; Verma et al., 2019). Younger patients also tend to report higher levels of sexual dysfunction and greater distress due to physical disfigurement (Lang et al., 2013). Moreover, HNC patients who live
in a rural area, are single or widowed, or in any other way socially isolated or lacking social support are also at increased risk of decreased role function and poorer QOL (Deng et al., 2013).

Another special consideration is the stage of disease and related treatment. Not all HNCs are treated the same, and the available descriptive and correlational data regarding disease stage and treatment can assist clinicians in the decision-making process and formulating recommendations. HNC patients with later stage disease tend to have higher rates of depression than those with earlier stages of disease and have different education needs (Llewellyn et al., 2006). Patients with modified radical neck dissection have greater shoulder impairments on average than patients who underwent selective neck dissection (Gallagher et al., 2015), and should therefore be screened carefully for shoulder dysfunction.

**Theme 3: Timing of Intervention**

The concepts of prehabilitation and intervention timing have been frequent subjects of research across cancer populations. The available level I and level II research is overwhelmingly clear that prehabilitative efforts in cancer populations – including HNC – are feasible, safe, and effective for improving physical function, QOL, and reducing fear and anxiety (D’souza et al., 2020; Faithfull et al., 2019; Gillis et al., 2014; Michael et al., 2021; Rodriguez et al., 2019; Samuel et al., 2013; Treanor et al., 2018; Yueh-Hsia et al., 2018; Yun-Jen Chou et al., 2018). The ideal combination is education provided prior to treatment or prior to impairment (Samuel et al., 2013; A. Schaller et al., 2017), followed by supervised, moderate aerobic and resistive exercise during treatment, and then transition into traditional rehabilitation as needed (Hunter et al., 2017b). Lukez & Baima (2020) emphasize the essentiality of intervening as early as is feasible, even if time is short. Indeed, even one week prior to cancer surgery or treatment can be beneficial (Lukez & Baima, 2020). Specific to the HNC population, Schaller et al. (2017) found that within the first 1-2 weeks of radiation, patients are not yet experiencing
significant physical limitations or changes to QOL, and this timeframe may lend itself well for an opportunity to provide education and other intervention if needed.

Timely screening for prehabilitative/rehabilitative needs is an essential component of patient success. In a quantitative, correlational study, Komar and colleagues (2018) state that “despite evidence suggesting that rehabilitation addresses many of their needs, survivors of HNC do not consistently receive rehabilitation services” (p. 1). The authors thus developed and validated the Brief Rehabilitation Assessment for Survivors of Head and Neck Cancer (BRASH) to guide the interdisciplinary team in properly identifying those patients who stand in need of rehabilitative services. The impetus behind the BRASH is consistent with other cross-sectional and qualitative studies in which nurse navigators and patients alike have reported significant unmet needs – needs that most often fall under the scope of supportive services such as occupational therapy, physical therapy, speech therapy, nutrition counseling, etc. (Fang & Heckman, 2016; McEwen et al., 2016; Ringash et al., 2018; Rogers et al., 2011).

In a reliable qualitative study performed by Semple et al. (2008), patients describe the posttreatment phase of HNC as a vulnerable time: HNC patients have fears about recurrence and concerns about the increasing number and persistence of cancer-related problems, but they encounter their team less frequently. Less interaction with the team results in fewer opportunities to share and address concerns. For example, shortly after surgery and shortly after radiation are common times for lymphedema to present. At both of these times, patients should already know the signs and symptoms for which they are looking and the team should be closely assessing for any changes (Nixon, Pigott, et al., 2018).

A secondary purpose of this review was to identify literature pertaining to OT, HNC, and prehabilitation. While overall there is a significant dearth of literature, it is known that the American Occupational Therapy Association (AOTA) and the American Occupational Therapy Foundation (AOTF) have identified prevention of secondary diseases, cancer care, and chronic disease management as imperative intervention outcomes and priorities for research (AOTA, 2020; AOTF, n.d.). Therefore,
prehabilitative efforts and early intervention should be a focus of occupational therapists working with HNC patients. This review identified a single systematic review that examined the timing of OT intervention provided after cancer patients were discharged from the hospital (Taylor et al., 2021). The study focused solely on early intervention after cancer surgery and did not evaluate pre-treatment OT intervention, and the authors identified a significant limitation across studies related to adherence. The results of the systematic review did not reveal a significant difference in outcomes for early or later intervention after surgery (which could be in part due to adherence issues), but programs that tailored their intervention to individual patient needs were most successful (and exhibited better adherence). Interpretation of this review is done so with some caution and there are other studies of higher rigor that can be utilized for program development.

**Theme 4: Return to Work**

Work has been identified as a meaningful area of occupation (AOTA, 2020), and in review of the available literature pertaining to HNC, work is a recurring theme and area of need for survivors. Much of the HNC RTW literature is descriptive and qualitative in nature, reporting on prevalence of early retirement in addition to the lived experience and meaning of work. There were few, low quality studies available that focused on outcomes of intervention. However, there are several promising pilot studies that demonstrate effective screening and planning processes. Patients with HNC are less likely to return to work than people with other types of cancer (Giuliani et al., 2019b); those working in skilled trades are among the most common lines of work to which HNC survivors do return (Yueh-Hsia et al., 2018). As would be expected and consistent with other cancer literature, greater degree of impairment is associated with greater disruption in work and leisure performance at or after 1 year posttreatment (Gallagher et al., 2015). The HNC journey is unique from other illnesses, even other types of cancers. The severity of impairments, number of body systems affected, interrelatedness of impairments, and the visible nature of these impairments are all contributing factors to retiring earlier than planned or
struggling with the RTW process (Isaksson, Wilms, et al., 2016). Moreover, the issues experienced by HNC survivors include but are not limited to: fatigue, psychological problems (concentration, depression, mental strain, burnout, sleep disturbance), nutrition (dysphagia related), communication problems, lack of physical strength, mouth problems, pain, cancer recurrence, facial paralysis, and breathing problems. Nearly all types of work would be affected by some if not all of these issues.

Work provides structure and it meets practical and financial needs. Work is a place where one establishes relationships and can find meaning in employing one’s skills. Loss of employment accentuates the financial strain of cancer, especially if the individual is unable to RTW at all or must seek another type of job (Isaksson, Wilms, et al., 2016; Schorn et al., 2020), and contributes to social isolation. Yuen et al. (2007) performed a cross-sectional study with 83 HNC patients posttreatment and report that 67.5% of their sample drove less frequently or stopped entirely as a direct result of cancer treatment. At the time of the study, 26.5% continued driving less or ceased altogether. For those that did return to driving comparably with pretreatment performance, they did so at approximately 6 months posttreatment. Driving was strongly, positively correlated with RTW; by the same token, driving cessation was strongly, negatively correlated with RTW.

Regarding personal meaning attached to work, Molassiotis & Rogers (2012) summarize HNC survivors’ experience, stating, “Returning to work was equated with returning to normal, which provided an opportunity to regain some control over their lives” (p. 202). RTW needs special attention and is affected by the interplay of physical, psychosocial, and environmental and contextual factors (Hunter et al., 2017b). In a series of pilot and validation studies, Amin et al. (2017) describe the Return to Work Planning Tool (RTW-PT) for cancer survivors. This tool allows occupational therapists to facilitate patient-employer communication and identify and address potential barriers for RTW. Multiple descriptive research studies offer recommendations for further research or intervention to address RTW, citing the need for preparation for the RTW process (Barnard et al., 2016; Fang & Heckman, 2016;
Guided preparation may include educating the patient on what to expect in terms of fatigue or other physical, temporal, or psychological factors that may impact work performance. Furthermore, addressing the physical, virtual, and social environment is essential for successful RTW.

**Significance and Innovation of the Project**

**Significance**

Head and neck cancer nearly always results in multiple, complex, chronic secondary conditions and changes to daily life. There is a plethora of research that indicates patients’ informational and educational needs are vastly unmet, and patients desire more information earlier on in their treatment process (Deng & Murphy, 2016; Fang & Heckman, 2016; Lang et al., 2013; Llewellyn et al., 2006; Rogers et al., 2011). Physical needs are often likewise unmet, overlooked, or minimized in comparison to the greater goal of prolonging the patient’s life (D’souza et al., 2020; Hunter et al., 2017a; Loewen et al., 2021; Nixon, Pigott, et al., 2018; Rodriguez et al., 2019). Primarily qualitative and level II research has identified and characterized unmet psychosocial needs (Barnard et al., 2016; Gillis et al., 2014; Howren et al., 2010; Molassiotis & Rogers, 2012; C. Semple et al., 2013; Yun-Jen Chou et al., 2018). And, while not explicitly named in terms of occupational performance, a number of systematic reviews identified gaps in services and research regarding multi-faceted problems (i.e. the combined effects of neck/shoulder pain, dysphagia, lymphedema, and fatigue) people with HNC experience following medical treatment, such as returning to work, performing self-care, and/or returning to driving (Giuliani et al., 2019a; Isaksson, Salander, et al., 2016; Yuen et al., 2007).

One major aim of the literature review for this project was to determine if evidence supports early intervention models of care (Silver & Baima, 2013). The available, high level research is overwhelmingly clear that prehabilitative efforts in cancer populations, including HNC, are feasible, safe, and effective for improving physical function, QOL, and reducing fear and anxiety (D’souza et al., 2020;
Faithfull et al., 2019; Gillis et al., 2014; Michael et al., 2021; Rodriguez et al., 2019; Samuel et al., 2013; Treanor et al., 2018; Yueh-Hsia et al., 2018; Yun-Jen Chou et al., 2018). In addition to timely, comprehensive education and exercise programs (e.g.), ongoing screening for traditional rehabilitative needs is essential. Some symptoms or issues may be inevitable, but patients have better outcomes when problems are identified and addressed right away (Fang & Heckman, 2016; McEwen et al., 2016; Nixon, Pigott, et al., 2018; Ringash et al., 2018; Rogers et al., 2011).

These findings support the significance of this project: patients with HNC have severe and complicated issues affecting their daily lives, a prehabilitative approach is feasible and more effective than a traditional rehabilitative approach alone, and there is a gap in supportive services, including OT, in place to address these documented issues. In addition to summarizing the needs identified by the current body of research, evidence-based intervention strategies were explored. Each knowledge translation project will provide clinicians with resources to better understand and apply the needs and evidence-based intervention strategies.

Innovation

Current practice trends in OT are focused more on rehabilitation, or providing OT intervention once a patient is already experiencing occupational performance issues or dysfunction. Prehabilitation as a concept aims to prevent issues or dysfunction, and identify and address any issues immediately. Prehabilitation takes many forms, and there are two key definitions of prehabilitation: one emphasizes intervention beginning prior to cancer treatment and one that emphasizes intervention beginning prior to impairment incurred by cancer treatment (Loewen et al., 2021). In the second definition, intervention may be provided after the initiation of cancer care, but before impairment arises. For the purposes of this review, both definitions were included. The following themes emerged regarding effective interventions for patients with HNC: 1) effective educational intervention, 2) other evidence-based intervention, 3) timing of intervention, and 4) return to work. All four of these themes are
interconnected, and demonstrate the need for OT as well as the gap in resources and research specific to OT.

This project highlights a needed paradigm shift for patients with HNC from a reactive approach to one focused on prevention and well-being. This paradigm shift is consistent with desired outcomes of the OT process (AOTA, 2020), the profession’s stated research priorities, including cancer and secondary disease prevention, (AOTF, n.d.), and interdisciplinary practice guidelines pertaining to the lifelong process of survivorship (National Comprehensive Cancer Network, 2021). While there will always be needs in the rehabilitative setting, this approach seeks to prevent and minimize issues as much as possible. Additionally, a prehabilitative or early intervention approach promotes agency and autonomy of the individual, equipping patients to make informed decisions and take actions that lead to more fulfilling lives.

There is additional evidence that prehabilitation at large may be a more cost-effective approach. For example, in a comparison of a prospective surveillance model for breast cancer-related lymphedema versus a traditional model of care (treating lymphedema when it becomes symptomatic), the total cost per person was approximately one-fifth the cost (Stout et al., 2012). It stands to reason that if secondary diseases such as lymphedema or other cancer treatment sequela can be prevented or lessened, financial burden on the patient and other payers would be less. Of course it should be noted that lymphedema prevalence differs significantly between breast and head and neck cancers, with a range of 5-40% and 75-98% respectively (Brayton et al., 2014; Deng et al., 2012; Jeans et al., 2020; Pereira de Godoy et al., 2020; Young-Afat et al., 2019).

A few examples of tools or measures identified in the literature include the Brief Rehabilitation Assessment for Survivors of Head and Neck Cancer (BRASH; Komar et al., 2018) which was developed to assist the interdisciplinary team in identifying when and to which discipline a referral may be indicated post-treatment. The Return to Work Planning Tool (RTW-PT; Amin et al., 2017) was developed
specifically for patients with cancer to assist the patient in identifying barriers for success at work throughout and after cancer treatment. Additional strategies were identified in the literature, including but not limited to: exercise programs (D’souza et al., 2020; Loewen et al., 2021), management of radiotherapy mask anxiety (Effeney et al., 2021), lymphedema management (Deng & Murphy, 2016; Nixon, Pigott, et al., 2018), and education content and delivery methods (Fang & Heckman, 2016; Hortense et al., 2020; Lang et al., 2013; Llewellyn et al., 2006; Lukez & Baima, 2020; Steves & Scafide, 2021; Verma et al., 2019). Furthermore, if prehabilitative or early intervention models are successful in preventing or minimizing physical and emotional effects related to cancer treatment, patients would, in theory, be less likely to be undesirably unemployed, less dependent on others for assistance, and require less healthcare resources in the future. Throughout the literature review, there were no studies identified that evaluated resource use or financial outcomes pertaining to comprehensive prehabilitation/early intervention in HNC populations, although it would be a worthwhile study.

This project overall aims to identify interventions that better meet the needs of people with HNC and communicate the findings to OTs specializing in oncology, generalist OTs and the broader OT community, and interdisciplinary oncology practitioners.

**Proposed Aims of the Project**

The following aims describe the specific purpose and intended impact of each knowledge translation project.

- **Knowledge Translation Project 1**: Disseminate findings, themes, and recommendations for occupational therapy practice to the Minnesota Occupational Therapy Association (MOTA) membership.

- **Knowledge Translation Project 2**: Create a comprehensive evidence-based service delivery model of prehabilitation for patients with head and neck cancer and disseminate the key
tenets of the model to the Michigan Occupational Therapy Association membership in an Oncology Special Interest Section meeting.

- Knowledge Translation Project 3: Advocate for the role of occupational therapy in HNC interdisciplinary supportive care through the development of a paper in an interdisciplinary journal.

The desired impact or results of these projects is that the audience/participants will 1) gain a better understanding of the unique needs of patients with head and neck cancer, 2) have increased awareness of evidence-based intervention strategies, and 3) be able to identify the role of OT in the context of the broader interdisciplinary team.
Chapter 2. Evidence-Based Practice: Prehabilitation in Head and Neck Populations

Knowledge Translation Project 1

Project Aim

The aim of this knowledge translation project is to disseminate findings, themes, and recommendations for occupational therapy practice to the MOTA membership.

Description

This first of three knowledge translation projects occurred within a series of presentations throughout the month of February 2022. The series was a collaborative effort between St. Catherine University and the MOTA and was offered for one hour weekly over four weeks. Two post-professional occupational therapy doctoral students presented each week (eight total students) for 30 minutes each. Within each 30-minute segment, at least five minutes was reserved for participant questions. The cost of attendance was $5 for association members and $25 for non-members, and participants were eligible to receive 1 professional development unit for each hour session attended.

The session in which I presented occurred on a virtual platform on Tuesday, February 22, 2022, from 6:00-6:30 pm CST. My presentation focused on the evidence surrounding early intervention models for patients with head and neck cancer, including implications for interdisciplinary practice, occupational therapy’s role, and general information about the literature review process. The title of my presentation was, “Evidence-Based Practice: Prehabilitation in Head and Neck Cancer Populations.”

Approach

Audience and Venue

The overall approach of this knowledge translation project was dissemination via a virtual continuing education session on Zoom. Those in attendance included practicing occupational therapists, academicians, and students. I utilized PowerPoint and a script prepared ahead of time. A copy of my slides and script can be found in Appendix A.1. A representative from the MOTA moderated the overall
session, while each presenter monitored and voiced questions asked by participants in the chat.

Additionally, a link to the evaluation survey (Google Forms) was pasted into the chat for participants to rate and provide feedback about my presentation.

**Learning Objectives**

Following this portion of the continuing education session, participants will:

- Describe research supporting prehabilitative intervention for head and neck cancer survivors
- Identify gaps in current service models
- Analyze the relationship between OT research priorities and prehabilitation
- Examine recommendations for OT practice related to prehabilitation with head and neck cancer survivors

**Evidence of Approach Used**

For each night of presentations, a combined proposal was submitted. My classmate, Paula Stommes, and I prepared a proposal which included the titles, supporting references, objectives, and presenter biographies. Dr. Kathleen Matuska, PhD, MPH, OTR/L, FAOTA submitted all four proposals to the MOTA, which were then reviewed, accepted, and promoted on the association’s website. A copy of my proposal and can be found in Appendix A.2.

**Evaluation Method**

A survey created using Google Forms was utilized to elicit feedback from the presentation participants. The link was provided in the chat during the presentation, and it was sent by the MOTA again in an email along with certificates of attendance. The survey consisted of six total questions, with five questions asking the participant to rate the degree to which objectives were met, organization of the presentation, and the presenter’s communication abilities on a 5-point Likert scale. The sixth question was open ended, inviting the participant to offer any comments or written feedback. There
were 9 responses (82% response rate) to the post-presentation survey. Survey questions and results are located in Appendix A.3 and Appendix A.4 respectively.
Chapter 3. Evidence-Based Practice: Implementing A Prehabilitative Approach with Head and Neck Cancer Populations

Knowledge Translation Project 2

Project Aim

The aim of the second knowledge translation project is to create a comprehensive evidence-based service delivery model of prehabilitation for patients with head and neck cancer and disseminate the key tenets of the model to the Michigan Occupational Therapy Association membership in an Oncology Special Interest Section meeting.

Description

The second knowledge translation project occurred during a semi-annual meeting of the Michigan Occupational Therapy Association (MiOTA) Oncology Special Interest Section (SIS) on March 10, 2022. Of the 60-minute meeting, 45 minutes were allotted for the presentation while the remainder of the time was reserved for updates and other business relevant to the group. There is no cost associated with SIS or chapter meetings for MiOTA members, and non-members are allowed to attend one event free of charge prior to membership. (MiOTA membership is then requested of those who wish to continue or further participate in association meetings.) All attendees are eligible to receive one professional development unit.

I presented via a virtual platform (Google Meet) on Thursday, March 10, 2022 from 7:05-7:50 pm EST. My presentation focused on fostering the understanding of current literature surrounding OT’s role in prehabilitation in the HNC population and developing a conceptual model for implementation. Approximately two-thirds of the presentation time was devoted to content delivery, while the other third was devoted to guided discussion. The title of the presentation was, “Evidence-Based Practice: Implementing A Prehabilitative Approach in Head and Neck Cancer Populations.”

Approach
**Audience and Venue**

This knowledge translation project was a virtual continuing education session embedded within a semi-annual meeting of the Oncology SIS. There were 18 participants. Those in attendance included practicing and retired occupational therapy practitioners, educators, and students. Most of those in attendance had clinical experience and/or advanced training in oncology. It was expected that the participants in this session had a minimum foundational knowledge of oncology practice (i.e. side effects of common cancer treatments) and the content and design of the presentation was tailored accordingly. In a similar manner to the first project, I utilized PowerPoint and a prepared script, both of which can be found in Appendix B.1. The chair of the Oncology SIS moderated the meeting and the assigned MiOTA liaison kept minutes and documented attendees. A link to the evaluation survey (Google Forms) was made available on the Google invitation, pasted into the chat for participants, and included in the attendance certificate email to rate and provide feedback about my presentation.

**Learning Objectives**

Following the presentation, participants will:

- Examine the needs of patients with head and neck cancer
- Identify evidence-based prehabilitative / early intervention approaches
- Discuss strategies for implementing prehabilitation in head and neck cancer populations

**Evidence of Approach Used**

As the co-chair of the MiOTA Oncology SIS, I participated in a planning meeting for the next official SIS meeting. This meeting was also attended by the SIS chair, the MiOTA liaison, and the Michigan Cancer Consortium (MCC) representative. The four leadership members in attendance constituted a quorum for decision-making purposes. The only leadership member not in attendance was a second MCC representative. The group reviewed notes and requests from the last semi-annual meeting, which was the inaugural meeting of the Oncology SIS, which had received its formal approval,
acceptance into, and authority from MIOTA earlier in 2021. It is intended that each semi-annual meeting contains a professional development component in addition to association news updates and opportunities for resource inquiries and professional networking. On review of requests for professional development, I offered to present my findings related to prehabilitation in HNC. I briefly shared my process and methodology, project oversight in my doctoral program, overarching objectives, and relevance to the group members. The leadership group unanimously agreed I am qualified to provide this presentation and that it would benefit the group. Agenda meeting minutes can be located in Appendix B.2. The meeting was then promoted in an email blast and on the association website and Facebook page prior to the meeting.

**Evaluation Method**

I created a survey using Google Forms to elicit feedback from participants. There were seven questions in total. The first item asked the participant to disclose his/her discipline and professional capacity, such as an OT student, clinician, and/or educator. Questions 2-6 asked the respondent to rate the degree to which they believed the objectives were met, organization of the presentation, and the effectiveness of the presenter’s communication abilities on a 5-point Likert scale. The seventh question was open ended and asked respondents to offer any feedback, questions, or comments. There were 11 responses (61%) to the post-presentation survey. Survey questions can be found in Appendix B.3 and results in Appendix B.4.
Chapter 4. A Comprehensive Prehabilitative Model of Care for Head and Neck Survivors: A Scoping Review

Knowledge Translation Project 3

Project Aim

The aim for the third knowledge translation project is to advocate for the role of occupational therapy in HNC interdisciplinary supportive care through the development of a paper or poster presentation in an interdisciplinary journal or conference.

Description

For this knowledge translation project, I plan to prepare and submit a manuscript in an interdisciplinary journal. The title of the article is, *A Comprehensive Prehabilitative model of Care for Head and Neck Cancer Survivors: A Scoping Review*. This article is a scoping review of the evidence on prehabilitation in HNC populations. The article describes the collective unmet needs of patients with HNC and to meet these needs, a comprehensive, interdisciplinary model of care will be proposed based on the best available evidence. While interdisciplinary in nature, describing the role of OT will be included as well.

Approach

The approach will be an article submitted to an interdisciplinary journal, *The Archives of Physical Medicine and Rehabilitation*. This journal was selected due to its quality, interdisciplinary audience, and scope. In review of the journal’s *Information for Authors* (Archives of Physical Medicine and Rehabilitation, 2009) and as a joint decision between the doctoral student and advisory committee, it was determined the project was most appropriately submitted in the “Article” section and format, which includes articles that:

- Present new and important basic and clinical information, extend existing studies, or provide a new approach to a traditional subject. Manuscripts should be limited to 3000 words of text.
Figures, tables, and references should be limited to the number needed to clarify, amplify, or document the text. (Archives of Physical Medicine and Rehabilitation, 2009, p. i.)

Dr. Katie Polo, DHS, OTR/L, CLT-LANA has agreed to be a co-author of this article and will provide editing for both content and technical considerations. A copy of the article manuscript can be found in Appendix C.1 and the article references can be found in Appendix C.2.

**Audience and Venue**

The intended audience for this article is the readership of *The Archives*, which includes clinicians, students, educators, and researchers focusing on “physical, behavioral, and pharmaceutical agents in providing comprehensive care for individuals with chronic illness and disabilities” (Archives of Physical Medicine and Rehabilitation, n.d.). The aim of this article is to provide a new approach for the supportive care of HNC populations.

**Learning Objectives**

As a result of reading this article, the reader will be able to:

- Identify the multi-faceted supportive care needs of HNC survivors
- Identify the key tenets of the evidence-based interdisciplinary model, including the timeframe, disciplines, assessments, and interventions

**Evidence of Approach Used**

Following the *Information for Authors* (Archives of Physical Medicine and Rehabilitation, 2009), I submitted my article along with the accompanying submission materials using the journal’s online submission platform. It is anticipated the article manuscript will be prepared for online submission by May 2022. As stated above, the article manuscript can be located in Appendix C.1 and references in Appendix C.2. A copy of the additional submission materials (cover letter, Disclosure Statements and Copyright Assignment form, abstract, and completed Manuscript Checklist) can be located in Appendix C.3.
Evaluation Methods

This is a peer-review journal; all articles submitted will be first reviewed by an editorial board member, and if accepted to the next phase, will be submitted for peer review. This step will determine if the article is indeed methodologically sound, relevant to the readership, within the scope of the journal, and useful for practice. Communications with the editorial board can be located in Appendix C.4.
Chapter 5. Evaluation Outcomes and Analysis

The purpose of this chapter is to evaluate the project outcomes and analyze the comprehensiveness, alignment, and feasibility of the knowledge translation plan. The *Knowledge Translation Planning Template*© (Barwick, 2008/2021) and the *Knowledge Translation Plan Appraisal Tool* (KT-PAT©; Barwick, 2018) were utilized as an evaluation framework. Therefore, the language and headings are consistent with those used in these knowledge translation tools.

**Evaluation Outcomes**

*Knowledge Translation Project 1: Evidence-Based Practice: Prehabilitation in Head and Neck Populations*

**Knowledge Users.** The knowledge users were general practitioners in OT who attended the collaborative webinar series through MOTA and St. Catherine University on February 22, 2022. Knowledge users included students, educators, and clinicians representing a variety of backgrounds, years of experience, and practice settings.

**Main Messages.** There were several main messages intended for the knowledge users of this project:

1) Research supports early intervention in HNC populations.

2) The research identifies a number of significant needs among the HNC population.

3) There is a gap in services and research pertaining to intervention aimed at meeting multiple needs simultaneously (i.e. participation, role fulfillment) versus single-factor intervention (i.e. shoulder ROM, dysphagia).

4) In view of the needs of the HNC population, the gaps identified, and the scope and skill of the OT profession, OT is a logical fit to meet these needs.
Knowledge Translation Goals. The goals for this knowledge translation project were to increase awareness about the needs of HNC survivors and share knowledge pertaining to research-supported prehabilitative and early intervention methods.

Knowledge Translation Strategy. The strategy selected for this knowledge translation project was a 30-minute webinar in a series of doctoral project knowledge translation webinars in collaboration between the MOTA and St. Catherine University. A PowerPoint presentation was delivered, summarizing the methodology, main findings, and implications for interdisciplinary teams and OT practice (PowerPoint slides and narration can be located in Appendix A.1). Participants were given the opportunity to ask questions at the end of the presentation.

Knowledge Translation Evaluation. Participants of the webinar were invited to complete a post-presentation survey as a strategy for evaluating the effectiveness and impact of the webinar. Participants were asked to rate the degree to which objectives were met, organization of the content, and the presenter’s ability to communicate the information. The final question of the survey provided an optional opportunity to offer feedback or comments. Survey questions and survey results can be located in Appendices A.3 and A.4 respectively.

Knowledge Translation Project 2: Evidence Based Practice: Implementing A Prehabilitative Approach with Head and Neck Cancer Populations

Knowledge Users. The knowledge users for this project were members of the MiOTA who specialize of have a special interest in oncology. Attendees included OT clinicians, educators, and students.

Main Messages. The main messages of knowledge translation project 2 were:

1) HNC survivors have numerous, complex treatment-related problems affecting their daily lives throughout survivorship.
2) There is a clear fit between OT’s scope of practice and the needs of HNC survivors within a prehabilitative model of care.

3) Implementation of such a practice will require strategic communication of the evidence with key stakeholders.

**Knowledge Translation Goals.** The chief aims of this project were to generate awareness of the problems and opportunities within prehabilitation and HNC, share knowledge about evidence-based services and timelines, and to inform clinicians and educators about evidence that may impact decision making.

**Knowledge Translation Strategies.** The strategy and approach to the second project differed slightly from the first. While both were in the format of a webinar, this was a stand-alone presentation embedded within an Oncology SIS meeting. Therefore, the content delivered and discussion facilitated were tailored to the audience, who was assumed to have had at least basic knowledge and skill in oncology practice. See Appendix B.1 for the PowerPoint slides and accompanying narration.

**Knowledge Translation Evaluation.** An electronic post-presentation survey was utilized to obtain feedback about the effectiveness and impact of the webinar. Participants were asked to rate the degree to which the objectives were met, the organization of the presentation, and the presenter’s ability to communicate the information. Additionally, participants were asked to provide their professional status (i.e. educator, student, or practitioner; occupational therapist or OT assistant) and they were provided the opportunity to offer general comments or feedback. Survey questions are located in Appendix B.3 and results are located in Appendix B.4.

**Knowledge Translation Project 3: A Comprehensive Prehabilitative Model of Care for Head and Neck Cancer Survivors: A Scoping Review**

**Knowledge Users.** The intended knowledge users or target audience for knowledge translation for this project were comprised of the readership of the *Archives of Physical Medicine and*
Rehabilitation. The readership includes any and all rehabilitative and allied health professionals, including, but not limited to, occupational therapists, physical therapists, speech and language pathologists, recreational therapists, social workers, physicians, nurses, physician’s assistants, nurse practitioners, and alternative medicine providers. Readership also includes researchers, policy-makers, practicing and retired clinicians, educators, and students.

**Main Messages.** In the context of a scoping review, the main messages I intended to communicate were as follows:

1) It is consistently and thoroughly documented that HNC survivors often experience significant changes and incur lasting treatment effects that can negative impact their daily lives.

2) While the needs of HNC survivors are well documented, research also highlights the distinct lack of support for meaningful living, including chronic secondary disease self-management, return to work and driving, role fulfillment, ADL performance, and mental health.

3) According to the research collectively, a purposeful combination of prehabilitation, early intervention, and traditional rehabilitation – with an emphasis on prospective screening for known complications or side effects – provided by specialized, interdisciplinary teams comprises the most effective approach for HNC survivors.

**Knowledge Translation Goals.** The goals of this article were to generate awareness and share knowledge with the wide readership of the *Archives of Physical Medicine and Rehabilitation* pertaining to prehabilitative approaches in HNC survivorship care. Additionally, the knowledge provided may inform researchers, leaders, and educators for decision-making and planning.

**Knowledge Translation Strategies.** The strategy selected for this project was a scoping review article in a peer-reviewed publication. A copy of the original manuscript submission can be found in Appendix C.1 and article references in Appendix C.2. Upon completion of the doctoral project,
accompanying projects are in planning stages, such as a follow-up commentary article with a call to action for occupational therapists and interdisciplinary teams as well as a poster presentation at the American Congress of Rehabilitation Medicine 2022 fall conference.

**Knowledge Translation Evaluation.** This is a peer-review journal; all articles submitted will be first reviewed by an editorial board member, and if accepted to the next phase, will be submitted for peer review. This step will determine if the article is indeed methodologically sound, relevant to the readership, within the scope of the journal, and useful for practice. Refer to Appendix C.3 for article submission documents and Appendix C.4 for communication documents with the editorial staff. Per the *Author Information Pack* (Archives of Physical Medicine and Rehabilitation, 2022), decisions are typically communicated within 60 days of submission and undergo a double-blind peer review. The impact factor of the journal is 3.966.

**Evaluation Analysis**

In analysis of the whole doctoral project, there are a number of strengths and areas for continued growth that have been identified using the KT-PAT© (Barwick, 2018). Each individual knowledge translation project addressed different groups of knowledge users, reached different geographical locations of knowledge users, and focused on different portions of the overall project. Together, the knowledge translation plan covers all three projects and is analyzed below.

**Comprehensiveness**

Overall, the rating of items pertaining to comprehensiveness is from good to excellent. In most categories, the feature is very well described and underpinned with supporting evidence. There were four areas that I rated as good, indicating the feature is briefly described but there is no elaboration (Barwick, 2018). In other words, the areas that were addressed but could be stronger were: “degree of knowledge user engagement,” “definitive outlining of partner roles,” “outlining the benefits for the
users having gained the knowledge” I intended to translate, and the “evaluation methods for meeting each knowledge translation project’s goals” (Barwick, 2018).

In the KT-PAT© (Barwick, 2018), item 2 speaks to the degree of knowledge user engagement and item 7 speaks to the benefits for the users. On reflection, I believe the connection could have been made more clearly to the knowledge users in project 1 (MOTA webinar) why this information should matter to them. As members of MOTA, as educators, as clinicians – how does this information benefit them as general practitioners? By contrast, in project 2 (MiOTA webinar), I felt I produced a presentation that was a better fit for the audience. This perception is bolstered by the follow up messages and emails I received from a few of the attendees. One participant explained she was unaware of the issues faced by HNC survivors prior to my presentation. Another participant asked for my slides to share with her department. In a follow up email, she stated she shared what she learned at my presentation with nine other OTs and together they are working to make changes to their approach with their HNC patients.

From the beginning of the project, I believe it would have been helpful to have partner roles (item 3) more clearly defined and engage the full committee earlier on in the process. In doing so, it may have allowed for earlier decisions about knowledge translation projects, general project flow, and changed my approach to certain aspects of the project (i.e. utilizing a particular theory during theme analysis).

Finally, pertaining to item 10 on the KT-PAT® (Barwick, 2018), I learned much from my evaluation survey at MOTA that I was able to incorporate into my MiOTA post-presentation survey. I included a question about professional background (i.e. occupational therapist, student, educator, etc.) to better document and understand who actually attended. I more explicitly referenced my objectives throughout the MiOTA presentation based on feedback from my MOTA presentation. The way I sought responses was also different through MiOTA. Instead of only having the link available in the chat during
the presentation as I did with MOTA, I included the survey link in the original invitation, provided the
link in the chat during my presentation, and it was included with the continuing education certificates
from MiOTA. I believe this enhanced opportunity for user engagement with evaluation of the project.
For all items in the comprehensiveness section of the KT-PAT© (Barwick, 2018), I believe my third
knowledge translation project (scoping review article) has the greatest strengths. Chronologically,
project 3 was performed last and I was able to incorporate what I learned from projects 1 and 2. Also in
this project there have been the best opportunities for partner engagement compared to the other
projects. The third project reaches the most diverse audience with arguably the farthest reach.

Although there is always room for improvement, I was able to adapt my approach based on new
learning throughout the entire project. Furthermore, each project addressed different audiences and
caveats of the overall message. In view of all three projects together, there is good to excellent
comprehensiveness of the doctoral project.

Alignment

The KT-PAT® (Barwick, 2018) was next utilized to assess the alignment between the stated
objectives of the knowledge translation plan and the actual outcomes. Post-presentation survey data
from the first knowledge translation project demonstrates the learning objectives – and translation of
main messages – were largely achieved. For participant survey questions 1 (how well the research
pertaining to the topic was described), 4 (content organization), and 5 (speaker’s ability to communicate
the information), the average participant rating was 5, where 1 indicates “Not at all” and 5 indicates
“Very well.” For participant survey questions 2 (how well the gaps in current services models were
identified) and 3 (how well the recommendations for OT practice related to prehabilitation with HNC
survivors were examined) each received an average participant rating of 4.9. The participants’ scores

Knowledge translation project 2 was tailored specifically for the knowledge user audience
(primarily practicing occupational therapists in Michigan with at least minimal oncology skill/knowledge
base) and with the feedback in mind from project 1. The second project focused more on application of
the evidence and communication needs to implement the content presented into practice. A post-
presentation survey was utilized again to obtain the participants’ perceptions of the degree to which
objectives were met. Thirteen (68%) of 19 participants completed the survey. Survey question 1 was a
demographic question, which revealed 11 participants were currently practicing occupational therapists,
one participant was an OT student, and one participant was a retired occupational therapist. The
average participant rating for questions 2 (how well the needs of patients with HNC were described) and
3 (how well evidence-based prehabilitation approaches were identified) was 4.9/5, where 1 indicates
“Not at all” and 5 indicates “Very well.” The average participant rating for items 4 (how well
implementation strategies were discussed), 5 (content organization), and 6 (presenter’s ability to
communicate the information) was 4.8. See Appendix B.4.

For both webinars, the final item in each survey invited respondents to offer feedback and
comments. The narrative responses contributed to continual development of the overall knowledge
translation process. There were three narrative responses from the presentation to MOTA (project 1), all
of which focused on appreciation for evidence provided and thoroughness of the presentation. There
were six narrative responses from the presentation to the MiOTA Oncology SIS (project 2). Several
respondents stated they gained increased awareness of this area of practice. One respondent stated,
“Claire did an amazing job demonstrating the need for OT in this area of practice. I loved the discussion
piece at the end that really had me motivated to research this area of practice/these specific diagnoses
in the future.” Another stated, “Would love to see it as a continuing series.” The narrative comments,
follow up emails and networking from participants, and numeric ratings on survey items support
excellent alignment between the stated goals or objectives and what actually occurred.

At this time, the alignment is not yet fully known regarding knowledge translation project 3 as
the manuscript is prepared and submitted but no publication decision has yet been communicated from
the publisher. However, there is good to excellent alignment between the main messages, knowledge users, goals, and strategies. For the wide range of readership of the *Archives of Physical Medicine and Rehabilitation*, the goals of increasing awareness, informing decision-making, and sharing knowledge will be met through the strategy of peer-reviewed publication.

**Feasibility**

The overall feasibility of the doctoral project is excellent. Project mentors aided not only by providing technical and clinical expertise, but also in determining appropriate depth and breadth of the project in proportion with the time, skills, and resources available. All team members have different clinical, academic, programming, and knowledge translation experience, which contributed to the effectiveness of the project. Additionally, library resources and state associations (Minnesota and Michigan) further facilitated project development and delivery. The benefit for knowledge users was increasingly communicated as the projects progressed.
Chapter 6. Reflection and Recommendations

In the spirit of reflection, I have come to appreciate the knowledge translation process as one that is, by nature, an evolution. Reflecting on the alignment between my projects and professional aims, and about my own growth and professional development is an important piece of the knowledge translation process. Doing so offers me insight into strengths and weaknesses of the project and ongoing needs related to the original practice dilemma, and it helps me formulate next steps.

Reflection

Throughout the knowledge translation process, these projects have been designed and carried out in line with professional and university standards and principles.

AOTA Vision 2025

AOTA’s current vision (Vision 2025) and accompanying key tenets have been stated as follows: As an inclusive profession, occupational therapy maximizes health, well-being, and quality of life for all people, populations, and communities through effective solutions that facilitate participation in everyday living.

- **Effective.** Occupational therapy is evidence-based, client-centered, and cost-effective.
- **Leaders.** Occupational therapy is influential in changing policies, environments, and complex systems.
- **Collaborative.** Occupational therapy excels in working with clients and within systems to produce effective outcomes.
- **Accessible.** Occupational therapy provides culturally responsive and customized services.
- **Equity, diversity, and inclusion.** We are intentionally inclusive and equitable and embrace diversity in all its forms. (AOTA, 2022).

The entire doctoral project helps to enact multiple facets of the above statements. By focusing on secondary disease prevention and improving an understanding of interdisciplinary roles, all three
individual knowledge translation projects support improved accessibility to care (including OT), promote collaboration among the interdisciplinary team, influence change that applies evidence into practice, and ultimately promote engagement in meaningful everyday living for HNC survivors.

**St. Catherine University Henrietta Schmoll School of Health**

This doctoral project also supports the mission statement of the interdisciplinary Henrietta Schmoll School of Health at St. Catherine University, which states, “The Henrietta Schmoll School of Health educates diverse learners and engages clinical and community partners to influence health, health systems and health policy. The School is distinguished by an emphasis on relationship-centered care, socially responsible leadership and interdisciplinary initiatives” (Department of Occupational Therapy, 2020, p. 9).

This doctoral project represents the discipline of OT, and it has implications for advancing the practice of OT as well as collaborative interdisciplinary oncology teams. Prehabilitation is a paradigm shift from usual care. A traditional rehabilitative model is typically hallmarked by referral to supportive services upon development of a problem – and often only when the secondary disease is subjectively evaluated to have had “severe enough” impact on daily life to warrant a referral. All three knowledge translation projects together support the School’s vision for influencing “health, health systems and health policy” (Department of Occupational Therapy, 2020, p. 9) by promoting evidence-supported changes to usual care. Inherently, prehabilitation also contributes to social responsibility as prehabilitative models of care seek to empower and meet the unique needs of the individual. Preventing or lessening the impact of secondary disease may reduce financial and resource burdens as well.

**St. Catherine University Department of Occupational Therapy**

The final mission statement to reflect on is that of the Department of Occupational Therapy, which is stated as:
The Department of Occupational Therapy provides an excellent education in occupational therapy to students from diverse backgrounds, conducts scholarly inquiry on human occupation, and serves the broader community by promoting occupational health and wellbeing. We prepare students to respect the dignity of every individual, value humans as occupational beings, understand the development of occupational competence, apply ethical, spiritual and social justice principles, engage in a healthy balance of life occupations, and lead and influence the advancement of occupational therapy. (Department of Occupational Therapy, 2020, p. 9-10).

In view of this statement, there are four principles in particular with which my project is well-aligned. First, the doctoral project is inherently designed to facilitate scholarly inquiry, and at each stage of the process, the research questions, knowledge translation strategies, and outcomes were all focused on human occupation.

The second principle I identified as well-supported by my project is leading and advancing OT. This project aims to affect change: to enhance what we (oncology specialists) know, to change the way we deliver care, and to advocate for the services that will improve the lives of HNC survivors. Moreover, the recommendations specifically for OT exemplify (see chapter 1) moving OT to the forefront of prehabilitative care for HNC survivors. These recommendations include taking ownership as a profession of the aspects OT is best qualified to address (i.e. return to work, driving, occupational engagement), advocating for a constant position on the interdisciplinary team, and conducting participation-based research that better represents OT.

Upholding the dignity of the individual is the third principle and applying ethical principles the fourth that are supported by my doctoral project. From the formation and planning stages of this project, I have been driven by the unmet needs of real people in my own community and the greater population of HNC survivors. According to the OT profession’s Code of Ethics (AOTA, 2020b), OT
practitioners are responsible for applying the best evidence available, to avoid harm to those whom they serve, and take action that is to the benefit of those they serve. Prehabilitation as the focus of this project is in line with and equips OT practitioners with means to uphold the ethical code by which they are bound.

**Knowledge Translation as a Focus for Advanced Practice**

Despite having heard the term “knowledge translation” and reading material on the topic, I did not truly understand the depth and breadth of the term – nor did I connect it with day to day clinical practice. However, throughout this experience, I have come to the conclusion knowledge translation is deserving of greater recognition and effort among the general OT population. In some ways, prior to my doctoral work, I believe I was attempting to apply knowledge translation principles without awareness of it. And I was certainly without evidence-based strategies to carry it out. So, I have learned the value of knowledge translation and all it entails: identifying a practice dilemma, diving deep into the background information, performing rigorous and systematic searches of the evidence, synthesizing evidence, and communicating the evidence in practical terms to the people who need the information, in a place and at a time that optimizes the communication.

When I look over my curriculum vitae, I realize how much I seek to share knowledge with the people around me. I enjoy teaching in the clinic and in the classroom, and every year I have multiple professional presentations in the form of in-services and community education. But what surprised me was the way I have incorporated new learning. For example, I did some coursework a few years ago pertaining to cancer-related fatigue, and I incorporated it in academic content, used it as my topic for a local women’s health event, and spoke on the topic during a breast cancer support group meeting. I really did not think about it in a strategic sort of way; I simply had information that I thought would be beneficial for different groups in different venues to have! Now, having gone through the entire knowledge translation process, I have specific tools and strategies to identify needs, gather relevant
information, and more effectively accomplish what has, apparently, been a professional objective for me all along. I am excited to not only apply these learned skills to new practice dilemmas but also to encourage my coworkers and colleagues to better understand and participate in knowledge translation.

An irreplaceable component of knowledge translation is professional networking. It does not happen overnight, and the fruit of networking does not sustain by chance. It has also been my experience that people who enjoy collaborating tend to find each other! But being relatively new to the broader OT and interdisciplinary oncology community is intimidating. Knowledge translation has quickly bolstered my own knowledge base and given me a stronger framework for advocacy, professional presentations, and clinical practice. It has given me greater confidence to seek out partnerships and opportunities to share knowledge.

Finally, I have learned that, by definition, knowledge translation is truly a process. In advancing OT practice, each step and project inform the next. For example, from the first project, I realized I needed to more explicitly refer to my stated objectives in my presentations. I did so in the second project and the participants were better able to identify key concepts and discuss them at the end. I learned much more about characteristics of each audience, the process for entry to professional venues, and identifying the kind of support or feedback I need to be successful.

**Reflection on Professional Development**

The focus of the last year has been chiefly on knowledge translation. I have gained invaluable skills that have already changed the way I practice; I prioritize goals for programming and advocacy differently than I did before, and the way I talk about my clinical decisions in terms of the evidence has changed. I have noticed that my patients buy in readily and it is easier to engage in process/policy changing conversations with administration.

Gathering and appraising evidence are personal competencies that have grown significantly throughout this project. I can more effectively sift through professional and interprofessional resources,
navigate databases, and critique methodology. Gaining much practice with these skills has increased my efficiency as well. Librarians and library resources contributed to development of these competencies, and I have a deeper appreciation for both.

In the first week of my first year as an entry-level OT student in 2012, we were given a small writing assignment, simply to begin practicing professional writing and APA writing style. I naively thought, since writing had been an area of strength in my undergraduate work, that I would maybe get a few but minimal recommendations. My professors had even said, “[we] are going to make you a lot better writers by the end of this semester!” I received a lot of feedback and recommendations, insight and clarifying questions; and I grew as a writer. Through the lens of a clinician and educator now, I have an entirely different relationship with writing. Throughout the doctoral project I have not only enjoyed the stoking of a deep passion for writing, but I am no longer afraid or intimidated by my shortcomings as a writer. On the contrary, I believe what I have to say has merit, and I have grown a profound appreciation for people who edit my writing. At times the most subtle changes can communicate a clearer, more impactful message. And in a profession such as OT, it is essential to speak and write clearly and compellingly, but with accuracy and fairness. While I will never be finished honing my communication skills, I believe this in area in which I have experienced substantial growth.
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Hello! My name is Claire Dolislager, and today we are going to talk about evidence-based prehabilitation in head and neck cancer populations.

I selected this topic because, in my practice, I work with a fair amount of people affected by HNC. And I have been frustrated by the late referrals, I have seen how challenging each phase of survivorship can be...and the effects of fragmented care. So I wanted to learn more about HNC survivors and what the evidence has to say about prehabilitation. Does getting at them earlier make a difference in their lives?
Objectives

- Describe research supporting prehabilitative intervention for head and neck cancer survivors
- Identify gaps in current service models
- Analyze the relationship between OT research priorities and prehabilitation
- Examine recommendations for OT practice related to prehabilitation with head and neck cancer survivors

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01

Background
“Head and neck cancer” describes a collection of cancers affecting the pharynx, larynx, and any part of the oral cavity. (It does not include glioblastomas or other brain cancers.) Squamous cell carcinoma is the most common type of cancer in the head and neck, and is most often caused by either long time tobacco and alcohol abuse or human papilloma virus (HPV). Tobacco rates are declining, while rates of HPV rise; and the HNCs associated with each are following the same trends.

According to the National Cancer Institute, in 2021, there are about 54,000 new cases of HNC, which accounts for approximately 2.8% of all new cancer diagnoses. People of all races, genders, and ages can get HNC, but the average person with HNC in the U.S. is a 64 year-old, white male. The 5-year survival rate across all types of HNC diagnoses is 66.7%. Of course, if caught early, survival rates are higher, greater than 80%. But unfortunately, since screening for HNC is currently based on the presence of symptoms or palpable tissue changes, the vast majority of HNCs are identified after there is already lymph node involvement.

Typical Cancers
- Tissues/structures
- Histologic types
- Causes

2021 Statistics
- 54,000 new cases
- 2.8% of all cancers

Survival
- 5-yr survival rate = 66.7% overall

(Islami et al, 2021; Lawrence et al, 2015; National Cancer Institute, n.d.)
Understanding some of the medical treatment for HNC provides insight into the side effects, and ultimately, the occupational performance impairments. Some combination of chemo, radiation, and/or surgery are the most common types of treatment. Surgery is typically rather invasive, removing 20 or more lymph nodes and the tumor itself, and/or reconstructing part of the mouth, face, or throat with titanium or other parts of the body. Commonly, these treatments in all or in part result in:

- Dysphagia
- Speech impairments
- Facial disfigurement and associated psychosocial dysfunction
- Lymphedema
- Severe fatigue
- Malnourishment
- Pain
- Hearing loss
- Tooth decay and poor dentition
- Non-healing wounds, recurrent infections
- Poor neck ROM and shoulder dysfunction
- Scar adhesions and lymphatic cording

Patients with HNC have unique needs that occupational therapists are well-suited to address. And yet, little is known about the evidence supporting occupational therapy models of care and interventions for patients with HNC, including prehabilitation.
Based on the background information and my own professional experience, the problem can be summed up as this:

To date, there has never been a critical appraisal of the evidence supporting the occupational therapy intervention and models of care that have been described for treating patients with HNC including prehabilitative approaches.

My focused research question, or my PICO, is broken up into two parts:

1) Do clients with HNC who participate in a prehabilitation program experience better occupational outcomes than clients who do not?

2) Do clients with HNC who receive occupational therapy services at any point in the cancer care continuum experience better occupational outcomes than clients who do not?

Occupational outcomes – meaning, do they participate in the things that matter to them and to the degree they find satisfying?
02
Resource & Literature Review
Narration

I started with intraprofessional resources first. While there were no HNC-specific OT resources, AOTA does have cancer fact sheets and the OT Practice Guidelines for Cancer Rehab with Adults. These provide an outline of OT intervention in general for oncology populations.

Interestingly, looking at the research priorities listed on AOTF’s website, the very first is to expand research on health behaviors to prevent and manage chronic conditions. Additional relevant priorities include meeting family and caregiver needs, and improving health care access, care coordination, and utilization.

That’s really what I’m aiming for in this project: to prevent and manage chronic problems, promote comprehensive and coordinated care, and provide a better framework for clients and their caregivers to work with. All the way around, this project is well-aligned with the profession’s stated research priorities.
Interprofessional Resources

霭国癌患研究院

- 研究优先级
- 报道详细
- 最佳的医疗实践

其他跨学科资源

美国头颈部医学会
国家综合癌症网
美国语音和听觉学会

Interdisciplinary sources flesh out the various professional roles and goals.

The NCI has a set of research priorities with which the AOTF complements nicely, and the NCI itself was created based on national research priorities. The NCI is always helpful for up-to-date statistics, patient and provider handouts, and other evidence-based information.

The AHNS is physician driven, but they do have quite a few educational fact sheets that talk about survivorship topics.

Of all the NCCN® guidelines, the Survivorship Guidelines are the most relevant regarding prehabilitation topics and OT.

Our speech therapy colleagues have done quite a lot of work with HNC in recent years, and of this list, we probably have the most in common with them. ASHA’s head and neck resources define SLP’s scope, and simply observing how they talk about and approach head and neck is informative.
In my formal literature review, I began with reviews of research, such as systematic reviews and meta-analyses from the Cochrane Library and the PEDro databases. The best keywords/key terms are listed here, all of which relate specifically to components of my PICO question.

Then I selected the “browse the Cochrane Library” option and looked at relevant topics, such as “cancer,” “effective practice and health systems.”

I found a total of 23 relevant reviews of research on the Cochrane database and 18 from PEDro.
Next, I looked at individual primary research studies. I used a lot of the same keywords and combination processes, but I refined my outcome terms to include “quality of life,” “return to work,” “activities of daily living,” and “social participation.”

I searched 3 databases: PubMed for the medical perspective of this topic, CINAHL, hoping to find allied health professional and interdisciplinary articles, and PsychInfo to capture the lived experience aspects of HNC.

I also used citation chaining as an alternative search method.
Results
Here were the main types and focuses of the articles I found. The most prevalent literature was descriptive in nature and confirm... people with HNC indeed have severe, persistent needs. This was helpful for understanding their experience and identifying needs, but not so much for finding out what interventions actually work or help. There were randomized control trials and cohort studies that support exercise to prevent or minimize dysphagia, fatigue, and shoulder and neck dysfunction. There was a moderate amount of well-designed qualitative studies and cross-sectional surveys that identify more specific needs (i.e. education about their diagnosis and what to expect with treatment) and how intervention should be conducted.
There was a lot of generic oncology literature, especially in the systematic reviews and practice guidelines, that did include HNC along with others. There were general studies about prehabilitation across cancers that really promoted earlier intervention and working in specialist, multi-disciplinary teams.

There were only a handful of OT-specific studies that were identified, but those that were, were of high quality and insightful for practice.
Next I am going to highlight a few articles that make a strong case for the importance of prehab in HNC.

In this prospective qualitative study, Molassiotis and Rogers (2012) conducted semi-structured interviews with 16 HNC survivors soon after their diagnosis and at around 3, 6, and 12 months posttreatment.

The researchers identified common themes, such as education needs, effects of fatigue, anxiety about the radiotherapy mask, and maintaining normality – especially in RTW. At one year posttreatment, anxiety about the future and continued fatigue persisted. Social activity was still reportedly less than at baseline. At one year, there was lacking continuity of medical care.

The conclusions of this article echo national research priorities we discussed. They point to the opportunity here for concrete, proactive information, strategies, and therapies to aid in self-management of known side effects. RTW should be an especial focus of comprehensive programs due in part to its connection with a sense of control and normality. Traumatic aspects of treatment should be addressed preemptively (i.e. radiotherapy mask).
Narration

In case you’re wondering what the radiotherapy mask looks like and why it might induce such a response...here it is! The purpose is to hold the head and neck in exactly the same place / position every single treatment to ensure precisely the right radiation dosage and location. Usually treatments are about 15 minutes, 5 days/week for 4-6 weeks.
Prehabilitation in Head and Neck Cancer

Slide 18

Key Article #2


- Purpose: “Examine amount and nature of research..., highlight publication trends.... and identify gaps in existing literature” (p. 2381).

- Conclusion: Among others, notable needs identified in pretreatment and survivorship programs. There is also a gap in research regarding participation.

Narration

In this article, Parke and colleagues conducted a scoping review relating to HNC to identify, what research is being conducted, by whom, and how much. This study is important for helping us understand the overall strength of the research out there and what is missing.

The authors found that HNC rehabilitation research is increasing at a substantially slower rate compared with cancer research over all as well as cancer rehabilitation research, HNC research is increasing at 30-40% of the rate in the same timeframe.

Although a wide range of issues have been previously identified, most studies primarily addressed chewing and swallowing.

With their results in view, Park and colleagues pointed out that the degree of impairment does not necessarily equate to QOL, but many studies look at single outcomes or component outcomes rather than holistic concepts, such as occupational performance. There is a significant gap in participation-focused studies.

The complex nature of HNC treatment sequelae denotes the imperative inclusion of rehabilitation services, yet there is a need for more members of rehabilitation to be involved in research: out of 250 studies, there was only 1 with a first author who was an OT.
In this systematic review of 18 articles, representing 9 different countries, the authors compared the outcomes of prehabilitation across cancer types to usual care (i.e. refer to rehab when there is a problem big enough to bother the patient or for the provider to notice). There are both generalizable and diagnosis-specific findings presented in this article. Prehabilitation overall appears to be of benefit.

Overall, prehabilitation is acceptable to patients and feasible to implement despite logistical challenges. As long as prehabilitation was unlikely to interfere with their treatment, adherence was good across studies.

The authors argue that in the age of evidence-based medicine, prehabilitation must become usual care and incorporated into international guidelines. Prehabilitation tends to reduce the frequency and severity of treatment-related side-effects.
04
Themes
Putting all of that information together, there were 4 themes I identified. Education is listed first for a reason!

HNC survivors experience significant changes to their life roles, routines, and health. Research shows that these patients are NOT satisfied with the amount of information given ahead of time: they want more information, and they want it earlier – right away. They especially want to know how it will affect their lives and what the treatment actually entails.

More specifically, they want more information on sleep disturbance and fatigue, speech and eating, length of recovery, attaining/maintaining a healthy lifestyle, severity of surgery, and human papilloma virus (HPV; Fang & Heckman, 2016; Rogers et al., 2011). Unsurprisingly, patient satisfaction with the information they’re provided is associated with better mental health (Llewellyn et al., 2006).

Although lymphedema affects at least 75% (Deng et al., 2012) and up to 98% of HNC survivors by 3 years posttreatment (Jeans et al., 2020), patients frequently identify lymphedema as a topic on which they receive insufficient information (Deng & Murphy, 2016; Jeans et al., 2019; Nixon, Pigott, et al., 2018). Appropriate and timely lymphedema education and intervention can reduce the risk of physical and functional problems, and it can also reduce distress associated with head and neck lymphedema (Nixon, Pigott, et al., 2018).

How education is delivered is also important. Therapeutic alliance is the essential foundation for any education to occur. Strategies built on self-management principles are most effective. It doesn’t appear to matter what medium you use to provide info (i.e. tablet, app, printed material). Those media are well accepted by patients, as long as they have something to reference later.
The second theme centers on other evidence-based intervention. Regarding psychological intervention, there is moderate to strong evidence to support coping strategies training for managing depression and anxiety. We also need to recognize that patients are not always comfortable bringing up functional issues because, for example, they may think functional issues are insignificant when compared with successful curative treatment. That means we, the clinicians, need to take on the responsibility of bringing up uncomfortable topics, such as dissatisfaction with appearance after surgery.

Regarding physical health intervention, patients benefit from supervised exercise during radiation, exercise for dysphagia, medical management for xerostomia, early traditional therapy for trismus, and timely referral to lymphedema therapy. The literature also identifies several HNC subpopulations that present with unique challenges. HNC patients who are younger tend to have lower QOL and greater care needs overall compared to older counterparts (Deng et al., 2013; Schorn et al., 2020; Verma et al., 2019). Younger patients tend to report higher levels of sexual dysfunction and greater distress due to physical disfigurement (Lang et al., 2013). Moreover, HNC patients who live in a rural area, are single or widowed, or in any other way isolated or lacking social support are also at increased risk of decreased role function and poorer QOL. Those who are younger or more isolated should be on our radar.
One of the main purposes of this review was to determine if timing was a key factor in the care for people with HNC. The research is clear: it absolutely matters! Education should be provided prior to treatment, exercise should be encouraged throughout the journey and supervised / tailored and prescribed throughout treatment, and there should be ongoing screening for secondary sequelae and traditional rehab needs.
Narration

Work is a deeply meaningful, stability-producing occupation for many, and it is a recurring theme in the HNC literature. Many people with HNC retire earlier than planned, and as an earlier slide described, there are a number of reasons why this is the case, ranging from physical endurance to feeding problems, decreased frequency of driving (which is also common in HNC) to embarrassment about facial disfigurement.

Work was a common problem area, yet few studies researched intervention relating to RTW. Screening and planning for work is clearly needed.
05
Recommendations &
Implications for OT Practice

Narration
There is a lot of information here that pertains to the whole interdisciplinary team, but I wanted this final segment to focus on OT: what can we take from this information and apply to practice? The recommendations and principles I am suggesting were formulated based on interdisciplinary literature available in addition to the pillars of our profession, such as the OTPF, code of ethics, AOTA/AOTF research priorities, etc.
Number 1: The likeliest opportunity for successful OT intervention is to provide it early. Patient and caregiver training is a cornerstone of OT intervention. As experts in daily living, OTs can meet the expressed desire of patients to know more about how the HNC journey will impact their daily life.

It is recommended that OTs become more involved in prehabilitative education from as close to the time of diagnosis as possible up to and including the first 1-2 weeks of radiation.

Topics that OTs would be most appropriate to cover include lymphedema risk and early identification; anticipated routine, task, and environment modifications; radiotherapy mask anxiety; pretreatment neck and shoulder exercises; and planning for work and driving.
Principles for OT Practice #2

Occupational therapists should work closely with other members of the interdisciplinary team.

Narration

Number 2: OTs should work closely with other members of the interdisciplinary team. It is impossible for a single profession to fully address all of the many issues that HNC survivors face. Occupational therapists should advocate for collaboration and partnership, and interdisciplinary teams should include OT. There are a number of barriers and facilitators to building such a partnership that are beyond the scope of this review, but the fact remains that OT is an ideal team member for HNC teams.
In the *Occupational Therapy Practice Guidelines for Cancer Rehabilitation with Adults* (Braveman & Hunter, 2020), the authors differentiate several aspects of entry-level practice or generalist knowledge occupational therapists possess versus advanced practice. Entry-level and general practitioners should be able to apply the OT process in any context with any diagnosis. Advanced practitioners can do this and apply diagnosis-specific knowledge. Advanced practitioners can anticipate problems and have mastered techniques that are unique to cancer populations. HNC is complex. Its cure is frustrating and exhaustive. The relative medical frailty of the individual coupled with complicated treatments, procedures, and surgeries result in highly complex and evolving effects on daily life. The foundational OT training is essential and readily applicable to this population, but advanced training is indicated to optimize patient success, rightly identify clinical red flags, and promote occupational identity and engagement.
OT has a long-standing positive reputation in addressing driving, work, and ADLs—including addressing the personal skills and factors, the task itself, and the environment or context in which these occupations take place (AOTA, 2020; Cole & Tufano, 2008; Dickerson et al., 2011). In a prehabilitative model of care, it is recommended that OT take the lead in these three areas.

Driving is a valued occupation by many, and it also provides access to other occupations, role fulfillment, and personal health management. Knowing patients with HNC are at risk of prolonged decreased driving or driving cessation, occupational therapists should broach the topic and be prepared to provide or refer for preventative, remedial, and compensatory intervention (Yuen et al., 2007). Relating to work within the HNC population, it is recommended that occupational therapists provide guidance in the process through the use of a planning tool (such as the RTW-PT, Amin et al., 2017). Skilled guidance aims to prevent unwanted loss of employment, promote satisfaction and self-efficacy with work, prevent work-related injury, and maintain important relationships, financial means, and productive contributions to society. Occupational therapists are already well-prepared and suited to address this occupation in HNC populations.

ADLs are also chiefly grounded in OT practice. Generalists and advanced practitioners alike possess foundational skills needed to enhance ADL performance, including energy conservation techniques, bathroom modifications, and fall risk assessments, in addition to many other strategies. At the risk of redundancy, occupational therapists should advocate for the role of OT in ADL training within this population as well.
Despite what is known across disciplines, clearly more research is needed to demonstrate the distinct value of OT in HNC care. Whether the authors realized they were speaking of OT or not, this issue has already been identified by a number of high level studies, stating we don’t have enough studies regarding daily function, role fulfilment, and participation. More specifically and in view of professional priorities posed by AOTA and AOTF, the following recommendations for research have emerged:

We need prospective observational and interventional studies, with researchers representing support services (as defined by the NCCN® Guidelines; National Comprehensive Cancer Network, 2021), including OT, that are currently under-represented in the literature (Hunter et al., 2017b; Parke et al., 2019).

Future research must focus on participation limitations and a combination of impairments or issues – rather than a single problem (like shoulder range of motion alone)– to more accurately reflect the patient experience (Parke et al., 2019).

Further research relating to the efficacy of comprehensive prehabilitation programs in the HNC population specifically are needed (Treanor et al., 2018).
Slide 31

References


Slide 32

References


REFERENCES


REFERENCES


Acknowledgements

Dr. Kathleen Matuska
Classmates Amy Carrier, Elizabeth Campbell, Jennifer Brady-Johnson, Jessica McGuire, Deb McKernan-Ace, Emily Petersen, and Paula Stommes
Appendix A.2

Minnesota Occupational Therapy Association Presentation Proposal

MOTA Virtual Presentation Application

MOTA Course Application

**Event Name/Course Title**: Evidence-based prehabilitation for head and neck cancer populations and Evidence-based presentation on non-pharmacological interventions to promote sleep in children with developmental disabilities

**Date of Event**: Tuesday, Feb 22, 2022

**Start Time**: 6:00pm  **End Time**: 7:00 pm

**Category**: Presentation – Webinar (virtual but presenters are live)

**Timed Agenda**:  
6:00-6:25 Presentation – EBP: Prehabilitation for head and neck cancer survivors  
6:25-6:30 questions  
6:30-6:55 Presentation – EBP: Non-pharmacological interventions to promote sleep in children with developmental disabilities  
6:55-7:00 Questions

**Event Description**:  
- Presenters will share the evidence found for the topics above, including the search strategy, level 1 and level 2 evidence, summary of themes and recommendations.  
- It will be a 25 minute powerpoint presentation

**References**:  

**EBP: Prehabilitation for head and neck cancer survivors**  
Molassiotis, A., & Rogers, M. (2012). Symptom experience and regaining normality in the first year following a diagnosis of head and neck cancer: A qualitative longitudinal study. *Palliative & Supportive Care, 10*(3), 197–204. [https://doi.org/10.1017/S147895151200020X](https://doi.org/10.1017/S147895151200020X)


**EBP: Non-pharmacological interventions to promote sleep in children with developmental disabilities**

**Speaker Credentials and Biographies:**

Claire M. Dolislager, MS, OTRL, CLT-LANA

Claire has been practicing occupational therapy since 2014. She is a graduate of Grand Valley State University and currently works for Holland Hospital (Michigan), specializing in oncology and lymphedema. Claire is passionate about improving client understanding of the cancer process – diagnosis to survivorship and beyond – and advocating for the role of occupational therapy in addressing barriers to participation at any point in that process. Claire enjoys teaching in clinical and academic, inter- and intra-professional settings. Claire is currently pursuing a post-professional doctorate in occupational therapy at St. Catherine University.

Paula M. Stommes, MA, OTR/L, ATP

Paula has been an occupational therapist since 1995. She is a graduate of St. Catherine University and currently works at an urban school district as well as for an outpatient pediatric clinic. Paula is motivated to provide treatment and education to her pediatric clients and their families in both a school and rehabilitative setting. Paula has also obtained her assistive technology professional certification (ATP) and is interested in how medical equipment can enhance her patient’s lives. Paula is pursuing a post-professional doctorate in occupational therapy at St. Catherine University.

**Learning Objectives:**

**EBP: Prehabilitation for head and neck cancer survivors**
Participants will:
- Describe research supporting prehabilitative intervention for head and neck cancer survivors
- Identify gaps in current service models
- Analyze the relationship between OT research priorities and prehabilitation
- Examine recommendations for OT practice related to prehabilitation with head and neck cancer survivors

**EBP: Non-pharmacological interventions to promote sleep in children with developmental disabilities**
Participants will:
• Describe research supporting the occupational of sleep and interventions to promote sleep in children with developmental disabilities
• Analyze the relationship between sleep and the role OT plays with this occupation
• Examine recommendations for OT practice related to sleep and interventions that are effective in promoting sleep in children with developmental disabilities

Target Audience: All

Level of Content: Advanced

AOTA Practice Area   Children & Youth and Rehabilitation & Disability,

CEUs  presentation – 1 hr

MOTA Members only? No

Primary Speaker #1 Contact information
• Name: Claire Dolislager
• Phone: (616) 566-2074
• Email: cmdolislager745@stkate.edu

Primary Speaker #2 Contact information
• Name: Paula Stommes
• Phone: (952) 406-9713
• Email: pmstommes263@st.kate.edu

Would you like to use any additional technology tools on the day you present? These can be set up to use the beginning of the presentation, during the presentation, or at the end.
• Will you be using a Powerpoint or other presentation tool?
  X Yes, I will be using Powerpoint. Please email your presentation to motafunctionfirst@gmail.com at least 24 hours prior to your presentation.
  ○ No ______

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Post Presentation Survey Questions: Add a link to your own Survey Monkey or Google Form

1. What information was the most helpful to you, or what information was presented the most effectively?

2. What information could be presented more fully, or what about the presentation could be strengthened?

3. What information or skills can you apply to your practice after participating in this presentation/discussion?

PO Box 582687    Minneapolis, MN  55401
Email: info@motafunctionfirst.org
www.motafunctionfirst.org
Appendix A.3

Minnesota Occupational Therapy Association Presentation Evaluation Survey Questions

**Prehabilitation for Head and Neck Cancer: Evidence Based Approaches**

Participant Survey

* Required

**Presentation questions**

Thank you so much for providing your feedback!

1. Please indicate how well the stated objective was met: "Describe research supporting prehabilitative intervention for head and neck cancer survivors" *

   *Mark only one oval.*

   1  2  3  4  5
   Not at all  ○  ○  ○  ○  Very well

2. Please indicate how well the stated objective was met: "Identify gaps in current service models" *

   *Mark only one oval.*

   1  2  3  4  5
   Not at all  ○  ○  ○  ○  Very well
3. Please indicate how well the stated objective was met: "Examine recommendations for OT practice related to prehabilitation with head and neck cancer survivors" *

Mark only one oval.

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4. Please indicate how well the content of the presentation was organized *

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5. Please indicate your overall impression of the presenter’s ability to communicate this information. *

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6. Please share any additional comments, suggestions, or questions.

________________________________________________________________________

This content is neither created nor endorsed by Google.
Appendix A.4

Minnesota Occupational Therapy Association Presentation: Summary of Survey Responses

Question 1

Please indicate how well the stated objective was met:
"Describe research supporting prehabilitative intervention for head and neck cancer survivors"

Question 2

Please indicate how well the stated objective was met:
"Identify gaps in current service models"
Question 3

Please indicate how well the stated objective was met: "Examine recommendations for OT practice related to prehabilitation with head and neck cancer survivors"

Question 4

Please indicate how well the content of the presentation was organized
Question 5

Please indicate your overall impression of the presenter’s ability to communicate this information.

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Question 6

Please share any additional comments, suggestions, or questions.

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<tr>
<td>Wonderful work, Claire. Identifying evidence-based practices is an area of importance for OT and I appreciated your hard work!</td>
</tr>
<tr>
<td>Excellent work! Very thoughtful and intelligent presentation. Thank you for practical applications too.</td>
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<tr>
<td>You presented the information very thoroughly and captured both the physical and psychological factors that happen with HNC.</td>
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Thank you all for joining us tonight. I am very excited to share with you current literature on prehabilitation, or “prehab”, in head and neck cancer (HNC) populations. I am an occupational therapist (OT) in Holland, MI, and I specialize in oncology and lymphedema. Right now, I am finishing up my post-professional doctorate in OT at St. Catherine University.
I want to take a moment and acknowledge my committee members, Dr. Wickboldt, Dr. Coss, and Dr. Polo, who have been absolutely instrumental in this endeavor and continue to guide me as we move toward publication.
Slide 3

Narration
So here are our objectives: we are going to...

- Examine the needs of patients with head and neck cancer
- Identify evidence-based prehabilitative / early intervention approaches
- Discuss strategies for implementing prehabilitation in head and neck cancer populations
Tonight’s presentation is one of three knowledge translation projects on this topic. Knowledge translation is all about taking a systematic, deep dive into existing resources and literature – and learning what evidence exists on a given topic, appraising the evidence, and then making sense of it all together for day-to-day practice. Instead of it taking about 30 years to incorporate research into practice, the ultimate end point of knowledge translation is to synthesize the evidence and get the word out there (Lencucha et al., 2007; Metzler & Metz, 2010).

In the knowledge translation process, the first step is to identify a practice problem. In my own practice, I have seen a big difference between patients that receive therapy early on in their cancer journey and those that don’t. For patients with HNC, their care is rather fragmented and their problems affecting daily life seem to go largely unaddressed, or they are referred for therapy late.
In this process to learn about OT for HNC populations in a prehab model, I reviewed professional and interprofessional resources, like practice guidelines and interactive national data. And then I performed an extensive, methodical review of systematic reviews and meta-analyses, followed by primary research studies. I did keep track of each search filter, keyword, etc., and I’d be happy to share that information at another time if you’re interested!

But before I get into what I found, I want to highlight are our professional research priorities put forth by the American Occupational Therapy Foundation. The very first priority is to expand research on health behaviors to prevent and manage chronic conditions. A couple other priorities relevant to this project include meeting family and caregiver needs, and improving health care access, care coordination, and utilization.

These are the reasons “why” behind this whole project: to take what evidence is out there and use it to help prevent and manage chronic problems, promote comprehensive and coordinated care, and provide a better framework for clients and their caregivers to work with.
It is important to note that prehab refer to either intervention provided prior to cancer treatment itself OR intervention provided prior to impairment due to the cancer treatment. Programs working with either definition have the same goals: to educate patients about their conditions, prevent problems as much as possible, and address problems right away.
Narration
For some more background on HNC in the US right now:

“Head and neck cancer” describes a collection of cancers affecting the pharynx, larynx, and any part of the oral cavity. Squamous cell carcinoma is the most common type of cancer in the head and neck, and is most often caused by either long time tobacco and alcohol abuse or human papilloma virus (HPV). Tobacco rates are declining, while rates of HPV rise; and the specific types of HNCs associated with each are following the same trends.

According to the National Cancer Institute, in 2021, there were about 54,000 new cases of HNC, which accounts for approximately 2.8% of all new cancer diagnoses. People of all races, genders, and ages can get HNC, but the average person with HNC in the U.S. is a 64 year-old, white male. The 5-year survival rate across all types of HNC diagnoses is 66.7%.

These data are important – there are some things that are a bit more personal hidden in these numbers. First, there aren’t a lot of reliable screening tools for HNC: it is often found because the patient developed a raspy voice, felt a lump, or could see something different in their mouth (to name a few examples). By the time the patient is symptomatic, there is a good chance it is already spreading to regional lymph nodes. It is hard to catch it early, meaning they will often need more intensive medical intervention.

These numbers also help me thing through, What is this patient hearing from the doctor? Mortality and recurrence are very real concerns on the minds of these individuals. And 2.8% of all new cancer diagnoses? They really don’t get a lot of press coverage like breast and other types of cancers. It certainly isn’t because they have fewer needs.
With that in mind, I am next going to share the needs and service gaps that have been broadly identified in the literature. Then I will talk about themes and recommendations.

The most prevalent type of literature available related to HNC is descriptive in nature. Combined with well-designed, reliable qualitative studies and cross sectional surveys, HNC survivors’ experiences and needs are very well documented. These are the major needs:

Knowledge: they want to know what to expect ahead of time relating to their medical treatment and the impact on their lives so they can plan for the future. They are also often blindsided by the financial stress associated with cancer and often go without financial resources.

Sequelae: we are all probably at least somewhat familiar with the chronic problems secondary to cancer, such as radiation fibrosis, lymphedema, loss of tissue extensibility, problems with ROM, dysphagia, lymphatic cording, etc. We can’t forget about the radiotherapy mask anxiety, lymphatic cording, hearing loss, and vestibular dysfunction associated with radiation to the head and neck. Particularly the interplay of these issues contributes to occupational performance impairments, and the remedies are not always so obvious to our patients.

Patients with HNC have many problems in the areas of instrumental and basic activities of daily living (ADLs). In a study conducted by Yuen and colleagues (2007), 2/3 of their sample of HNC survivors reported driving less frequently or had stopped entirely as a direct result of cancer treatment. And in the long term, 26.5% continued driving less frequently or ceased altogether. Driving was strongly positively correlated with return to work (RTW) and driving cessation was strongly negatively correlated with RTW. Those who stopped driving stopped working.
Narration

Just to quickly remind us of their experience – this is what the radiotherapy mask looks like. In one study, patients a year after completing radiation still spoke about the mask with vivid recollection, and in a very negative, distress-inducing manner.
Narration

This is an example of internal and external lymphedema – this gentleman clearly has both. While there’s a clear difference between this patient’s worst and best in both appearance and internal space, it still isn’t “normal.”
Narration

This is one of the kindest flap reconstruction pictures I could find, but it gives an idea of how reconstructing part of the face quickly becomes challenging from a surgical perspective, but also from an occupational perspective! If he doesn’t have control over that part of his mouth, how does he keep food or saliva in? How articulate is his speech? How does he perform his job as a salesman or kiss his wife? And that’s only one piece!
As we would expect, the literature identifies a number of psychosocial concerns with HNC survivors. Facial disfigurement, communication impairments, and dysphagia challenge one’s confidence, and it is more challenging or less motivating to participate in social activities involving food, standing and talking in front of people, or putting oneself in a position that draws attention to the physical changes of cancer. This population also worries a lot about recurrence. And among all other types of cancer, the HNC population has the highest suicide rate.

Baxter and colleagues (2017) argue that cancer itself is best approached as a chronic condition, as well as all of the issues afterwards. Patients and their families lack the skills and information about implementing all of these changes into their routines. An article I came across by MacDonald et al (2021) was aptly entitled, “‘Cured’ but not ‘healed’...” Personal health management for HNC survivors is a whole new frontier for these patients, and the research is clear: they need help.

As OTs we are intimately aware of the value of work and other productive occupations. Work is part of our identity, it helps us contribute to society, it provides stability and meets practical needs, and it offers us a deep connection to other people. Retiring early, returning to work and struggling, or going on disability is cause for much distress among this population.
Those were the main needs and gaps identified, and I am sure your wheels are already spinning about the role of OT. We’ll cover that next, but now we are going to talk about the interdisciplinary themes I identified that pertain to the question, “how do we meet those needs?” Education is listed first for a reason! With such significant changes to their life roles, routines, and health, research shows that these patients are NOT satisfied with the amount of information given ahead of time: they want more information, and they want it earlier – right away. They especially want to know how it will affect their lives and what the treatment actually entails.

More specifically, they want more information on sleep disturbance and fatigue, speech and eating, length of recovery, attaining/maintaining a healthy lifestyle, severity of surgery, and human papilloma virus (HPV) if their cancer was caused by HPV (Fang & Heckman, 2016; Rogers et al., 2011). Unsurprisingly, patient satisfaction with the information they’re provided is associated with better mental health (Llewellyn et al., 2006).

Education can improve patient outcomes, and lymphedema is a good example of that. Although lymphedema affects at least 75% (Deng et al., 2012) and up to 98% of HNC survivors by 3 years posttreatment (Jeans et al., 2020), patients frequently identify lymphedema as a topic on which they receive little to no information about (Deng & Murphy, 2016; Jeans et al., 2019; Nixon, Pigott, et al., 2018). But research has demonstrated that appropriate and timely lymphedema education and subsequent intervention can reduce the risk of physical and functional problems, and it can also reduce distress associated with head and neck lymphedema (Nixon, Pigott, et al., 2018).

How education is delivered is also important. We know that therapeutic alliance is the essential foundation for any education to occur effectively, and the research reiterates that fact. Strategies built
on self-management principles are most effective for carry over long term. It doesn’t appear to matter what medium you use to provide info (i.e. tablet, app, printed material). Those media are well accepted by patients, as long as they have something to reference later.

**Slide 15**

**Narration**

The second theme centers on other evidence-based intervention. Regarding psychological intervention, there is moderate to strong evidence to support coping strategies training for managing depression and anxiety. We also need to recognize that patients are not always comfortable bringing up functional issues because, for example, they may think functional issues are insignificant when compared with successful curative treatment. That means we, the clinicians, need to take on the responsibility of bringing up uncomfortable topics, such as dissatisfaction with appearance after surgery. Regarding physical health intervention, patients benefit from supervised exercise during radiation, exercise for dysphagia, medical management for xerostomia, early traditional therapy for trismus, and traditional lymphedema therapy.

The literature identifies several HNC subpopulations that present with unique challenges. HNC patients who are younger tend to report lower QOL and have greater care needs overall compared to older counterparts (Deng et al., 2013; Schorn et al., 2020; Verma et al., 2019). Younger patients tend to report higher levels of sexual dysfunction and greater distress due to physical disfigurement (Lang et al., 2013). Moreover, HNC patients who live in a rural area, are single or widowed, or are in any other way isolated or lacking social support are at increased risk of decreased role function and poorer QOL. Those who are younger or more isolated should be on our radar.
One of the main purposes of this review was to determine if timing was a key factor in the care for people with HNC. The research is clear: it absolutely matters! As we discussed just a moment ago, a strong education component of comprehensive programs should be initiated as close to the time of diagnosis as possible.

Exercise to prevent or minimize dysphagia should be initiated about 4 weeks prior to radiation, if possible. During radiation whole body, moderate resistive + aerobic exercise is effective to minimize fatigue. People also tend to do better if that exercise is tailored and supervised throughout radiation. Interestingly, patients who start earlier are more likely to maintain an active lifestyle when treatment is complete. They’re already in the habit and know the benefits.

Ongoing screening is essential for addressing mental health concerns and physical function as well. This aids in timely referrals and our patients getting the supportive care they need. So the best overall approach combines prehab and traditional rehab.
Narration

Work is a recurring theme in the HNC literature. Many people with HNC retire earlier than planned, and as an earlier slide described, there are a number of reasons why this is the case, ranging from poor physical endurance to feeding problems, decreased frequency of driving to embarrassment about facial disfigurement.

Despite how prevalent an issue this is, there are few studies that have researched intervention relating to RTW. Screening and planning for work is clearly needed.
Implications for OT Practice

1) The likeliest opportunity for successful occupational therapy intervention is to provide intervention early.
2) Occupational therapists should work closely with interdisciplinary teams.
3) Occupational therapists should seek out advanced training in HNC.
4) There are aspects of HNC care that may be best addressed by occupational therapy.
5) More research is needed to demonstrate the distinct value of occupational therapy in HNC care.

Narration

Implications for OT practice. There was really no appreciable literature that included prehab and OT and HNC. Yet, the gaps in services, the numerous needs identified in the literature sort of scream for OT. So, within a larger interdisciplinary service delivery model, I am making the following recommendations based on interdisciplinary literature available in addition to the pillars of our profession, such as the OTPF, scope of practice, code of ethics, our professional research priorities, etc.

Number 1: The likeliest opportunity for successful OT intervention is to provide it early.

This is no surprise to us clinicians, is it? Patient and caregiver training is a cornerstone of OT intervention. As experts in daily living, OTs can meet the expressed desire of patients to know more about how the HNC journey will impact their daily life.

It is recommended that OTs become more involved in prehabilitative education from as close to the time of diagnosis as possible up to and including the first 1-2 weeks of radiation.

Topics that OTs would be most appropriate to cover include lymphedema risk and early identification; anticipated routine, task, and environment modifications; radiotherapy mask anxiety; pretreatment neck and shoulder exercises; and planning for work and driving.

Number 2: OTs should work closely with other members of the interdisciplinary team.

Pts have a better experience when they are working with comprehensive, specialized, interdisciplinary teams. It is impossible for a single profession to fully address all of the many issues that HNC survivors face. Occupational therapists should advocate for collaboration and partnership, and interdisciplinary teams should include OT.
Number 3: OTs should seek out advanced training in HNC.

In the *Occupational Therapy Practice Guidelines for Cancer Rehabilitation with Adults* (Braveman & Hunter, 2017), the authors differentiate several aspects of entry-level practice or generalist knowledge occupational therapists possess versus advanced practice. Entry-level and general practitioners should be able to apply the OT process in any context with any diagnosis. Advanced practitioners can do this and apply diagnosis-specific knowledge. Advanced practitioners can anticipate problems and have mastered techniques that are unique to cancer populations. HNC is complex. Its cure is frustrating and exhaustive. The relative medical frailty of the individual coupled with complicated treatments, procedures, and surgeries result in highly complex and evolving effects on daily life. The foundational OT training is essential and readily applicable to this population, but advanced training is indicated to optimize patient success, rightly identify clinical red flags, and promote occupational identity and engagement.

Number 4: There are aspects of HNC care that may be BEST addressed by OT.

OT has a long-standing positive reputation in addressing driving, work, and ADLs – including addressing the personal skills and factors, the task itself, and the environment or context in which these occupations take place (AOTA, 2020; Cole & Tufano, 2008; Dickerson et al., 2011). In a prehabilitative model of care, it is recommended that OT take the lead in at least these three areas. Knowing patients with HNC are at risk of prolonged decreased driving or driving cessation, occupational therapists should broach the topic and be prepared to provide or refer for preventative, remedial, and compensatory intervention (Yuen et al., 2007). Relating to work within the HNC population, it is recommended that occupational therapists provide guidance in the process through the use of a planning tool (such as the RTW-PT, Amin et al., 2017). Skilled guidance aims to prevent unwanted loss of employment, promote satisfaction and self-efficacy with work, prevent work-related injury, and maintain important relationships, financial means, and productive contributions to society. ADLs are also chiefly grounded in OT practice. Generalists and advanced practitioners alike possess foundational skills needed to enhance ADL performance, including energy conservation techniques, bathroom modifications, and fall risk assessments, in addition to many other strategies. Occupational therapists should advocate for the role of OT in ADL training within this population as well.

Number 5: More research is needed to demonstrate the distinct value of OT in head and neck cancer care.

Despite what is known across disciplines, more research is needed to demonstrate the distinct value of OT in HNC care. Whether the authors realized they were speaking of OT or not, this issue has already been identified by a number of high level studies, stating we don’t have enough studies regarding daily function, role fulfilment, and participation. More specifically and in view of professional priorities posed by AOTA and AOTF, the following recommendations for research have emerged:

- We need prospective observational and interventional studies, with researchers representing support services (as defined by the NCCN® Guidelines; National Comprehensive Cancer Network, 2021), including OT, that are currently under-represented in the literature (Hunter et al., 2017b; Parke et al., 2019).
• Future research must focus on participation limitations and a combination of impairments or issues – rather than a single problem (like shoulder range of motion alone)– to more accurately reflect the patient experience (Parke et al., 2019).
• Further research relating to the efficacy of comprehensive prehabilitation programs in the HNC population specifically are needed (Treanor et al., 2018).

Narration
We see these gaps; we know OT is a logical fit. How in the world could we make this happen?
I want to start the discussion with, what are your initial thoughts about OT’s role in prehabilitation with HNC?

What surprised you? What burning questions do you have? What bothers you?
Discussion

2. What barriers do you foresee or have you experienced?

What solutions have been successful?

Narration

What barriers do you foresee or have you experienced? What solutions have you found effective?
Discussion

3. Who needs to hear this?

- Students
- OTs
- Physicians
- Patients
- Caregivers
- Colleagues
- Insurance
- Administrators
- Policy makers

Narration

In general or on a broader scale, who do you think needs to hear about this?
I want to leave you with this. I want you to think about who in your world needs to hear about this. What’s their discipline? Logistics involved?

What would your strategy look like? When I’m creating a plan I like to use pictures! Is your strategy that is coming to mind a linear process? Is it cyclical or recurring? What’s the timeline? What actions are associated? Which people or stakeholders are associated?
In summary, HNC survivors have a number of unmet needs. Meeting these needs requires the whole team within an early intervention or prehabilitation model. Occupational therapy has a huge role to play and is a logical fit to help meet these needs. Implementation will require strategic communication of the evidence and, if I may add, a willingness and a boldness on our part.

Email address:
claire.dolislager@gmail.com
Acknowledgements

Dr. Kathleen Matuska
St. Kate PP-OTD class of 2022
Committee members Dr. Wickboldt,
Dr. Coss, and Dr. Polo

References


References


References


Appendix B.2

Michigan Occupational Therapy Association Oncology Special Interest Section Planning Meeting

Minutes

Oncology SIS Meeting
1-20-2022

Attendance
Claire Dolislager
Denise Justice
Danning Wang
Marion

Agenda
1. Future speaker/in-service topic for the Oncology SIS
   Claire on head and neck cancer
2. Date/time for next
   Thursday, March 10, 2022, at 7 PM
3. Oncology SIS meeting
   30-minute presentation
   Question/answer
   Discussion on what’s going on in cancer
   Updates on MCC
   Determine journal club
   Encourage participation in Facebook
4. Develop a resource list for patients
   Therapists across the state who address certain conditions in different areas of the state
   Claire to begin the spread sheet in a google doc
5. MCC coordination
   Schedule for upcoming meeting have not been established

Future Meeting Topic Ideas
- Lymphedema – Claire is a specialist working on doctorate with focus on head and neck cancer
- Late effects of chemo and radiation
Appendix B.3

Michigan Occupational Therapy Association Presentation Participant Survey

Implementing Evidence-Based Prehabilitation Approaches in HNC Populations
Participant Survey

* Required

Presentation questions
Thank you so much for providing your feedback!

1. What is your professional status (i.e. OT student, educator, researcher, and/or clinician)? *

2. Please indicate how well the stated objective was met: “Examine the needs of patients with head and neck cancer” *

   Mark only one oval.

   1  2  3  4  5

   Not at all  □ □ □ □ □ Very well

3. Please indicate how well the stated objective was met: “Identify evidence-based prehabilitative / early intervention approaches” *

   Mark only one oval.

   1  2  3  4  5

   Not at all  □ □ □ □ □ Very well
4. Please indicate how well the stated objective was met: "Discuss strategies for implementing prehabilitation in head and neck cancer populations" *

Mark only one oval.

1 2 3 4 5
Not at all ◯ ◯ ◯ ◯ ◯ Very well

5. Please indicate how well the content of the presentation was organized *

Mark only one oval.

1 2 3 4 5
Not at all ◯ ◯ ◯ ◯ ◯ Very well

6. Please indicate your overall impression of the presenter’s ability to communicate this information. *

Mark only one oval.

1 2 3 4 5
Not at all ◯ ◯ ◯ ◯ ◯ Very well

7. Please share any additional comments, suggestions, or questions.

________________________________________

This content is neither created nor endorsed by Google.
Appendix B.4

Michigan Occupational Therapy Association Presentation Participant Survey Results

Question 1

What is your professional status (i.e. OT student, educator, researcher, and/or clinician)?

- Occupational Therapist: 84%
- Occupational Therapist, not actively practicing: 8%
- Occupational Therapy Student: 8%

Question 2

Please indicate how well the stated objective was met: "Examine the needs of patients with head and neck cancer"
Question 3

Please indicate how well the stated objective was met: "Identify evidence-based prehabilitative / early intervention approaches"

Question 4

Please indicate how well the stated objective was met: "Discuss strategies for implementing prehabilitation in head and neck cancer populations"
**Question 5**

Please indicate how well the content of the presentation was organized.

**Question 6**

Please indicate your overall impression of the presenter's ability to communicate this information.
Question 7

Please share any additional comments, suggestions, or questions.

<table>
<thead>
<tr>
<th>Participant Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is great to keep learning.</td>
</tr>
<tr>
<td>Thank you for your time and presenting this material. It was very informative.</td>
</tr>
<tr>
<td>Claire did an amazing job demonstrating the need for OT in this area of practice. I loved the discussion piece at the end that really had me motivated to research.</td>
</tr>
<tr>
<td>New area of interest and definitely the presenter provide additional evidence to support the value of OT.</td>
</tr>
<tr>
<td>Claire has completed a significant amount of research on this topic! It was greatly appreciated that she shared her knowledge.</td>
</tr>
<tr>
<td>Would love to see it as a continuing series.</td>
</tr>
</tbody>
</table>
Appendix B.5

Michigan Occupational Therapy Association Presentation Supplementary Materials Handout

Evidence Based Practice: Implementing Prehabilitative Approaches in Head and Neck Cancer

March 10
2022

Michigan Occupational therapy Association – Oncology Special Interest Section

Claire M. Dolislager, MS, OTRL, CLT-LANA
Post-professional Doctoral Student
St. Catherine University

Supplementary Materials
Background Information: Problem Statement and PICO

Problem statement

To date, there has never been a critical appraisal of the evidence supporting the occupational therapy intervention and models of care that have been described for treating patients with HNC including prehabilitative approaches.

PICO₁

Do clients with HNC who participate in a prehabilitation program experience better occupational outcomes than clients who do not?

PICO₂

Do clients with HNC who receive occupational therapy services at any point in the care continuum experience better occupational outcomes than clients who do not?

Background Information: Intra- and Inter-professional Resources

<table>
<thead>
<tr>
<th>Source</th>
<th>Resource Example</th>
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</thead>
<tbody>
<tr>
<td>American Occupational Therapy Association</td>
<td>Cancer Fact Sheets</td>
</tr>
<tr>
<td></td>
<td><em>Occupational Therapy Guidelines for Cancer Rehabilitation in Adults</em></td>
</tr>
<tr>
<td>American Occupational Therapy Foundation</td>
<td>Professional research priorities</td>
</tr>
<tr>
<td></td>
<td>Research resources</td>
</tr>
<tr>
<td>National Cancer Institute</td>
<td>Statistics</td>
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<td></td>
<td>Patient &amp; provider handouts</td>
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<tr>
<td>American Head and Neck Society</td>
<td>Survivorship handouts</td>
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<tr>
<td>National Comprehensive Cancer Network</td>
<td>NCCN® Survivorship Guidelines</td>
</tr>
<tr>
<td>American Speech and Hearing Association</td>
<td>Therapist educational resources</td>
</tr>
<tr>
<td></td>
<td>Research</td>
</tr>
</tbody>
</table>
### Literature Review: Evidence Matrix

<table>
<thead>
<tr>
<th>Reference</th>
<th>Type of Article</th>
<th>Type of Publication</th>
<th>Purpose</th>
<th>Methods</th>
<th>Results</th>
<th>Conclusions and Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Costanzo, E. S., Stawski, R. S., Ryff, C. D., Coe, C. L., &amp; Almeida, D. M. (2012). Cancer survivors’ responses to daily stressors: Implications for quality of life. <em>Health Psychology, 31</em>(3), 360–370. <a href="http://dx.doi.org/10.1037/a0027018">http://dx.doi.org/10.1037/a0027018</a></td>
<td>Empirical Study, Quantitative Study</td>
<td>Non-randomized control trial</td>
<td>To examine the experiences of cancer survivors related to daily stressors and QOL.</td>
<td>Those who participated in the National Study of Daily Experiences and indicated they had had cancer were solicited. 111 cancer survivors and 111 socio-demographically matched controls had identical tasks. Over an 8-day period all participants recorded stressful events and the impact thereof. Measures included the Daily Inventory of Stressful Events, positive and negative affect (self-rating), physical symptoms, salivary cortisol samples, and health conditions and medication use.</td>
<td>The number and type of stressful events recorded were comparable between the cancer survivors and control group. Cancer survivors tended to view stressful events as slightly more disruptive and impactful, especially interpersonal conflicts. “Relative to the comparison group, cancer survivors showed less pronounced changes in positive affect and cortisol output when stressors occurred, but a greater increase in negative affect response to interpersonal conflicts” (p. 360). Resilience was identified in social well-being, personal growth, and spirituality.</td>
<td>Cancer survivors experience similar numbers and types of daily stressors compared to people without cancer. However, they may attach more disruptive meaning to them, especially if it involves conflict with other people. Emotionally and physiologically, cancer survivors do demonstrate resilience in response to day-to-day challenges. Daily stressors and coping are another aspect of a cancer survivor’s life that healthcare workers must consider in overall physical and mental health, and subsequently address.</td>
</tr>
<tr>
<td>Yueh-Hsia, C., Wei-An, L., Chung-Yin, H., Guo, S.-L., Lien, S.-H., Hsiao-Jung, T., &amp; Yuan-Hung, C. (2018). Functional outcomes and quality of life after a 6-month early intervention program for oral cancer survivors: A single-arm clinical trial.</td>
<td>Single-arm preliminary pilot study, Clinical trial</td>
<td>Open access, scholarly peer-reviewed journal</td>
<td>Determine if multimodal early intervention program for HNC survivors results in better functional outcomes and QOL 6 months after surgery.</td>
<td>Pre-post measures of the entire cohort. Group comparisons at baseline, 1 month, 3 months, and 6 months. Early intervention, 40 mins 5x/week: Shoulder, TMJ, neck ROM exercises; modalities; soft tissue mobilization; ADL and functional training. Middle intervention, 50 mins 1x/week: Soft tissue mobilization, modalities, shoulder PRE, oral motor exercises.</td>
<td>65 participants: 60 male, 5 female; mean age 51.6 yrs. Shoulder dysfunction less problematic than in the literature. Achievable TMJ ROM is positively correlated with stage of disease. Participants demonstrated significant improvements in physical function at 3 and 6 months post-surgery. QOL continued to improve at 3 and 6 months post-surgery. QOL differed between early and advanced stage disease groups.</td>
<td>There is moderately strong evidence that patients with HNC benefit from an early intervention program targeting overall physical function, TMJ and shoulder ROM, and QOL. While stage of disease had effects on outcomes, all groups had significant improvements in these domains. This study highlights the likely benefits of early intervention, long term follow up (1x/week for approx. 6 months), and the need for a RCT to corroborate these results.</td>
</tr>
</tbody>
</table>
Late intervention, 60 mins, 1x/week (+3-5x/week independently at home): Pain and scar management, shoulder PRE, intra-oral scar massage.


Mixed methods, Pilot testing Scholarly, peer-reviewed journal To develop a planning tool for cancer survivors and other stakeholders to utilize in preparing for RTW.

The Return to Work Planning Tool (RTW-PT) was piloted with 15 HNC survivors over 4 months. Survivors who had utilized the tool were called 2 weeks after therapy ended to solicit feedback. An additional meeting with 43 medical and related professionals to elicit feedback. Snowball sampling was utilized to identify the 43.

Initial validity was established prior to this pilot study and reported elsewhere. Following pilot testing, changes were made to the content. First, two versions were needed: one for the survivor-employee, and one for the employer. The employee version is longer and includes more self-reflection about work and potential protected health information that is not necessary to be known by the employer. Employers’ feedback included space for upcoming appointments to best accommodate time off and scheduling. Phrasing in some sections was altered to frame accommodation requests in a more positive light (i.e. instead of “5-min rest breaks hourly to compensate for decreased stamina,” “breaks to optimize concentration and productivity”). Employees and employers alike found the communication plan to be the most beneficial section.

RTW is a challenging aspect of HNC survivorship, and it should be planned and prepared for from the beginning. This planning tool is one that would be appropriate for use in a prehabilitation program to identify potential barriers, facilitate the best RTW fit, and prepare the patient for a smooth and successful return.


Cross-sectional study Scholarly, peer-reviewed journal To examine the factors associated with QOL while HNC patients are in early stages (first 1-2 weeks) of radiation.

Of patients referred to the pain and rehabilitation clinic, participants meeting study criteria were solicited. Adult, Swedish speaking HNC patients undergoing radiation for curative intent were included. “A survey questionnaire using 5 validated patient-reported outcome measurements was used in this study” (p. 1698),

There were 54 HNC patients who agreed to participate; 45 were newly diagnosed and 9 were non-newly diagnosed. Twenty-three (42.6%) were over the age of 65, and 31 (57.4%) were under; 36 (66.7%) were men, and 18 (33.3%) were women. Twenty-three (42.6%) were non-smokers, 9 (16.3%) were current smokers, and 23 (42.6%) were former smokers. Questionnaires were completed in a mean of 6 days (SD 3 days) after radiation began.

The authors argue several reasons results may differ with other studies, including the possibility of cancer denial (one study cited a rate up to 47%, and may be an adaptive response of terminally ill patients). QOL may also be preserved in early weeks because they have not yet experienced pain. There may have also been a selection bias as those who declined to
measuring pain, QOL, anxiety and depression, and pain catastrophization.

In the early days and weeks of radiation, patients’ QOL and pain status are largely preserved, with minor depressive and anxiety symptoms. Pain intensity and depression negatively affect QOL. Less pain interference may reflect that patients had not yet experienced treatment side effects. While some studies report lower QOL due to fear and anxiety about treatment early on in treatment, this study found that QOL was preserved in early treatment.


Scoping review Scholarly, peer-reviewed journal

“Examine the amount and nature of research activity in HNC rehabilitation; highlight publication trends...and identify gaps in the existing literature” (p. 2381).

PubMed, Embase, and CINAHL databases were reviewed. Included studies published between 1/1/1990-4/30/2017, with HNC patients at any point of disease, and evaluation of rehabilitation outcomes. Studies were excluded if the intervention or outcome was not specific to rehabilitation or the HNC population.

Initial return of 2228 studies, final total of 258 articles included. Publication rate increased over time, with 145 (56%) published after 2010. Study design: Clinical studies (72% total; 150 observational and 35 interventional), and opinion pieces, book chapters, reviews, and guidelines (28% total; 14 systematic reviews). 8 of the systematic reviews were related to speech and swallowing, 3 to QOL and functional outcome measures, 2 to shoulder and neck function, and 1 in exercise. Most common intervention studied (in descending order) focused on: chewing and swallowing, aerobic or resistive exercise, voice or speech intervention, multi-disciplinary rehabilitation intervention, alternative and complementary medicine, and physiatrist-led intervention. There were no studies focused on vocational counseling, rehabilitation psychology, or recreation therapy. No interventional studies studied pre-treatment population. Most interventional studies measured impairment (61%), activity limitations.

Although HNC research has increased (390% increase), it is not nearly the same rate of cancer rehabilitation (810%) and general cancer research publications (1056%) in the same timeframe. The majority of studies have small samples (<100), are outpatient based, retrospective, and observational. Interventional and prospective observational studies are needed. Degree of impairment does not necessarily equate to QOL; there is a significant gap in participation-focused studies. The complex nature of HNC treatment sequelae denotes the imperative inclusion of rehabilitation services, yet there is a need for more members of rehabilitation to be involved in research. Many disciplines are vastly under-represented, including OT. Although a wide range of issues...
Prehabilitation versus rehabilitation: A randomized control trial in patients undergoing colorectal resection for cancer.

https://doi.org/10.1097/ALN.0000000000000393

To determine if a tri-modal intervention program (exercise, nutrition, anxiety management) was more effective when provided before (prehabilitation) or after (rehabilitation) colorectal cancer resection.

Prehabilitation group received intervention beginning 4 weeks prior to surgery through 8 weeks after surgery. Rehabilitation group received intervention beginning within 1 week after surgery through 8 weeks after surgery. Intervention: individualized moderate exercise program; nutrition education and whey protein supplementation; coping strategies to reduce anxiety.

Prehabilitation had significantly better adherence with the program after surgery than the rehabilitation group. Prehabilitation was associated with improvements in physical functioning while the rehabilitation group declined physically.

This program structure may prevent or minimize decline related to cancer surgery, and intervening prior to surgery appears to be advantageous.
[https://doi.org/10.1016/j.oraloncology.2018.05.025](https://doi.org/10.1016/j.oraloncology.2018.05.025)

For the qualitative interview component, participant checking was completed to ensure accurate coding.

**Themes:**

*Psychosocial impact*

Negative impact on appearance, emotional about HNL, worried, overwhelmed, reminder of disease.

*Physical experience and pattern/timing*

Onset was consistently either after surgery and/or radiation. Swelling was worse after radiation and in the morning. Swelling improved with HNL treatment.

*Experience of receiving treatment*

Education/information, self-management instruction, massage, compression, exercise, and lymph tape were named as beneficial in reducing swelling and distress.

*Day-to-day distress*

Results varied. Some reported HNL-associated distress significantly impacted daily routines and role function, for others it became part of the daily routine readily. Some limited community activities while others continued normally.

*Supports that helped manage distress*

People resources were the main source of distress management (healthcare professionals, family, and friends).

*Adjustment to a “new normal”*

Ongoing fears and anxiety related to HNC itself, less specifically about HNL. Some used downward social comparison to accept and cope with HNL. 6 of 10 reported moving on with their lives, beyond HNC and HNL.


“To explore the driving behaviors of HNC patients during and after Adult patients with a diagnosis of HNC who received either chemotherapy, radiation, or both, and were listed on at

Of the 183 mailed questionnaires, 86 were returned. However, 18 had never driven or were deceased. An additional 15 patients completed the questionnaire in the clinic at their follow up visit.

HNC treatment affects many skills that are needed for driving, including physical, psychological, and cognitive domains.

cancer therapy” (p. 675).

least one of several tumor registries were recruited. A 7-page, 72-item questionnaire was developed and validated. All items were rated on a Likert scale, and covered perceptions about impact of treatment sequelae on driving, concern about driving situations, transportation assistance, driving impact on ADLs, and amount of traffic accidents. Therefore, 83 were included in analysis. Mean age was 61.4 (SD=10.8) yrs; 65 were male (78.3%); 69 were white (83.1%), 10 (12%) were black; 57 (68.7%) were married; and 37.3% were employed at the time of the survey. Many (67.5%) patients drove less or stopped driving during cancer treatment; 26.5% patients continued driving less/cessation after cancer treatment. There was not an association between age and cessation. Resumption occurred about 6 months after treatment. Daily mileage decreased significantly overall during and after cancer treatment. Dependence on others increased for transportation. Driving behaviors were significantly correlated with work status, social and leisure activities, and household errands – all of which were reduced compared to baseline. This trend continued for work and social and leisure activities after treatment. Participants felt less confident in adverse driving conditions, and there was an increase of traffic violations after cancer treatment. Concern about driving ability was predictive of self-restricting behaviors. Surgery in addition to chemotherapy and/or radiation was not a significant factor related to driving behaviors.

Decreased participation in leisure and social activities is an area for opportunity for the interdisciplinary team. To safely return to driving, HNC patients may benefit from strategies/intervention to prevent or mitigate treatment related impairments, education on alternative transportation options available, driver’s rehabilitation, and confidence-producing driving experiences. Work opportunities not relying on transportation may be another are to explore. In general, limitations in driving after cancer treatment are correlated with limitations in work, household errands, and social and leisure participation.

| Llewellyn, C. D., McGurk, M., & Weinman, J. (2006). How satisfied are head and neck cancer (HNC) patients with the information they received pretreatment? | Cross-sectional survey | Scholarly, peer-reviewed journal | To determine if there exists an association between patient-perceived satisfaction with pretreatment information | All newly diagnosed HNC patients between July, 2003 and July, 2004 were recruited from 4 hospitals. Baseline data was obtained after diagnosis and before treatment using questionnaires and medical chart review. | Sample included 82 HNC patients, with a mean age of 60 (23-89) yrs, and 66% were male. Stages of disease were evenly distributed. Baseline = T1, 1 month = T2, +6-8 months = T3. At T2, 68 patients responded; at T3, 50 patients responded (dropouts due to death, disease recurrence, complications). | Initially participants were fairly satisfied with information received pretreatment, however, as their journey progressed, they were less satisfied with the information they had and felt unprepared for/ surprised by aspects of their journey. |

| Barnard, A., Clur, L., & Joubert, Y. (2016). Returning Qualitative, Exploratory Scholarly, peer-reviewed To explore the adjustment and coping process A hermeneutic phenomenological approach. Participants were recruited of the 8 participants, 6 were female and 2 were male; 5 were married, 2 were single, and 1 was divorced. All had recovered | Financial advice was among the most common areas of information need. HNC patients desire more information up front about treatment side effects and expected length of recovery. The content desired by patients focuses on how it will affect their lives, while clinicians tend to focus on the specifics of the procedure or treatment. Education needs vary depending on stage of disease. Dissatisfaction with information more greatly affects mental health than physical. Information should be tailored to meet the needs of the individual patient. Findings from this study provide relevant information regarding the type of information needed at the time of diagnosis and after treatment for patients with HNC. |

Measures were repeated at 1 month after treatment, and then after an additional 6-8 months. Measures included HADS, General Health Survey Questionnaire, Short form (SF-12v2), and satisfaction with information profile (SCIP). Prior to treatment, patients indicated they lacked information regarding financial support, patient support groups, understanding and managing treatment side effects, how treatment would affect work ability, and long term effects on QOL and daily function. After treatment, most patients indicated they still lacked information regarding financial support, possibility of further treatment, and support groups. Before treatment, 52% did not believe they needed more information, but only 31% of posttreatment patients believed they did not need more information at the beginning. Specific issues needing additional information: physical effects of treatment, long term effects of treatment, likely length of recovery, and severity of surgery. There was a significant reduction in satisfaction with the amount and content of information, and helpfulness of information. Higher depression scores after treatment were associated with higher depression scores, lower satisfaction scores at baseline, and more advanced stages of cancer. Greater mental functioning, higher satisfaction with information at baseline, and earlier stages of disease were predictive of better mental functioning after treatment. Physical component and anxiety scores were not associated with information satisfaction.

Before treatment, 52% did not believe they needed more information, but only 31% of posttreatment patients believed they did not need more information at the beginning. Specific issues needing additional information: physical effects of treatment, long term effects of treatment, likely length of recovery, and severity of surgery. There was a significant reduction in satisfaction with the amount and content of information, and helpfulness of information. Higher depression scores after treatment were associated with higher depression scores, lower satisfaction scores at baseline, and more advanced stages of cancer. Greater mental functioning, higher satisfaction with information at baseline, and earlier stages of disease were predictive of better mental functioning after treatment. Physical component and anxiety scores were not associated with information satisfaction.
to work: The cancer survivor’s transformational journey of adjustment and coping. 

http://dx.doi.org/10.3402/qhw.v11.32488

Open access article of HNC survivors underpinning their experience returning to work. 

from an oncology facility and support facility, and purposeful sampling occurred, resulting in 6 participants. Further snowball sampling resulted in 2 more. Unstructured interviews, digitally recorded and then transcribed. Accuracy assured through multiple listenings. 

from cancer treatment and returned to, predominantly, office work. In view of respondents’ reports, their coping styles and adjustment change over time, and are characterized as follows: 1) Early on survivors feel overwhelmed and respond with irrational and defensive coping mechanisms. 2) Acceptance occurs, and survivors communicate about cancer in factual language. Humor and hope resurface. 3) Continual reflection promotes problem-solving and attaching meaning to their cancer experience. 4) Survivors can see their ability to impact others. 

Themes: Avoidant coping with overwhelming emotions Seeking understanding and positive affectivity to face reality Taking control and responsibility Reassessing life through meaning-making 

https://doi.org/10.1188/18.ONF.726-736

Systematic review Scholarly, peer-reviewed journal 

Explore the components of cancer prehabilitation programs and determine their effectiveness in restoring/enhancing QOL. 

Following PRISMA guidelines, identified 12 full text RCTs for appraisal through a database search. 

Physical cancer rehabilitation (exercise programs) improve physical function, but only 4 showed differences between control and intervention groups; programs began in these cases 4-8 weeks prior to surgery. Psychological cancer rehabilitation (stress management and psycho-educational methods): 1 of 3 studies demonstrated difference in QOL compared to control group; 2 sessions prior to and 2 after surgery during a 5 week period. Multimodal cancer rehabilitation programs: no differences between groups related to QOL. 

Across a variety of types of cancer, there is strong evidence in favor of earlier intervention. Related to impacting QOL specifically, unimodal physical or psychological programs to date appear most effective. These all begin several weeks prior to surgery and extend after surgery. 

Hortense, F. T. P., Bergerot, C. D., & RCT, experimental Scholarly, peer-reviewed journal

Evaluate the effectiveness of Measures conducted at baseline and at 3, 6, and 12 months. 20 participants total. Majority male, in advanced stages of cancer treatment. 

In the HNC population, there is strong evidence to support self-
<table>
<thead>
<tr>
<th>Source</th>
<th>Study Title</th>
<th>Type</th>
<th>Participants</th>
<th>Intervention</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domenico, E. B. L. D. (2020).</td>
<td>Quality of life, anxiety and depression in head and neck cancer patients: A randomized clinical trial.</td>
<td>Reviewed journal</td>
<td>54(e03546), 1–8.</td>
<td>7-part video series of topics related to common issues and given strategies for management, given a booklet and DVD with this information, and a 60-min integrated educational session.</td>
<td>Presence of anxiety and depression significantly, negatively correlated with QOL.</td>
</tr>
<tr>
<td>Samuel, S. R., Maiya, G. A., Babu, A. S., &amp; Vidyasagar, M. S. (2013).</td>
<td>Effect of exercise training on functional capacity and quality of life in head and neck cancer patients receiving chemoradiotherapy.</td>
<td>RCT</td>
<td>48 total participants, 21 male and 3 female in each group.</td>
<td>Overall, the 6MWT distance improved by an average of 42 meters in the exercise group, decreased by 96 meters in the control group.</td>
<td>Exercise is safe and appropriate to provide in the prehabilitative setting, and it is an effective modality for improving QOL and functional capacity.</td>
</tr>
<tr>
<td>Howren, M. B., Christensen, A. J., Karnell, L. H., &amp; Funk, G. F. (2010).</td>
<td>Health-related quality of life in head and neck cancer survivors: Impact of</td>
<td>Prospective, repeated measure design</td>
<td>There were 306 participants (male = 192, female = 114).</td>
<td>There were 306 participants (male = 192, female = 114).</td>
<td>Identifying pretreatment depression in patients with HNC may allow an opportunity for early intervention and prevention of lower post-treatment QOL.</td>
</tr>
<tr>
<td>Loewen, I., Jeffery, C. C., Rieger, J., &amp; Constantinescu, G. (2021). Prehabilitation in head and neck cancer patients: A literature review. <em>Journal of Otolaryngology -- Head &amp; Neck Surgery</em>, 50(1), 1–11. <a href="https://doi.org/10.1186/s40463-020-00486-7">https://doi.org/10.1186/s40463-020-00486-7</a></td>
<td>Systematic review</td>
<td>Open access, peer-reviewed scholarly journal</td>
<td>Identify current best practice models for prehabilitation in HNC, specifically addressing dysphagia.</td>
<td>There were 29 original research studies reviewed. Publication date of 2006-2020. Examined program timing and details. Database search.</td>
<td>Two definitions of prehabilitation: pretreatment and treatment concurrent, although key factor of any prehabilitation program = intervention provided prior to impairment. Majority of articles published in the last 8 yrs. There is a range of exercise type, frequency, and duration protocols. Inconsistent use of outcome measures.</td>
</tr>
<tr>
<td>Steves, S. L., &amp; Scafide, K. N. (2021). Multimedia in preoperative patient education for adults undergoing cancer surgery: A systematic review. <em>European Journal of Oncology</em></td>
<td>Systematic review</td>
<td>Peer-reviewed scholarly journal</td>
<td>To determine if there is sufficient evidence to support the use of multimedia for education delivery in cancer prehabilitation.</td>
<td>Systematic database search, original articles published between 2010 and 2020. Outcomes of study: levels of anxiety, knowledge acquisition, satisfaction, and compliance.</td>
<td>There were 9 studies included in the review, 7 using video, 1 using tablet, 1 using computer program. Total of 847 participants. Most studies excluded participants with cognitive dysfunction, emotional instability, psychological disease, and hearing or visual impairments. Focus of education ranged from understanding cancer, surgery expectations, and usual postoperative care. Others perioperative experience. Some studies allowed participants</td>
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<tr>
<td>Study</td>
<td>Type of Study</td>
<td>Scientific Journal</td>
<td>Results</td>
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<td><em>Nursing</em>, 52, 101981. <a href="https://doi.org/10.1016/j.ejon.2011.101981">https://doi.org/10.1016/j.ejon.2011.101981</a></td>
<td>Systematic review</td>
<td><em>European Journal of Cancer Care</em>, 28(4), e13023. <a href="https://doi.org/10.1111/ecc.13023">https://doi.org/10.1111/ecc.13023</a></td>
<td>Unlimited access to the educational material, while others only viewed it once. Anxiety: methodology, tools, timing (one-time or longitudinal), although one with the most rigorous methods demonstrated preoperative educational video reduced 3 measures of postoperative anxiety compared to usual care. Knowledge: Mixed results for knowledge acquisition. Satisfaction: Patients in nearly all studies were highly satisfied with the education medium. Compliance: participants in in-person and video groups were similarly compliant. Clinicians should not hesitate to include multimedia in preoperative education.</td>
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<td>Faithfull, S., Turner, L., Poole, K., Joy, M., Manders, R., Weprin, J., Winters-Stone, K., &amp; Saxton, J. (2019). <em>Prehabilitation for adults diagnosed with cancer: A systematic review of long-term physical function, nutrition, and patient-reported outcomes</em>. <em>European Journal of Cancer Care</em>, 28(4), e13023. <a href="https://doi.org/10.1111/ecc.13023">https://doi.org/10.1111/ecc.13023</a></td>
<td>Systematic review, peer-reviewed journal</td>
<td>To determine the effectiveness of prehabilitation in cancer survivors in physical fitness, nutrition, and patient-reported outcomes at or after 30 days post-treatment.</td>
<td>Systematic database search. Articles published between 2009-2017. Few studies reported on comorbidities and how they changed over time. “Prehabilitation improved gait, cardiopulmonary function, urinary continence, lung function, and mood 30 days posttreatment but was not consistent across studies” (p. 1). Relating to physical function, nutrition, and patient-reported outcomes, prehabilitation is most effective when combined with rehabilitation.</td>
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<td>Michael, C. M., Lehrer, E. J., Schmitz, K. H., &amp; Zaorsky, N. G.</td>
<td>Systematic review, meta-analysis</td>
<td>Scholarly, peer-reviewed journal</td>
<td>To determine the impact of prehabilitation exercise therapy</td>
<td>Followed PRISMA guidelines. Systematic database search. 6MWT was used to determine physical function. 21 studies included in qualitative analysis. 5 studies included in meta-analysis. Studies with aerobic + resistive exercises: 10; aerobic only: 3; resistance only: 1; Exercise is an effective method for maintaining or improving physical function after cancer surgery.</td>
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</table>

The role and scope of prehabilitation in cancer care. Seminars in Oncology Nursing, 36(1), 150976. [https://doi.org/10.1016/j.soncn.2019.150976](https://doi.org/10.1016/j.soncn.2019.150976)

<table>
<thead>
<tr>
<th>Unimodal</th>
<th>Gastrointestinal cancers: Cycling intervention prehabilitatively improved respiratory muscle and aerobic parameters, but no difference in QOL; aerobic + resistive exercise improves strength despite predicted muscle loss during chemotherapy.</th>
</tr>
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<tbody>
<tr>
<td>Lung cancer:</td>
<td>Prehabilitation can decrease risk of pulmonary complications, decreased time requiring intercostal catheter, decreased length of stay, and improved 6MWT and pulmonary function.</td>
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<tr>
<td>Prostate cancer:</td>
<td>Prehabilitation, including pelvic floor exercises, increased physical function and endurance (6MWT), quicker recovery.</td>
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<td>Breast cancer:</td>
<td>Exercise improves physical and mental health domains. No differences in seroma formation between exercising and non-exercising cohorts. Exercise groups started before surgery and continuing throughout treatment and into survivorship produced less anxiety compared with controls. There is emerging evidence that “suggest[s] metabolic and genetic pathways for protective effects of presurgical exercise in breast cancer” (p. 4).</td>
</tr>
<tr>
<td>Gynecologic cancers:</td>
<td>Obesity is a known risk factor, aptly targeted by exercise. Exercise prehabilitation group participants demonstrated improved fitness-related QOL and decreased waist circumference, decreased anxiety and depression; no change in lung function or BMI.</td>
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</table>

Interpreted in light of a sole data source. Prehabilitation is common and either effective or promising for improving patient outcomes. In HNC specifically, prehabilitation may improve physical capacity; speech, mastication, and swallowing; and early identification of lymphedema. There is a distinct lack of occupational performance outcome data. Interdisciplinary collaboration is essential for successful prehabilitation programs, including a high-performing nurse navigator.
Head and neck cancers:
Peak voice change occurs at 10 weeks posttreatment, level off at 1 yr posttreatment.
Patient-preferred frequency/duration of exercise: 30 mins/session, 3x/week or less.
Multiple short duration sessions may be best approach for this population.
All studies reviewed focused on speech, mastication, and/or swallowing.
**Multimodal:**
- **Colorectal cancer:** Kinesiologist + dietician + psychologist prehabilitation was effective for recovering baseline function faster and more completely compared to controls.
- **Lung cancer:** Smoking cessation counseling preoperatively is not necessarily effective.
- **Prostate cancer:** Not studied.
- **Breast cancer:** Studies recommend comprehensive prehabilitation programs to include total body exercise, targeted exercise, nutrition, psychologic aid, and smoking cessation.
- **Gynecologic cancers:** Case reports and smaller studies. May decrease postoperative confusion. Further research needed, especially as medical intervention is more often favoring radiotherapy alone.
- **Urologic cancers:** Not sufficiently studied.
- **Head and neck cancers:** Most studies are with postoperative populations.
Prehabilitation resulted in earlier identification of lymphedema.

Silver, J. K. (2015). Literature Scholarly, "To examine the Sources included clinical Prehabilitation largely improves physical Author is a known expert in
https://doi.org/10.1016/j.soncn.2014.11.003

Prehabilitation, although interpretation of this article should be considered in light of lacking methodological descriptions: are the descriptions provided a complete representation of existing literature or only those that support the author’s arguments? There are many studies cited in this review that do support the effectiveness of prehabilitation. By reducing rates of complications or shortening hospital stays (e.g.), there is opportunity to demonstrate that prehabilitation may thus reduce health care costs.

https://doi.org/10.1016/j.semradonc.2017.08.008

There are significant unmet needs in patients with HNC and their family members. HNC prehabilitation and rehabilitation are beneficial and should be expanded to meet needs across domains/disciplines. Long term sequelae reported in this research informs treatment: comprehensive programs should address swallowing and speech impairments, psychological distress, CRCD, nutritional needs, role satisfaction, return to work, communication, and QOL.

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**Cancer prehabilitation and its role in improving health outcomes and reducing health care costs.**  
*Seminars in Oncology Nursing*, 31(1), 13–30.  
https://doi.org/10.1016/j.soncn.2014.11.003

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There are significant unmet needs in patients with HNC and their family members. HNC prehabilitation and rehabilitation are beneficial and should be expanded to meet needs across domains/disciplines. Long term sequelae reported in this research informs treatment: comprehensive programs should address swallowing and speech impairments, psychological distress, CRCD, nutritional needs, role satisfaction, return to work, communication, and QOL.
term psychosocial support is lacking. Subset of HNC survivors demonstrate CRCD and lack appropriate follow up. Limited research available on CRCD. Overall QOL may return to baseline at about 1 yr posttreatment, but impairment-specific QOL does not.

| Gallagher, K. K., Sacco, A. G., Lee, J. S.-J., Taylor, R., Chansowski, E. J. P., Bradford, C. R., Prince, M. E., Moyer, J. S., Wolf, G. T., Worden, F. P., Eisbruch, A., & Chepeha, D. B. (2015). | Cross-sectional study | Scholarly, peer-reviewed journal | With prior established association of HNC surgery and shoulder dysfunction in view, this study aimed to determine the effect of HNC surgery and shoulder impairment on work and leisure participation. | Adult patients were recruited through the University of Michigan Department of Otolaryngology-Head and Neck Surgery if they had had HNC surgery (+any other adjuvant treatment) >12 months ago. Outcome measures included the Neck Dissection Impairment Index (NDII), Constant-Murley Shoulder Test, and categorical status (yes/no) for change in employment and leisure status. | 127 men and 40 women; mean age was 57 (29-85) yrs. Median NDII score was 90, lower scores for patients with modified radical neck dissection compared with selective neck dissection. Advanced stage disease, radiation, and chemotherapy were all correlated with worse shoulder function. “Change in leisure activity was correlated with greater shoulder impairment…” Patients requiring pain medication reported greater shoulder impairment” (p. 891). No significant difference was demonstrated on NDII related to physical therapy intervention; however, there was a significant effect on shoulder dysfunction. | One reason to help explain lower RTW rates among the HNC population is posttreatment shoulder dysfunction. More aggressive cancer treatment results in greater shoulder impairment. Greater shoulder dysfunction is associated with greater disruption in work and leisure participation. Prospective planning is needed to facilitate employment maintenance or successful RTW and leisure engagement. Further research is needed to identify or develop effective methods for preventing shoulder dysfunction. |

| Molassiotis, A., & Rogers, M. (2012). Symptom experience and treatment outcomes in head and neck cancer survivors. | Qualitative, longitudinal study | Scholarly, peer-reviewed journal | “To explore and understand the experiences of receiving…” Prospective semi-structured interviews were conducted soon after diagnosis and at around 3, 6, and 12 months. | There were 16 participants: mean age was 61 (34-80) yrs; 14 were male, 2 were female. Themes: | There is opportunity to improve continuity of comprehensive care across the continuum of medical care for HNC survivors. |

https://doi.org/10.1001/jamaoto.2015.2049
regaining normality in the first year following a diagnosis of head and neck cancer: A qualitative longitudinal study. *Palliative & Supportive Care, 10*(3), 197–204. https://doi.org/10.1017/S147895151200020X

<p>| Effeney, L. C., Nixon, J. L., &amp; Pigott, A. E. (2021). Occupational therapy for people with mask anxiety undergoing radiotherapy. <em>Australian Occupational Qualitative Scholarly,</em> peer-reviewed journal | To explore the role of occupational therapists in providing intervention with HNC patients experiencing mask anxiety. Semi-structured interviews with a cohort of 20 participants, all of whom were HNC patients experiencing radiotherapy mask anxiety. All participants had been referred to OT due to mask anxiety. There were 20 total participants; 15 male, 5 female. There were 13 themes, 49 codes identified through thematic analysis. In the context of the Canadian Model of Occupational Performance and Engagement, themes were grouped into physical, cognitive, affective, and spiritual components. OT role is holistic and multi-faceted. Themes: Nutritional concerns, including dysphagia, loss of taste, throat pain due to radiation, xerostomia, fear of choking, poor dentition. Managing these issues was “ad hoc” and without concrete instruction from health care professionals. Most symptoms were self-managed. Tiredness, including weak muscles and feeling lethargic and generally poor endurance. Tiredness “crept up” on many patients, and was continuous for some, intermittent for others. Radiotherapy mask Even at 12 months posttreatment and often unsolicited (not a formal interview question), participants expressed distress relating to the radiotherapy mask. Maintaining normality “What now?” was a common thought/question expressed by participants. “Returning to work was equated with returning to normal, which provided an opportunity to regain some control over their lives” (p. 202). At T4, anxiety about the future and continued fatigue persisted. Social activity was still reportedly less than baseline. At T4, there was lacking continuity of medical care. There is opportunity for concrete, proactive information, strategies, and therapies to aid known side effect management, especially relating to nutritional needs and tiredness. RTW should be an especial focus of comprehensive programs due to its connection with a sense of control and normality. Traumatic aspects of treatment should be addressed preemptively (i.e. radiotherapy mask). Many of these issues experienced by HNC survivors are chronic in nature, and have implications for the lives of the people around them. Fatigue is an ongoing, long term symptom that “is not relieved by sleep,” “is frustrating,” “interferes with [RTW],” and “restricted daily activities” (p. 202). |</p>
<table>
<thead>
<tr>
<th>Authors</th>
<th>Methodology</th>
<th>Design</th>
<th>Data Collection</th>
<th>Data Analysis</th>
<th>Key Concepts</th>
<th>Targeted Interventions</th>
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<tbody>
<tr>
<td>Nixon, J. L., Cartmill, B., Turner, J., Pigott, A. E., Brown, E., Wall, L. R., Ward, E. C., &amp; Porceddu, S. V. (2018). Exploring the prevalence and experience of mask anxiety for the person with head and neck cancer undergoing radiotherapy. <em>Journal of Medical Radiation Sciences, 65</em>(4), 282–290. <a href="https://doi.org/10.1002/jmrs.308">https://doi.org/10.1002/jmrs.308</a></td>
<td>Mixed method, convergent design</td>
<td>Open access article; scholarly, peer-reviewed journal</td>
<td>To determine the prevalence and explore lived experience of people with HNC experiencing mask anxiety during radiotherapy.</td>
<td>Two phases of data extraction. Phase one: 100 patients undergoing radiotherapy were surveyed regarding self-perceived mask anxiety. Phase two: 20 patients who were identified as having mask anxiety participated in individual interpretative descriptive interviews.</td>
<td>Phase one: 26% of patients were identified as having mask anxiety. <strong>Themes (Phase two):</strong> Contributors to mask anxiety Vulnerability, response to experience, and expectations Mask anxiety management Strategies and mindset</td>
<td>Key concepts related to mask anxiety were identified by this study. Areas for targeted HNC pretreatment intervention include mask anxiety. Specifically, expectations need to be set appropriately with HNC patients, reassurance provided, and internal/external strategies provided.</td>
</tr>
<tr>
<td>Semple, C. J., Dunwoody, L., George Kernohan, W., McCaughan, E., &amp; Sullivan, K. (2008). Changes and challenges to patients’ lifestyle.</td>
<td>Qualitative</td>
<td>Scholarly, peer-reviewed journal</td>
<td>To explore lifestyle changes in HNC survivors following treatment.</td>
<td>Purposive sample. Semi-structured interviews of 10 participants who completed treatment for HNC 6-12 months earlier. Thematic analysis.</td>
<td>Experiences of HNC survivors are many and affect multiple aspects of the survivor’s life. Themes were categorized as affecting lifestyle (5) or affecting treatment and outcomes (2). <strong>Themes:</strong> Physical changes</td>
<td>Programs for HNC survivors should be holistic in nature, due to the varied, many, and effects of HNC treatment. Patients with HNC have increased confidence in their care when provided by specialist, interdisciplinary...</td>
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Appearance, speech, shoulder dysfunction, dysphagia. Concerns about cancer Recurrence and coping. Work and day-to-day tasks Including changes to routines by choice or were made out of necessity. Interpersonal relationships For some, no change or bringing closer together. Social functioning Some had greater success with graded return to social events; limitations due to physical function. Personal attributes (that helped or hindered coping and recovery) Positive restructuring and reappraisal of life, humor, religious beliefs all helped. Negative framing produced greater anxiety. Specific information needs in the pretreatment phase Advice on welfare benefits and financial resources; timely advice; and well-rounded information from a specialist HNC team.


To evaluate the current available evidence supporting OT practice with cancer survivors (all diagnoses). This article, Part 1 of 2, presents the evidence related to physical impairments and symptom management. To prepare Research question and search terms were developed and evaluated by a methodology consultant, American Occupational Therapy Association staff, and an advisory group. Search terms were related to adult cancer survivors, “types of intervention, outcomes, sequelae, and types of study design to be included in the systematic review” (p. 7102100030p2).

Included a total of 138 studies (86 relevant for Part 1): Exercise (n=25), Complementary (n=26), Rehabilitation (n=18), Lymphedema (n=12), Physical symptoms (n=19), Physical agent modalities (n=4), Work (n=3), Sexuality (n=2), and Psychosocial (n=29). Strong evidence that exercise is safe and beneficial for the majority of cancer types, regardless of age or stage of cancer. Moderate evidence that exercise improves health-related QOL. Lymphedema volume can be controlled. Many of these studies are within the scope of practice for OT. There is a distinct lack of outcome data related to function and participation. Wellness and health promotion approaches are recommended. Prevention of secondary chronic conditions is imperative. Cancer survivorship is viewed as a chronic condition.


To evaluate the current available evidence supporting OT practice with cancer survivors (all diagnoses). This article, Part 2 of 2, presents the evidence related to multidisciplinary rehabilitation, and psychosocial, sexuality, and RTW interventions. To prepare practice guidelines. Research question and search terms were developed and evaluated by a methodology consultant, American Occupational Therapy Association staff, and an advisory group. Search terms were related to adult cancer survivors, “types of intervention, outcomes, sequelae, and types of study design to be included in the systematic review” (p. 7102100040p2).

Few studies identified or measured occupation-based outcomes, however most argued that improvement in physical impairments (e.g.) would equate to resumption of previous work, participation, and/or ADLs. Strong evidence supports multidisciplinary teams are ideal for cancer survivors, regardless of age, cancer type, or cancer stage. Moderate evidence supports both prehabilitation and rehabilitation. Strong evidence supports cognitive behavioral interventions for reducing anxiety and depression. Moderate evidence supports short term life review and stress management groups in improving QOL and decreasing symptoms. Moderate evidence supports exercise to improve sexual dysfunction in prostate cancer survivors. Limited evidence supports couple-based and psychoeducational methods.

Comprehensive programs should include robust, well-trained interdisciplinary team members to meet the varied needs of cancer survivors. There are opportunities for cancer survivors in the neoadjuvant and adjuvant setting. Comprehensive cancer programs can address psychological distress and sexual dysfunction. RTW is a special area of concern which is affected by many of these areas, particularly psychosocial issues.
<table>
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<tr>
<th>Study</th>
<th>Design</th>
<th>Scope</th>
<th>Methods</th>
<th>Participants</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Jeans, C., Ward, E. C., Cartmill, B., Vertigan, A. E., Pigott, A. E., Nixon, J. L., &amp; Wratten, C. (2019). [Abstract] Patient perceptions of living with head and neck lymphoedema and the impacts to swallowing, voice and speech function. <em>European Journal of Cancer Care, 28</em>(1). <a href="https://doi.org/10.1111/ecc.12894">https://doi.org/10.1111/ecc.12894</a></td>
<td>Qualitative, interpretive description</td>
<td>Scholarly, peer-reviewed journal</td>
<td>To explore the experience of living with HNL and how it impacts swallowing, speech, and voice. Individual, semi-structured interviews. Thematic analysis with an inductive approach.</td>
<td>12 participants &gt;3 months after HNC treatment. Most participants felt HNL had a negative effect on swallowing, some on speech, and the effect on voice is unclear. <strong>Themes:</strong> &quot;It feels tight,&quot; indicating an effect on speech and swallowing. &quot;It changes throughout the day,&quot; indicating fluctuations in symptoms. &quot;It requires daily self-management,&quot; indicating a change in routine and the burden of ongoing care. &quot;It affects me in other ways,&quot; indicating a lack of knowledge about self-management and psychosocial well-being.</td>
<td>Additional education is needed for HNC patients at risk of HNL. Patients with HNL need earlier intervention and more education about HNL and self-management.</td>
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<tr>
<td>Komar, A., Dunphy, C., McEwen, S., Rios, J., Polatajko, H., &amp; Ringash, J. (2018). The Brief Rehabilitation Assessment for Survivors of Head Cancer (BRASH). <em>Research in Rehabilitation Medicine, 16</em>(1). <a href="https://doi.org/10.1002/jrsm.1164">https://doi.org/10.1002/jrsm.1164</a></td>
<td>Quantitative, correlational; validity testing</td>
<td>Scholarly, peer-reviewed journal</td>
<td>To establish content and discriminant validity for the BRASH; this was newly created specifically to address the needs of the healthcare professionals experienced with HNC (including occupational, physical, and speech therapists; dieticians; nurses; massage therapists; and physicians). Snowball sampling technique.</td>
<td>There were 20 healthcare professionals experienced with HNC (including occupational, physical, and speech therapists; dieticians; nurses; massage therapists; and physicians). Overall CVI score for the BRASH is 0.81, indicating adequate validity. Items in the cognitive / psychosocial domain received the lowest (0.7) scores. Correlation with standardized measure = 71%.</td>
<td>This is an acceptable tool for use by healthcare professionals to identify HNC patients who would benefit from rehabilitation services after treatment. The questionnaire items are relevant education opportunities prior to environmental modifications. Despite being the main objective, this review did not identify sufficient evidence that indicates the most ideal timing of intervention initiation but does highlight the need for person-centered care.</td>
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</table>
and Neck Cancer (BRASH): Content and discriminant validity. *Rehabilitation Oncology, 36*(4), 223–231. [https://doi.org/10.1097/01.REO.0000000000000107](https://doi.org/10.1097/01.REO.0000000000000107)

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<td>Descriptive, correlational</td>
<td>Scholarly, peer-reviewed</td>
<td>“To examine the associations among severity of internal and external lymphedema, symptoms, functional status, and QOL in patients with HNC” (p. 1026).</td>
<td>Physical examination completed to assess: external lymphedema, cervical ROM, jaw ROM, and hearing. Endoscopic assessment for internal lymphedema also occurred. Participants completed self-report measures related to QOL and symptoms related to lymphedema.</td>
<td>External lymphedema: 46.6% (n=48). Internal lymphedema: 68% (n=55). Both internal/external lymphedema: 38% (n=31). Increased intensity or number of cancer treatments was associated with increased lymphedema symptom burden. Most participants had mild body image concerns. Greater psychosocial distress was observed in younger participants, those in rural areas, and those who were single or widowed. A statistically significant correlation was identified between neck rotation and lymphedema severity. Increasing lymphedema severity was associated with indicators of impairment. Increasing age was associated with greater QOL.</td>
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</table>
| Deng, J., & Murphy, B. A. (2016). Lymphedema self-care in patients with head and neck cancer: A qualitative study. | Qualitative | To explore and describe HNC patients’ experiences with HNL related to self-management: perceived HNL education | Purposive sampling technique. Semi-structured, face to face interviews with 20 participants who had completed lymphedema therapy for HNL. Interviews were recorded and transcribed. | Mean age of participants was 58.7 (42-75) yrs; 13 were male, 7 were female. Themes: Self-care education All participants received self-care education, most received detailed, informative instruction with handouts and effective hands on learning in self-manual lymph drainage (SMLD), compression. | Considering the high rates of HNL, patients HNL need timely, appropriate education related to ongoing care. Considering the negative effects of HNL on daily living, patients with HNL need instruction that incorporates families and caregivers, promotes self-

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<th>Extracted Text</th>
<th>Analysis and Interpretation</th>
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<td>received, self-care routines, and suggestions related to self-care of HNL.</td>
<td>Themes were coded and analyzed. Uninvolved staff member checked accuracy of the transcription. Saturation determined end of participant enrollment.</td>
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<tr>
<td>garment use, and skin care. Some patients identified problems with garment fittings or discharging without really understanding what they needed to continue doing. There was not enough caregiver education offered.</td>
<td>A majority (n=17) of the patients reported continuing self-care on some level; 3 discontinued. 5 used a pillow/wedge to decrease swelling at night. Other exercises added independently (60%). Adherence rates: SMLD (85%), neck exercises (80%), compression garments (40%), and skin care (35%). Facilitators included family assistance, self-motivation, fear of altered appearance, and self-care as part of routine life. Barriers included time-intensive nature of self-management, difficulty following instructions or integrating into daily routine, discomfort, skin reactions, and/or financial burden of self-management.</td>
</tr>
<tr>
<td>Suggestions</td>
<td>Continued follow up after the end of lymphedema therapy, additional hands on practice, accommodation for various learning styles and including anatomical learning aides, and education prior to cancer treatment.</td>
</tr>
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</table>

Verma, N., Tan, X., Knowles, M., Bernard, S., & Chera, B. (2019). Patient-reported outcomes for dental health, shoulder-neck dysfunction, and overall quality of life after treatment with Exploratory, cross-sectional study Scholarly, peer-reviewed Journal To characterize survivorship issues related to HNC survivors, specifically regarding dental health and shoulder/neck dysfunction. Patients >1 year after treatment recruited through a radiation oncology clinic. Participants completed 3 questionnaires related to QOL, dental health, and neck/shoulder issues. Median follow up was 2.5 (1-6.58) yrs. Median age was 62, 78% were male, 22% were female. Majority were Caucasian (78%) and married (67%). Regarding health insurance, 53% were covered by Medicare, 26% had private insurance, and 10% were uninsured. Majority received chemotherapy (72%), and all received radiation (100%). In QOL measures, there were statistically significant results (lower compared to reference values) in emotional functioning efficacy and motivation, and promotes realistic incorporation into the patient’s routine. Advocacy and resources may also be needed related to funding and insurance coverage. Providing education about lymphedema prior to HNC treatment may help the patient identify appropriate supports and set the stage for anticipated changes to daily routines. This study demonstrates that radiation has a notable effect on survivorship related to dental health and shoulder/neck function. This study also demonstrated that patients are frequently not adequately counseled related to these issues prior to treatment. Understanding the extent and type of treatment modalities has implications for

There were lower scores overall in pain, swallowing, speech, sexuality, feeling ill, use of painkillers, use of feeding tube, and weight loss; higher scores in dry mouth. Dental counseling was reported by 79% of participants, 74% had a dental evaluation prior to radiation. After radiation, 79% saw a dentist, 19% had teeth extracted, and 35% had more dental problems compared to baseline. Counseling regarding shoulder/neck dysfunction occurred for 31% of participants, and 38% reported having shoulder/neck pain at night after treatment. Patients older than 65 yrs had higher functional scores in role fulfillment and emotional functioning, lower symptom scores in pain, insomnia, and financial problems compared to participants younger than 65 yrs. A lower dose of radiation was associated with better functional scores. Patients who received chemotherapy were more likely to receive counseling related to dental care.

| Schorn, L., Lommen, J., Sroll, C., Krüskemper, G., Handschel, J., Nitschke, J., Prokein, B., Gellrich, N.-C., & Holtmann, H. (2020). Evaluation of patient specific care needs during treatment for head and neck cancer. *Oral Retrospect*ive, descriptive study using qualitative analysis. To identify specific care needs while HNC patients are undergoing treatment. To identify and examine the implications of unmet needs. Data were retrieved from the exploratory international multicenter rehabilitation study of the German-Austrian-Swiss Cooperative Group on Tumors of the Maxillofacial Region. The Bochum questionnaire on rehabilitation and a questionnaire on tumor and treatment related issues were the primary measures. Mean age was 45 yrs, there were 1031 males and 328 females; total was 1359. Treatment: Surgery (n=754), surgery + radiation (n=410), surgery + chemo (n=67), surgery + chemo + radiation (n=114). Staging: pT1 (n=431), pT2 (n=550), pT3 (n=162), and pT4 (n=216). Statistically significant findings: Patients in a relationship rated HRQOL much higher, fears of recurrence much lower, and emotional support much higher compared to those not in a relationship. Patients in a relationship had lower rates of pain, swallowing, speech, sexuality, feeling ill, use of painkillers, use of feeding tube, and weight loss; higher scores in dry mouth. | This study identified important issues related to HNC survivorship, highlighting areas of need. HNC patients need support from people around them, including spouses, family members, and friends. QOL and depression and anxiety are notably poorer for those lacking social support. Opportunities exist for healthcare professionals to address these needs and facilitate social connections. Financial burden is also a significant concern. |
Depression and anxiety rates were significantly higher if no relative was part of their care (including children) or if they lacked reliable friendships. Coping with depression was associated with plentiful supportive relationships; and poorly managed depression and anxiety were associated with the need for more people to spend time with. The need for speech therapy was identified in 39.3% of cases; treatment was offered for <10% of those cases and occurred for 6% of those cases. Upon patient request, physical therapy was received in up to 24% of cases. Financially, 45% reported decreased income, 68% had to apply for social grants. Regarding work, 64% were no longer able to work, and 21% were not able to return to the same kind of work as before. Related to housing, for 92%, living situation was unchanged. Before treatment, 20% lived alone; after, 23% lived alone. Those living in institutional facilities increased from 12 to 21, those who were homeless decreased from 6 to 2.

The gap identified between rehabilitation needs and referral rates is alarming. All HNC patients should 1) receive instruction on available supports and therapies, 2) receive education about “normal” recovery and when they should seek help, and 3) be screened for problems and receive timely referrals to the appropriate specialist. Work is a noted area of need based on the data from this study.

Rogers, S. N., Clifford, N., & Lowe, D. (2011). Patient and carer unmet needs: A survey of the British Association of Head and Neck Oncology Nurses. Cross-sectional, peer-reviewed journal. To identify unmet needs for patients and their caregivers in regular follow up meetings. To identify services available to meet these needs. National survey sent to all members of the British Association of Head and Neck Oncology Nurses. Survey was piloted prior to this effort. Items included questions pertaining to frequency of patient/carer unmet needs, follow up related to unmet needs. Questionnaire results:
- 36% believed their outpatient clinics attempted to identify unmet needs.
- 78% believed they personally

Response rate was 61% (129/210), but some were retired or not providing outpatient care. Those that met the criteria (n=98) were included in analysis. This study highlights the interdisciplinary nature of HNC survivorship care, as well as the necessity of nurse navigation and follow up.

HNC patients have a range of needs and would often benefit from information from OT, SLP, social work, physical therapy, chaplaincy, and others.

86% believed identifying unmet needs would improve patient outcomes. 34% reported they had had sufficient training to identify unmet needs. 73% felt it was relatively easy for patients to be referred for services (i.e. the act or process of referring). Support services readily available at time of consultation: SLP (86%), dietician/nutritionist (84%), dentist (44%), oral rehabilitation consultant (27%), dental hygienist (26%), chaplain (20%), physiotherapist (15%), psychologist (15%), OT (13%), social worker (8%), and other (11%). Support services available by bleep communication: Physiotherapist (54%), chaplain (51%), SLP (45%), OT (45%), dietician/nutritionist (42%), social worker (38%), dentist (30%), oncologist (29%), psychologist (29%), emotional support therapist (28%), oral rehabilitation consultant (27%), and dental hygienist (23%).

According to HNC nurse navigators, there is a gap between the need and those who actually receive care to meet those needs. Accessibility could be improved, but largely the respondents felt the referral process was feasible and simple. Most of the nurses felt they worked hard to identify needs, but needs were often missed by the larger team. All team members, particularly those providing oversight for the patient’s care (often medical or radiation oncology, or an ear, nose, and throat specialist), should regularly screen for support services needs.

| Literature review | Scholarly, peer-reviewed journal. Open access article. | To review and summarize the current literature regarding informational and support needs for HNC survivors. To identify emerging issues and research priorities. | No systematic methods described. Data sources include clinical studies, systematic reviews, and meta-analyses. | HNC patients experience a number of treatment side effects: body image issues and facial disfigurement, swelling, drooling, speech, swallowing, and loss of teeth. In one study, patients expressed a desire to have had a clearer understanding of the extent of the scarring and disfigurement to be expected after reconstructive surgery (25%), after radiation (32%), and after chemotherapy (44%). Patients desire to have more education preoperatively and preparation for postoperative changes, especially with speech and eating. One study reported 61% of patients and 81% of spouses | With the nature of this article in view (literature review), the authors summarize important current issues and implications for research. Overall, they lack information about treatment-related side effects, attaining/ maintaining a healthy lifestyle, and HPV-related diagnoses. Comprehensive programs to address the severe and varied needs are indicated. HNC patients would benefit from more information prior to treatment about the expected |

believed the information received prior to treatment was insufficient. Needs differ between patients undergoing laryngectomies and those who do not; many patients undergoing laryngectomy do not understand they will lose the ability to speak. Other studies identified further informational needs related to sleep disturbance (associated with younger patients and higher symptom burden) and fatigue. Greater facial disfigurement was associated with decreased sexuality and increased social isolation. Financial burdens and psychosocial issues are additional areas of lacking information. Limitations of existing literature: most studies have smaller sample sizes, utilize convenience samples of predominantly non-Hispanic white participants. Evidence based tobacco cessation programs exist but are vastly underutilized, and the majority of HNC patients who smoked previously continue to do so after treatment. Patients with HPV-mediated cancers seek additional information related to HPV, and often utilize the internet to learn more. A small study (n=62, all HPV-related) demonstrated that only 35% understood their cancer was caused by HPV; the other 65% was either unsure or stated it was not related to HPV. Healthcare workers can support HNC patients by facilitating a therapeutic alliance, acknowledging their experiences, and creating a space in which the patient can truly share their perspectives.

| Lang, H., France, E., Williams, B., Humphris, G., & Wells, M. (2013). *The psychological experience of living with head and neck cancer*. Scholarly, peer-reviewed journal. To summarize the lived experience of HNC survivors, using qualitative research. Utilized 3 search strategies across 7 databases to retrieve primary qualitative research articles. Themes and concepts were identified from each paper. Next, meanings and There were 29 articles published between 1993 and 2011 that met inclusion criteria. Sample sizes ranged from 1 to 60 (mean 12, mode 9), with a total of 345 patients. There were 81 concepts identified across all of the papers, grouped into 11 preliminary concepts, and upon final healthcare workers can support HNC patients by facilitating a therapeutic alliance, acknowledging their experiences, and creating a space in which the patient can truly share their perspectives. |
interpretations were compared across papers. Synthesis of common concepts then took place, followed later by an update. Synthesis, 6 themes:

1) **Uncertainty and waiting.**
   “Rollercoaster”
   “Waiting for treatment...waiting to be cured...”

2) **Disruption to daily life.**
   Concerns related to losing one’s job, changes to eating routines, and difficulties with roles and social participation. Feeling isolated, changes in roles, decreased sexuality.

3) **The diminished self.**
   “I am not now the person my friends befriended, my wife married. I’m not me anymore” (p. 2656).
   Communication deficits and visible disfigurement are off-putting to others – affecting relationships and job opportunities.

4) **Making sense of the experience.**
   Patients make sense of their experience through an inner dialogue. They reassess their priorities and attempt to anticipate the future.

5) **Sharing the burden.**
   Supportive relationships with family, friends, healthcare workers, and other people with HNC helped the participants feel more supported and have a better QOL.
   Of healthcare workers in particular, “You need someone who sees you through...do you manage? What do you wonder about? You feel so incredibly deserted and vulnerable” (p. 2657).
   Patients need to feel acknowledged by their healthcare team; suffering needs to be recognized. Patients often downplay how severe their symptoms may be, or be selective about what they disclose at a given time.

6) **Finding a path.**
   and problems, and to ask questions.
   HNC patients feel particular vulnerable.
   Response to changes in routine vary widely; the team should be ready to support coping needs.
   Healthcare workers should also take ownership of starting the conversation about disfigurement; patients often feel guilty or ungrateful to complain about their appearance after they’ve received curative treatment and therefore often diminish the effect of disfigurement on their lives.
   “…supporting HNC patients requires a detailed understanding of the ways in which an individual’s sense of self and daily life are disrupted, and a recognition that uncertainty is likely to pervade both the individual’s present and future” (p. 2661).
Some participants struggle more than others; some cope well and others remain angry and uncertain about “where to go from here.” Some relationships change for the better (i.e. feeling closer to a spouse), while others experience alienation. Some limit their focus to the present, especially if their cancer is terminal. Viewing this disruption to life as a change or enhancement is associated with better coping and QOL, while viewing it as diminished results in greater anxiety and poorer coping. Cancer severity and stage of survivorship “does not predict how a person views the future after HNC” (p. 2660). The exact mechanism, be it internal or external, that facilitates successful coping is unclear.

<table>
<thead>
<tr>
<th>Authors</th>
<th>Study Type</th>
<th>Source</th>
<th>Method</th>
<th>Results</th>
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<tr>
<td>D’souza, M., Samuel, S. R., &amp; Saxena, P. P. (2020). Effects of exercise training during concomitant chemoradiation therapy in head-and-neck cancer patients: A systematic review. Indian Journal of Palliative Care, 26(4), 531–534. <a href="https://doi.org/10.4103/IJPC.IJPC_14_20">https://doi.org/10.4103/IJPC.IJPC_14_20</a></td>
<td>Systematic review</td>
<td>Scholarly, peer-reviewed journal</td>
<td>PRISMA checklist utilized. Systematic search of 4 databases. The first 2 authors maintained a data extraction spreadsheet and recorded the reference, chief intervention(s), and results, and then assigned a PEDro score. There were 4 studies that met the criteria for the study (including two in which the second author of the present article was the first author of the study). All were RCTs or pilot controlled trials. Three types of exercises: strength training, aerobic training, and a home-based walking program. All were carried out while the participants were undergoing concurrent chemotherapy and radiation. Sample sizes were 48, 11, 148, and 72 participants. Outcomes all included a component of physical functioning along with QOL.</td>
<td>All 4 studies were in agreement that exercise is safe and feasible during chemo-radiation and have a positive effect on physical capacity (in some manner or another) and QOL. The results of this review have implications for the timing and program design of HNC prehabilitation programs. With only 4 studies, results should be interpreted with some caution.</td>
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<tr>
<td>Treanor, C., Kyaw, T., &amp; Donnelly, M. (2018). An international systematic review, meta-analysis</td>
<td>Scholarly, peer-reviewed journal</td>
<td>To identify current evidence-based exercise interventions in the HNC population during chemoradiation that successfully improve outcomes.</td>
<td>Inclusion criteria: RCT; Systematic search of 5 databases, using the PRISMA checklist. There were 18 studies that met all criteria. Studies were conducted in the USA (n=8), Italy (n=3), the UK (n=1), the Netherlands (n=1), turkey (n=1), Australia (n=1), and Other (n=6). Prehabilitation overall appears...</td>
<td>There are both generalizable and diagnosis-specific findings presented in this article.</td>
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effectiveness of prehabilitation interventions compared to usual care in cancer patients. published up to April, 2017; baseline measurements obtained; initiation of intervention prior to acute treatment with curative intent; adult population; and with a purpose to improve physical or psychological health, or resource utilization. Each study was assessed for risk of bias. Switzerland (n=1), China (n=1), and Denmark (n=1). Studies involving each type of cancer: lung cancer (n=7), prostate cancer (n=5), breast cancer (n=4), bladder cancer (n=1), and multiple cancer sites (n=1). Total of 1381 patients. Interventions initiated 1-2 weeks (n=9), 1-5 days (n=2), 1 month (n=2), 3 weeks (n=1), and the day preceding treatment (n=1); 3 studies did not specify when the intervention began. There were 5 studies that provided treatment only in the pretreatment phase, while the rest of the studies continued intervention after treatment. Number of contacts with the patients varied widely and were both in person and by phone call. Regarding risk of bias, 14 rated high risk, 2 moderate risk, and 2 low risk.

Results by cancer type:
Prostate cancer
At 6-months post intervention, the intervention group had significantly lower reports of severe/continual leakage, had significantly more days without any leaks, and overall better bladder function compared to control. Psychological foci resulted in better physical well-being compared to control at 6 weeks, 6 months, and 12 months. Immunological markers were better in the prehabilitation group of one study.
Lung cancer
Meta-analysis completed and revealed significant benefit for pre-surgical pulmonary exercise: reduction of hospital stays, reduction of hours in recovery from anesthesia, shorter chest intubation time, and pre-op exercise improved recovery time. There were no significant to be of benefit.

Challenges to implementing prehabilitation include the short time (often) between diagnosis and medical treatment initiation and patient anxiety. Overall, though, prehabilitation is acceptable to patients and feasible to implement despite challenges. As long as prehabilitation was unlikely to interfere their treatment, adherence was good across studies. The authors argue that in the age of evidence-based medicine, prehabilitation must become usual care and incorporated into international guidelines. Further research is needed to study cost-effectiveness, complications, and improvements in QOL. Prehabilitation tends to reduce the frequency and severity of treatment-related side-effects. There were no eligible studies relating specifically to HNC, indicating the logical potential for and need for research regarding prehabilitation in HNC.
differences between the groups related to baseline function. In one study, participants in the control group displayed worse physical function compared to the intervention group.

**Breast cancer**

Intervention and attentional groups demonstrated better body image and lower rates and severity of anxiety and depression than control groups.

**Bladder cancer**

One study (bladder studies n=1) found no effect on length of stay, complications, readmission rates, bowel function, energy intake, or protein intake.

**Multiple cancer sites**

In a study of a program designed to prevent and improve cancer-related fatigue, “there were no differences in fatigue, QOL, depression, anxiety, physical activity levels, or occupational activities” between intervention and control groups. However, adherence rate was poor.

*Note.* All articles are available in full text format unless noted otherwise.

- **6MWT** = 6-Minute Walk Test
- **ADL/ADLs** = Activity/activities of daily living
- **BMI** = Body mass index
- **CRCD** = Cancer-related cognitive dysfunction
- **HNC** = Head and neck cancer
- **OT** = Occupational therapy
- **PRE** = Progressive resistive exercise
PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PTSD = Post-traumatic stress disorder

QOL = Quality of life

RCT = Randomized control trial

RTW = Return to work

ROM = Range of motion

TMJ = Temporomandibular joint

TNM staging = American Joint Committee on Cancer (AJCC) guidelines for clinical staging where T = size of the tumor, N = grade of the extent of regional lymph node involvement, and M = presence and extent of distant metastasis. Additional indicators include “p,” indicating pre-treatment; “x,” indicating unstageable, unmeasurable, or unknown. Higher numbers indicate greater cancer involvement or worse disease. The algorithms for assigning the TNM stage account for the location of the tumor, the biology of the tumor, and common responsiveness to treatment. For example, pT1N0M0 indicates that prior to any treatment and with what is known based on pathology, imaging, and clinical examination, the tumor is rather small, has not advanced regionally, and there are no distant metastasis; 5-year survival rates are likely higher.
Submitted Title Page and Manuscript: A Comprehensive Prehabilitative Model of Care for Head and Neck Cancer Survivors: A Scoping Review

A Comprehensive Prehabilitative Model of Care for Head and Neck Cancer Survivors: A Scoping Review

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A Comprehensive Prehabilitative Model of Care for Head and Neck Cancer Survivors: A Scoping Review

Abstract

Objectives: Primary: To investigate if prehabilitation in head and neck cancer (HNC) populations reduces the severity and incidence of cancer treatment sequelae. Secondary: To investigate evidence-based prehabilitative methods resulting in best occupational outcomes in terms of participation, quality of life, and role satisfaction.

Data Sources: Methods included manual searches through catalogued topics (Cancer) and basic searches for level I articles (Cochrane Library and PEDro), advanced database searches for level II and qualitative articles (PEDro, PubMed, CINAHL, and APA PsychInfo). Citation chaining was completed using GoogleScholar.

Study Selection: Studies addressing at least one component of the PICO questions (HNC survivors; prehabilitation, occupational therapy; usual care; and occupational performance) were selected for detailed review. Articles were prioritized if intervention was initiated prior to, during, or within the first year of cancer treatment.

Data Extraction: During detailed review, the citation, article/publication type, purpose, methods, results, conclusions, and recommendations of each article were logged in a literature matrix. Key concepts and direct quotes were grouped together. Themes were developed and reviewed by project mentors and co-authors.

Data Synthesis: Fifty-three articles were included in the final review. There are a number of unmet physical, emotional, informational, and financial needs among HNC survivors. Patients who are single, widowed, live in rural areas, and/or younger tend to report greater negative
effects on daily life. Programs focusing on education, self-management, and prospective screening for ongoing rehabilitation needs are most effective in terms of quality of life, lymphedema, dysphagia, fatigue, and shoulder dysfunction. Research pertaining to multi-factorial intervention, such as returning to work, is limited.

Conclusions: Prehabilitation overall lessens the severity and incidence of cancer treatment sequelae in HNC patients. Themes developed center on patient experience; education needs; and what, when, and how intervention should be provided. Further research investigating participation-based outcomes and the role of OT is recommended.

Keywords: Head and neck neoplasms, Preoperative exercise, Prehabilitation, Occupational therapy

Abbreviations List:

ADL = Activity(ies) of daily living
HNC = Head and neck cancer
OT = Occupational therapy
QOL = Quality of life
More than 54,000 people in the US were diagnosed with head and neck cancer (HNC) in 2021. Treatment for HNC is typically invasive and extensive, involving surgery, radiation therapy, chemotherapy, dental procedures, and other related intervention (i.e. nutrition supplementation). These treatments often result in long term effects on physical functioning, social participation, mental health, communication, performance of activities of daily living (ADLs), and overall quality of life (QOL). Survivorship is identified as a chronic condition, and related secondary disease prevention is a prioritized national health initiative.

Prehabilitation is an increasingly promising model of care in oncology rehabilitation, but to date, there are no comprehensive guidelines pertaining to comprehensive prehabilitation in HNC populations. Furthermore, in review of the complex needs of HNC survivors, occupational therapy (OT) is a logical match to address some of these long term changes. However, there has been no critical appraisal of the evidence surrounding OT interventions and models of care (including prehabilitation) for patients with HNC.

Given the complexity and chronicity of HNC sequelae, the aim of this review was to determine if a) prehabilitative models of care are more effective at improving outcomes (such as QOL, ADL performance, or pain), and b) if OT intervention was effective at improving outcomes. Therefore, the PICO questions were stated as:

**PICO₁**: Do clients with HNC who participate in an occupational therapy prehabilitation program experience better occupational outcomes than clients who do not?

**PICO₂**: Do clients with HNC who receive occupational therapy services at any point in the cancer care continuum experience better occupational outcomes than clients who do not?

**Methods**
A scoping review was selected to form a better understanding of the scope and key concepts\textsuperscript{11–13} pertaining to prehabilitation in HNC populations.

**Study Selection**

Articles were considered for review if they were available in English and full-text, limited participants to adults over the age of 18 years, and addressed at least one component of the PICO question. Articles were excluded if participants in the study were not over 18 years of age, text was not available in full text or in English, or did not address at least one component of the PICO question.

Articles were eventually limited to narrow the final results: for population, articles needed to include HNC survivors, or multiple solid tumor cancer types that may or may not include HNC. There were some articles that were included specifically to offer insight into the HNC survivors’ experiences and needs in order to frame intervention and outcomes. To limit interventions, articles that focused on rehabilitative intervention only or initiated intervention greater than 1 year after diagnosis were excluded. Articles that involved medical prevention or management of cancer or cancer-related symptoms were excluded. Furthermore, articles pertaining to acupuncture, music therapy, dentistry, and alternative medicine were ultimately not included in this review for two reasons. First, one of the chief aims of this project was to identify evidence relevant to OT practice, and these topics are beyond the scope of the profession of OT. Secondly, while these professions and practices have their own roles in HNC survivorship, it was not practicable to incorporate all possible treatments or disciplines. Certain types of articles were excluded, such as case reports, opinion pieces, study protocols, and symptom measurement tool development.
Two overarching searches were completed: the first of level 1 research (including systematic reviews, scoping reviews, meta-analyses, and clinical practice guidelines based on research), and the second of level 2 research (including quantitative, qualitative, and mixed-methods design primary research studies).

**Data Sources**

Background information on current practice trends and initiatives was reviewed from a number of interprofessional sources, including the American Cancer Society, American Head and Neck Society, American Occupational Therapy Association, American Physical Therapy Association, American Speech-Language-Hearing Association, National Cancer Institute, and National Comprehensive Cancer Network (NCCN). The types of documents utilized in this step included practice guidelines, statistics, current medical treatment practices, patient education material, evidence maps, and other health professional information. This step aided in refinement of the research questions and literature review.

For all database searches, a preliminary review of MeSH terms using the U.S. National Library of Medicine MeSH Browser (https://meshb.nlm.nih.gov/search) was completed to identify the keywords and terms most representative of the PICO question. Articles were organized and catalogued using Zotero citation management tool (https://www.zotero.org).

The Cochrane Library and PEDro databases were selected for level 1 searches. In the Cochrane Library database, the date range was left unlimited due to the relatively small number of articles returned and it allowed for historical insight as well. Limiters applied included Title/Abstract and Systematic Reviews. The best keyword search was simply “Head and neck neoplasms.” A manual search was then conducted in the “Browse by Topic” section under the heading of “Cancer” and 2 (of 50) relating subtopics: “Palliative and Supportive Care,” and
“Head and Neck.” Additional main headings searched included “Complementary and Alternative Medicine” (subheadings of “Ear, Nose, and Throat” and “Cancer”), “Dentistry and Oral Health” (subheading “oral cancer”), and “Consumer and Communication Strategies.”

Within the PEDro database, only a basic search was indicated due to the relatively small number of results; the date range was unlimited and no other filter was applied. Using MeSH terms and related (preferred, broader, or narrower) concepts, the combinations yielding the greatest number and most relevant results were: occupational therapy AND systematic review AND cancer, systematic review AND head and neck cancer, systematic review AND prehabilitation, and systematic review AND oncology AND preoperative.

Primary research studies were next obtained from three formal database searches using PubMed, CINAHL, and APA PsychInfo, and one alternative search strategy using Google Scholar. PubMed was selected to encompass a wide variety of publications and to ensure the medical perspective was adequately represented. Using the advanced search option, publication dates were limited to 2000 or after; no other filters or limiters were applied. The combinations yielding the most relevant results were: head and neck neoplasms AND occupational therapy; head and neck neoplasms AND prehabilitation; head and neck cancer AND (fatigue OR cancer related fatigue); head and neck cancer AND (work OR return to work) AND rehab; head and neck cancer AND famil* AND rehab; head and neck cancer AND social participation AND rehab; head and neck cancer AND lymphedema; and head and neck cancer AND quality of life.

CINAHL was selected for its breadth of allied health disciplines represented. In the advanced search section, options “Suggest Subject Terms” and “Apply Equivalent Subjects” were selected. Limiter applied included full text, abstract available, English, human subjects, and publication date after 2000. The most relevant results were obtained from the following
combinations: head and neck cancer AND (occupational therapy OR occupational therapist OR occupational therapists OR OT); head and neck cancer AND (prehabilitation OR prehab OR pre-operative rehabilitation OR peri-operative rehabilitation); (occupational therapy OR occupational therapist OR occupational therapists OR OT) AND (prehabilitation OR prehab OR pre-operative rehabilitation OR peri-operative rehabilitation); head and neck cancer AND (social engagement OR social participation OR social inclusion OR social involvement); (oncology OR cancer) AND (prehabilitation OR prehab OR pre-operative rehabilitation OR peri-operative rehabilitation).

The third database selected for a formal search was APA PsychInfo to ensure the psychological, quality of life, and lived experience aspects of HNC survivors was adequately represented. Using the advanced search, the option to include spelling variants for terms was selected. Articles were limited to full-text, scholarly journals, and those published after the year 2000. The best keywords and term combinations were: head and neck cancer AND occupational therapy; head and neck cancer AND occupational therapy and activities of daily living; head and neck neoplasms AND prehabilitation; head and neck cancer AND fatigue; (social roles AND social participation) AND head and neck cancer; and head and neck cancer AND back to work.

Citation chaining was the final search strategy utilized, and was conducted in Google Scholar. Three base articles were selected\textsuperscript{9,25,26} to identify additional articles that pertain to the PICO question. With all strategies applied, searching ended when saturation was achieved.

**Data Charting**

Following title, abstract, and full reviews, articles meeting eligibility requirements were recorded in a literature matrix. For each article included in the present review, the following were recorded: full citation; type of article/study design; publication type; and a combination of
summaries and direct quotes of the purpose, methods, results, and conclusions and
recommendations.

Data Synthesis

During the review process and development of the literature matrix, data were organized
into developing themes and by component of the PICO addressed. Project mentors reviewed the
themes and descriptors identified by the first author. A comprehensive summary model was then
developed by the first author (see Figure 2).

Results

Of the total records returned (n=1,623), and after duplicates were removed, there were
254 articles were screened by title. Abstracts (n=193) were then screened, followed by full text
screening (n=99). A total of 53 articles were included in the final review. See Figure 1 for the
Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping
Reviews (PRISMA-ScR) flow chart.

There are two key definitions of prehabilitation; one emphasizes intervention beginning
prior to cancer treatment and one that emphasizes intervention beginning prior to impairment
incurred by cancer treatment. In the second definition, intervention may be provided after the
initiation of cancer care, but before impairment arises. The goal in both, however, is to prevent or
minimize the severity or onset of cancer sequelae through earliest intervention possible.

Theme 1: HNC Survivors’ Experience

The first theme identified is comprised of multiple sub-themes that outline the experience
of HNC survivors, their needs, and opportunities for improved care.

Physical Impact. The research identifies a number of cancer treatment side effects that
can negatively impact daily life. Many of the physical and psychosocial changes can linger well
beyond cancer treatment. Physically, HNC survivors experience pain \(^2^9\) swallowing and speech impairments \(^2^8,3^0-3^2\), muscle weakness and fatigue \(^3^3-3^9\), shoulder and neck dysfunction \(^4^0,4^1\), lymphedema \(^4^2\), xerostomia \(^2^8\), trismus \(^4^3\), infections \(^4^4\), dental problems \(^4^0,4^5\), pain \(^4^6\), and other limitations in accordance with the type of treatment they have undergone \(^4^7-5^0\).

**Psychosocial Experience.** There are considerable effects on psychosocial well-being resulting from HNC treatment. Across studies, participants identified substantial anxiety surrounding the use of the radiotherapy mask \(^3^9,5^1,5^2\). Indeed, even at 1 year posttreatment participants from one qualitative study \(^3^9\) spoke about the experience in terms of trauma and distress. Multiple studies have indicated a relationship between physical impairments and psychosocial well-being, both specifically in the HNC population \(^5^9,5^3-5^8\) and the general oncology population \(^2^6,5^9,6^0\). According to Costanzo and colleagues \(^5^9\), patients with cancer tend to attach greater meaning to daily stressors, especially those involving interpersonal conflict, although the type, amount, and frequency were similar with controls.

Not unlike other populations of cancer survivors, HNC survivors have difficulty “feeling themselves” during and after treatment, as though the diagnosis and sequelae of cancer treatment have had sufficiently drastic changes to their roles, relationships, and routines to redefine normality \(^3^2,5^4,5^5,6^1-6^4\). Another source of distress is related to finances. The cost burden associated with cancer \(^2^2\) in addition to changes in work status frequently contribute to financial distress for patients with HNC \(^5^4,6^1,6^5-6^7\). Body image distress is a common concern among HNC survivors as a result of reconstructive surgery \(^6^8\) and lymphedema \(^5^8\).

**Work.** Work in itself is an important topic in cancer survivorship, especially HNC. Work provides financial stability, but it is deeply meaningful in other ways, too. Work offers a sense of normalcy \(^3^9,6^6\), and Molassiotis and Rogers summarize in their qualitative study, “returning to
work was equated with returning to normal, which provided an opportunity to regain control over their lives. In a qualitative exploratory study with eight participants, Barnard et al. characterize the transformational process to coping in survivorship, and the authors name work as an especially valued component in that process. Returning to work signified an achievement of control and self-efficacy.

Whether or not an individual returns to work depends on a variety of factors. Those who are in skilled trades are statistically more likely to return to work than those working in other fields. Gallagher et al. report that greater shoulder impairment correlates with greater disruption in work and leisure performance at or after 1 year posttreatment. In a cross-sectional survey of 231 working age HNC survivors, researchers found that among the unemployed participants, significant factors associated with unemployment were increased depression and anxiety, decreased global health, and greater fatigue than the employed group. Likewise, a cross-sectional survey of 83 HNC survivors, 67.5% of the sample drove less often or stopped altogether during cancer treatment and 26.5% of the sample continued driving less often or was no longer driving after cancer treatment. Driving was significantly correlated with work status, social and leisure engagement, and household errands; those that returned to driving were more statistically more likely to return to work. Other factors limiting return to work include fatigue, psychological problems (poor concentration, depression, mental strain, burnout, sleep disturbance); dysphagia-related nutrition concerns; communication impairments; lack of physical strength; mouth problems (candidiasis, xerostomia, mouth pain); recurrence; facial paralysis; and breathing problems.

Information and Supportive Care. A common thread across studies is the unmet informational and supportive care needs. One study demonstrated that 68% (n=127) of HNC
survivors in their sample indicated at least one area of unmet needs. Commonly cited areas of unmet needs included swallowing and speech impairments, psychological distress, cancer-related cognitive dysfunction, nutritional needs, role satisfaction, return to work, communication, and quality of life (QOL). In an earlier cross-sectional survey (n=82), Llewellyn et al reported that at 1 month posttreatment, patients were largely satisfied with the information they were given prior to their treatment. However, by 6-8 months posttreatment the percentage of participants satisfied decreased from 52% to 33%. As patients incurred more issues or experienced living with posttreatment changes, they were less satisfied with the information with which they had been equipped. Furthermore, participants reported they desired more information ahead of time about financial assistance, support groups, and how treatment will affect the individual’s ability to work, change physical status, and affect daily routines. These findings are underscored by a level 1 study performed by Fang and Heckman, who reported that patients desire to have more education preoperatively regarding postoperative changes. The authors reviewed one study that reported 61% of patients and 81% of spouses believed the information they received prior to treatment was insufficient. For example, many patients undergoing laryngectomy do not understand they will lose the ability to speak, and another study involving HPV-mediated HNC demonstrated that only 35% of their sample understood their cancer was caused by HPV.

Other studies cite the disparity of sequelae prevalence and referral to the appropriate supportive care services. Molassiotis and Rogers concluded that many side effects are self-managed, and information from healthcare workers is often ad hoc, lacking concrete instructions for management during or after treatment. Verma et al have identified information needs pertaining to radiation-induced dental and shoulder and neck dysfunction given these issues are known complications of radiation and predictive of role fulfillment, emotional, and symptom
measures. In a retrospective, mixed methods study of 1359 patient records, researchers identified a clear need for speech therapy in 39.3% of cases, yet a referral was placed in less than 10% of cases\textsuperscript{61}. Patients were referred for physical therapy in up to 24% of cases, and in most of these cases, the patient specifically requested the referral. In a cross-sectional survey of 129 oncology nurse navigators working with HNC survivors, researchers identified a disparity between the percentage of navigators who believed they personally attempted to identify unmet needs (78%) and the percentage of navigators who believed they had sufficient training to do so (34%)\textsuperscript{73}.

Eighty-six percent believed identifying unmet needs would improve patient outcomes and 73% felt it was easy to facilitate a referral for a wide range of supportive services (speech therapy, dietician, dentist, dental specialists, chaplain, physiotherapist, occupational therapist, and social workers)\textsuperscript{73}.

**Special Considerations.** Several subpopulations within HNC survivors present with unique challenges. Patients who are younger\textsuperscript{40,58}, live in rural areas\textsuperscript{58}, are single or widowed\textsuperscript{58,61}, or lack reliable friendships\textsuperscript{61} are at increased risk of psychological distress, decreased role function, and poorer QOL. HNC patients who are younger also tend to have greater distress from physical disfigurement and experience disruption to sexual function\textsuperscript{64}. Patients with later stages of disease have been identified as having higher rates of depression and have different education needs\textsuperscript{72}. By the same token, more aggressive treatment tends to result in greater impairments. As such, patients undergoing a modified radical neck dissection have greater rates of shoulder impairment than those undergoing selective neck dissection\textsuperscript{57}, greater dosage of radiotherapy is associated with lower QOL scores\textsuperscript{74}, and total laryngectomy is associated with significantly lower QOL scores\textsuperscript{67}.

**Research**
Comparatively, the HNC population is underrepresented in rehabilitation research. In a scoping review of HNC rehabilitation research trends, Parke et al.\textsuperscript{75} reported the rate of HNC research has increased over recent decades (390\%) but not at the same rate as cancer rehabilitation (810\%), or oncology research in general (1056\%) over the same timeframe. A high number of studies have small sample sizes (n≤100) and focus primarily on unimodal intervention, despite the numerous impairments HNC patients often experience simultaneously.\textsuperscript{75} Additionally, of the 258 articles included in the review, the first authors of the articles represented medicine (79; 38\%), speech and language pathology (36; 17\%), PhD (25; 12\%), nursing (13; 6\%), physical therapy (10; 5\%), dentistry (9; 4\%), occupational therapy (1; 0.4\%), with the remaining either “other” (14; 7\%) or unlisted (19; 9\%). It is also worth noting by omission, HNC population is not always included in studies across cancer populations.\textsuperscript{76,77}

**Theme 2: Intervention – Who, What, When, and How**

The available evidence provides a large amount of information concerning intervention approaches in the broader body of oncology literature as well as HNC specifically.

**Prehabilitation and the Team.** Existing evidence supports early intervention for patients with various types of cancer,\textsuperscript{35,60,78–81} including HNC specifically.\textsuperscript{28,33,38,40,56,63,82} Across 22 primary studies, another review found that relating to physical function, nutrition, and patient-reported outcomes, prehabilitation is most effective when combined with early rehabilitative intervention.\textsuperscript{81} In another level 1 international review of 18 primary research studies across solid tumor cancer types, the authors concluded that prehabilitation overall appears to be beneficial, acceptable to patients, and feasible to accomplish, despite time constraints and other logistical challenges.\textsuperscript{76} Additionally, as long as prehabilitation was unlikely to interfere with medical treatment, adherence was good across studies, and it tends to reduce the frequency and severity...
of treatment-related side effects. "Whilst there is movement towards the implementation of evidence-based interventions in the period post-cancer treatment, there is a need to research and consider recommending the implementation of interventions in the prehabilitation period, as part of usual care." 

Both within HNC populations and cancer rehabilitation in general, specialized, interdisciplinary teams have been identified as the most ideal structure to address the varied and complex needs of HNC survivors. This approach improves patient confidence and facilitates screening and timely referrals to supportive services. The posttreatment phase is a vulnerable time for HNC patients: they present with persistent uncertainty about the future, and they start to experience more problems – but their encounters with their team are less frequent. Nurse navigators play a crucial role in identifying survivorship needs. Ongoing screening for rehabilitative needs is an essential component of meaningful survivorship. The Brief Rehabilitation Assessment for Survivors of Head and Neck Cancer (BRASH) was developed to assist navigators, physicians, and other oncology providers in determining more objectively who may benefit from additional supportive services.

The context in which intervention is provided can contribute substantially to the effectiveness of the intervention provided. Researchers name therapeutic alliance as the foundation for all education and intervention, especially in HNC populations. Patients need more information before treatment and better support after treatment; they need “permission” to share their problems they may perceive as insignificant (i.e. facial disfigurement) compared to successful curative treatment. Moreover, healthcare professionals should expect needs and take “ownership” of initiating empathetic conversations with patients about uncomfortable topics and
anticipate referring to the appropriate supportive services. Recommendations must always consider day-to-day stressors, and be tailored to the unique needs of the patient.

**Education.** A common finding across HNC studies is the need for pretreatment education. In HNC particularly, patients, caregivers, and health providers have identified education needs in the areas of posttreatment effects and physical changes, lymphedema, dental health, financial burdens and resources, sleep disturbance and fatigue, and human papilloma virus (for those whose cancers were associated with the virus), among others. Adequate information before treatment/procedures is essential for optimal mental health. Education is beneficial upon or near the time of diagnosis, even if time is limited. Moreover, side effects from definitive radiation typically do not affect QOL within the first 2 weeks of treatment, and researchers have determined it is feasible to provide education up to and including this time.

Tailored education that focuses on self-management has been associated with greater QOL. This is consistent with another study in which a correlation was identified between the level of patient satisfaction with preoperative education and higher scores on mental health measures. Relating to pain education and self-management in the HNC population, one study did not find a significant difference at baseline, 4 weeks, and 10 weeks posttreatment without other therapies.

Cancer patients enjoy multi-media education methods (i.e. tablet, video, computer) for preoperative education, but outcomes of anxiety, compliance, and knowledge acquisition were not significantly different in either group (multi-media methods versus traditional methods). It is noted, however, that regardless the method of delivery, handouts or other types of media the patient can reference later are important.
Exercise. To mitigate fatigue and minimize shoulder and neck dysfunction, level 1 research supports supervised, whole body exercise during definitive chemo-radiation as safe, feasible, and more effective than usual care or a rehabilitation approach alone\textsuperscript{33,35,38,77}. In a randomized control trial, patients who were strongly encouraged to “remain active” throughout chemo-radiation had significantly lower scores on physical functioning and QOL measures compared to the intervention group\textsuperscript{38}. Intensity of exercise should be moderate\textsuperscript{79}, and types of exercise should include a mix of aerobic and resistive\textsuperscript{33,37,65}. Yoga and mindfulness practices have produced favorable outcomes for mental health and flexibility\textsuperscript{26,77}.

In a randomized control trial of 77 patients with colorectal cancer, patients in the prehabilitation group had significantly better adherence to their exercise programs after surgery and improvements in physical function, while the rehabilitation group (usual care) had poorer adherence rates and experienced a physical decline\textsuperscript{79}. Similarly, across multiple solid tumor cancer populations, Chou et al\textsuperscript{80} reported that prehabilitative exercise consistently produced favorable physical and QOL outcomes, and psychological intervention (stress management and psycho-educational methods) demonstrated improvements in QOL.

Specifically in HNC populations, pretreatment neck and shoulder exercises may be beneficial in reducing neck and shoulder range of motion dysfunction\textsuperscript{40}. Moreover, exercise during chemo-radiotherapy has been demonstrated in multiple studies to be safe, feasible, and effective at reducing cancer-related fatigue and improving QOL\textsuperscript{33,38,77}.

Evidence supporting exercises for preventing or treating dysphagia is promising according to level 1 research, but protocols vary widely across primary studies\textsuperscript{28}. It is consistent, however, swallowing exercises initiated 4 weeks prior to treatment appeared to produce the most favorable results\textsuperscript{28}. Trismus onset and severity are associated with extent of treatment, and
existing prehabilitative exercise protocols have not resulted in improved outcomes compared with early traditional rehabilitation. Similarly, xerostomia is optimally managed through medical and dietary management.

**Lymphedema.** At least 75% and up to 98% of HNC survivors will develop lymphedema by 3 years posttreatment, yet patients frequently identify lymphedema as a topic on which they receive insufficient information. Lymphedema education prior to treatment is desired by patients and timely intervention can facilitate optimal lymphedema management (i.e. less facial disfigurement, improved swallow function). This approach can also reduce distress associated with head and neck lymphedema. More specifically, given the pattern and timing of head and neck lymphedema onset, the immediate post-radiation and post-surgery phases are important checkpoints for lymphedema screening. Education about lymphedema provided prior to treatment resulted in earlier diagnosis and treatment of it, according to one level 1 study.

**Psychosocial Well-being.** Another area requiring ongoing attention is mental health. Howren et al concluded that HNC patients who received at least one pre-treatment session with a mental health specialist, followed by two to three sessions after treatment began, reported higher QOL. The authors further support regular screening prior to, during, and after cancer treatment. Coping strategies training may be an effective approach for addressing depression and anxiety in HNC populations. During a 5-week period, two sessions prior to treatment and two sessions after treatment begins was identified as the most favorable timing for psychological prehabilitative intervention in terms of QOL. One study identified a predictive relationship between baseline and posttreatment depression and QOL, which may support pretreatment screening to identify individuals at risk of persistent or worsened depressive symptoms.
Mask anxiety is a unique aspect of HNC treatment that benefits from therapy intervention before and during radiation. There is emerging evidence that interventions focusing on education and setting appropriate expectations about the mask, external strategies (music, distraction) and internal strategies (shift thinking, prayer) are effective.

**Driving and Working.** While few studies focused on multi-modal intervention programs, two whole-task issues rose to prominence in the HNC literature: driving behaviors and return to work. In one survey of 83 HNC survivors, only 67.5% of patients drove less or stopped driving during cancer treatment, and after cancer treatment 26% of patients continued driving less or had ceased entirely. Interestingly, at the time of the survey, only 37.3% were employed and driving status was highly correlated with work status, social and leisure activities, and household errands – all of which were reduced compared to baseline. Return to work is affected by the interplay of physical, psychosocial, and environmental/contextual factors, and reduced employment rates are common among HNC survivors. These authors support earlier intervention to facilitate successful return to work. Participation in general rehabilitation alone did not translate to successful returning to work; thus, it is recommended that intervention is tailored specifically to the needs of the individual and the activity demands of their productive pursuits. Amin et al developed the Return To Work Planning Tool as a framework to assist patients and therapists in assessing the abilities needed and supports available in the workplace, structure conversations between patients and their employers, and make necessary preparations to minimize lost work time or prevent unwanted retirement. It is recommended this tool is utilized prior to cancer treatment and revisited immediately following treatment at a minimum.

**A Recommended Model**
Figure 2 outlines a summary of evidence-based intervention within a comprehensive, prehabilitative model of supportive care for HNC survivors.

**Discussion**

Secondary disease prevention is a national initiative which has been adopted by rehabilitation disciplines (such as OT\(^93\)). However, “usual care” in oncology supportive care often follows a traditional rehabilitative approach, that is, the provision of rehabilitative care upon presentation of a functionally limiting symptom or dysfunction\(^78\). The sequelae of HNC treatment have been well-documented and there is considerable effect on QOL, participation in daily activities, and overall well-being. Furthermore, there is strong evidence that earlier intervention, or a prehabilitative approach, would more effectively prevent or minimize effects of cancer treatment. There are disproportionate rates of suicide among HNC survivors compared with other types of cancer survivors\(^2,94\), which underscores the seriousness of their unmet needs. Qualitative studies have captured the need well, describing survivors as “cured but not healed”\(^95(p1)\).

The findings from this scoping review call for a more organized, proactive, objective, evidence-based approach to supportive care for HNC survivors. Parke et al\(^75\) highlighted gaps in the research pertaining to HNC care, and reported that, of the 258 articles included in the review, 79 (38%) of the first authors were physicians, 36 (17%) were speech therapists, 25 (12%) were PhD researchers, 13 (6%) were nurses, 10 (5%) were physical therapists, 9 (4%) were dentists, 1 (0.4%) was an occupational therapist, and the remaining first authors’ professions were either unlisted (19; 9%) or represented another discipline (14;7%). This vast underrepresentation of therapists in the literature may contribute to or be consistent with poor understanding of available supportive and preventative care. By the same token, studies are particularly lacking in evidence
on multi-modal interventions and interventions to enhance patient participation in daily activities.

**Indications for Occupational Therapy**

In view of the second component of the PICO question, OT is a logical fit to address at least some of the unmet needs, despite the lack of existing research specific to OT. Occupational therapists are trained in psychology, anatomy and physiology, environmental modifications – among others – *and* the therapeutic use of daily life. The existing, most robust literature (systematic reviews and meta-analyses) repeatedly notes the lack of outcome studies related to function, ADLs, and meaningful participation in what the OT profession defines as occupations. Furthermore, patients and nurse navigators readily identify needs consistent with the OT scope of practice or name the need for OT but often do not receive the services from which they could benefit.

OT at its core is a holistic, scientific, person-centered profession. OT authors in oncology have effectively argued the benefit of treating cancer survivorship as a chronic condition. In doing so, practitioners recognize that the cancer journey is not complete upon final dose of radiation or that daily life will be the same after physical healing has occurred from major cancer surgery. The needs of HNC patients extend well beyond the time of cancer treatment, even once they have crossed medical milestones of “completed medical intervention” or achieved “in remission” status. The literature offers insight into techniques that work and highlights emerging strategies and blaring gaps in care. Occupational therapists can use this information to create a program or enhance an existing program to better understand and meet the needs of their patients.
It is recommended that OT practitioners increase their presence in prehabilitative, interdisciplinary teams in order to promote a more comprehensive approach. As experts in daily living, OTs can meet the expressed desire of patients to know more about how the HNC journey will impact their daily life. It is recommended that OTs become more involved in prehabilitative education from as close to the time of diagnosis as possible up to and including the first 1-2 weeks of radiation. Topics that OTs would be most appropriate to cover include lymphedema risk and early identification; anticipated routine, task, and environment modifications; radiotherapy mask anxiety; pretreatment neck and shoulder exercises; and planning for work and driving.

OT has a long-standing positive reputation in addressing driving, work, and ADLs – including addressing the personal skills and factors, the task itself, and the environment or context in which these occupations take place\textsuperscript{24,98,99}. In a prehabilitative model of care, it is recommended that OT take the lead in these three areas.

**Limitations**

The background search was limited to the US and while the database searches were not limited to the US, no explicit effort was applied to ensure international representation. As identified earlier, there are more supportive services and disciplines involved in HNC survivorship identified in the NCCN Guidelines®, but they are likely underrepresented here as it is beyond the scope of the present review. Another limitation in this review is the lack of OT literature available relating specifically to HNC. To overcome this, general oncology literature, along with professional documents and guidelines were utilized to interpret researchers’ recommendations and formulate HNC-specific recommendations for OT practice. Risk of bias is inherent, although this was minimized by consensus among co-authors.
Recommendations

Future research should focus on participation measures in daily life, with better representation of supportive care disciplines. A focus on multi-modal interventions and the interplay of impairments is also indicated.

Conclusion

In this scoping review pertaining to prehabilitation in HNC, with an additional emphasis on implications for OT practice, findings support the efficacy, feasibility, and safety of a prehabilitative approach. Moreover, there is strong evidence that early initiation of a comprehensive intervention approach is superior to the traditional rehabilitation model alone. Recommendations are made here for intervention sequencing and employment of evidence-based methods.

Acknowledgements

The authors would like to acknowledge Dr. Kathleen Matuska, PhD, MPH, OTR/L, FAOTA for her contributions to this project as scientific advisor and mentorship that promoted the intellectual quality of this article.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors
Figure 1.

PRISMA-ScR Flow Chart

Identification

Records identified through database searching
n=1,156

Records identified through alternative search methods (citation chaining)
n=467

Screening

Records after duplicates removed and eligible for title screening
n=254

Eligibility

Records eligible for abstract screening
n=193

Records excluded
n=94
Beyond scope (n=37)
Did not include or directly relate to HNC (n=23)
Medical management of symptoms (n=22)
Article type, such as case report or editorial (n=12)

Full text articles assessed for eligibility
n=99

Records excluded
n=46
Intervention focused on rehabilitation (n=26)
Too broad (n=20)

Included

Studies included
n=53
Level 1 (n=20)
Level 2 (n=23)
Level 3 (n=3)
Qualitative (n=7)
Figure 2.

A Comprehensive Prehabilitative Model of Care for HNC Survivors.

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<td><em>Address social determinants of health</em></td>
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<td><em>Screen pretreatment depression</em></td>
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<td><em>Counseling</em>: 4 sessions, 1-2 before, 2-3 sessions after CRT or surgery</td>
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<td><em>Begin shoulder and neck ROM and strengthening exercises up to 4 weeks prior to surgery or CRT</em></td>
<td><em>Supervised, whole body exercise during CRT (Moderate exertion, aerobic + resistive exercises)</em></td>
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<td><em>Obtain baseline video swallow study</em></td>
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<td><em>Begin dysphagia exercises 4 weeks prior to surgery or CRT</em></td>
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<td><em>Begin return to work planning</em></td>
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<td><em>Work accommodations vs. Short Term Disability</em></td>
<td><em>Complete the RTW-PT</em></td>
<td><em>Implement results from RTW-PT 3-6 months posttreatment</em></td>
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Use the BRASH+ tool and refer to supportive services upon identification of functional problems (OT, PT, SLP, SW, nutrition)

Implement results from RTW-PT 3-6 months posttreatment

Continually reassess work needs
Appendix C.2

Submitted Manuscript References: A Comprehensive Prehabilitative Model of Care for Head and Neck Cancer Survivors: A Scoping Review

References


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Appendix C.3.1

Article Submission Materials: Submission Checklist

**SUBMISSION CHECKLIST**

To be completed and uploaded with the manuscript at submission.

Incomplete submissions will not be put into the peer-review process until requirements are met. Incomplete submissions will be removed from the system after 90 days.

A more complete description of each item that must be checked, including ethical considerations, is provided under the appropriate heading in the Information for Authors document available at [www.archives-pmr.org](http://www.archives-pmr.org).

All elements of the manuscript are printed in English and double-spaced with 1-inch margins at top, bottom, and sides. Right margins are unjustified.

Separate documents are submitted in the following order: (1) cover letter; (2) title page, including acknowledgments and explanation of any conflicts of interest; (3) main text file (manuscript without author identifiers) including a structured or standard abstract, keywords, list of abbreviations, body of the text, references, suppliers’ list, figure legends; (4) figures; (5) tables; (6) appropriate completed reporting guideline (e.g. CONSORT, PRISMA, etc.) (7) appendices; (8) supplementary files; (9) author submission checklist; (10) disclosure forms (ICMJE Form for Disclosure of Potential Conflicts of Interest. At initial submission, the corresponding author should complete the ICMJE form. Please note that for revised articles, completed ICMJE forms must be completed for all authors.)

**Cover Letter**

The cover letter should include essential information, including who the corresponding author will be and a statement signed by the corresponding author that written permission has been obtained from all persons named in the Acknowledgments and patient consent forms have been collected, if needed.

**Title Page**

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**PREHABILITATION FOR HEAD AND NECK CANCER**

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<td>Personal communications and unpublished observations are not used as numbered references but are mentioned in the text with the written approval of the person being quoted. Author must include a copy of the approval.</td>
</tr>
<tr>
<td><strong>X</strong></td>
<td>Suppliers are not listed in the reference list or included in the reference numbering (see below).</td>
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Suppliers

| N/A | Provide a list (after the Reference section) including all manufacturers and other nondrug products used directly in the study. They should be in an alphabetized, superscripted list (i.e., a, b, c...). |
| N/A | Provide names for each Supplier. |
| N/A | Equipment and/or materials are identified in text, tables, and legends by superscript lower case letters, corresponding to the list of suppliers. |
| N/A | Suppliers are listed consecutively in the order they are cited in the text. |

Figure Legends

| X | A list of figure legends should be provided after the reference list and suppliers’ list, listing each figure in order by number. |
| X | Legends/captions should not be embedded in the figure files themselves. |

Figures

| X | Each is numbered with an Arabic numeral and cited in numeric sequence in the text. |
| X | Each figure is provided in a separate document |
| N/A | Photographs of recognizable persons require a signed release from the patient or legal guardian authorizing publication. Masking eyes to hide identity is not sufficient. (Author should be able to provide signed release forms when requested but does not need to provide forms with submission.) |
| N/A | If a CONSORT diagram is included, it should be assigned a figure number and be included with the list of figure legends. |
| X | Figures should be submitted in PDF, JPG, EPS, or TIFF format. |

Tables

| N/A | Each table is provided in a separate document, headed by a title, and numbered in Arabic numerals. |
| N/A | Tables are cited in numeric sequence in the text. |
| N/A | Tables should be submitted in editable Word or Excel format. Please do not import tables into a Word document. |

Reporting Guidelines

To ensure a high and consistent quality of research reporting, original research articles must contain sufficient information to allow readers to understand how a study was designed and conducted. For review articles, systematic or narrative, readers should be informed of the rationale and details behind the literature search strategy. **To achieve this goal, Archives requires that authors upload a completed checklist for the appropriate reporting guideline during original submission.** The Archives specifically requests that the following Reporting Guidelines are used when appropriate and strongly encourages authors to use any of the Guidelines listed in the Equator Network ([www.equator-network.org](http://www.equator-network.org)):

- Randomized Controlled Trials – CONSORT - Consolidated Standards of Reporting Trials
- Observational Studies – STROBE – Strengthening the Reporting of Observational studies in Epidemiology
• Systematic Review of Controlled Trials – PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-Analyses
• Study of Diagnostic accuracy/assessment scale – STARD – Standards for the Reporting of Diagnostic Accuracy Studies
• Case Reports – CARE – for case reports

Highlights and Graphical Abstracts (optional)

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<th>Highlights are a short collection of bullet points that convey the core findings and provide readers with a quick textual overview of the article. Highlights should be submitted as a separate MS Word file in EES by selecting “Highlights” from the drop-down list when uploading files. Include 3 to 5 highlights. There should be a maximum of 85 characters, including spaces, per highlight. Only the core results of the paper should be covered. See <a href="http://www.elsevier.com/journal-authors/highlights">http://www.elsevier.com/journal-authors/highlights</a></th>
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<td>For Graphical Abstracts, authors must provide an image that clearly represents the work described in the paper. A key figure from the original paper, summarizing the content can also be submitted as a graphical abstract. Graphical Abstracts should be submitted as a separate file in EES by selecting “Graphical Abstracts” from the drop-down list when uploading files. Preferred file types are TIFF, EPS, PDF or MS Office files. See <a href="http://www.elsevier.com/journal-authors/graphical-abstract">http://www.elsevier.com/journal-authors/graphical-abstract</a></td>
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</table>

Similar Publication

| N/A | Upload with the manuscript files a reprint of each article and/or abstract the author and/or coauthors have previously published or is “in press,” and each manuscript the author and/or coauthors have submitted for possible publication or have in manuscript form dealing with the same patients, laboratory experiment, or data, in part or in full, as those reported in the submitted manuscript. Further explanation of the circumstances should be included in the cover letter, including similarities and differences. |

Disclosure Forms

<table>
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<th>(1) The ICMJE Form for Disclosure of Potential Conflicts of Interest must be completed by the corresponding author at initial submission.</th>
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<td></td>
<td>If a resubmission or revision, then all authors must each submit the ICMJE Form.</td>
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DEVICE STATEMENT

Please check off ONE statement below that pertains to your submitted work.

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<td>The device(s) is/are FDA approved for the indicated usage in the United States.</td>
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<td>The legal/regulatory status of the device(s) that is/are the subject of this manuscript is/are not applicable in the country where the author(s) resides.</td>
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<td>The device(s) that is/are the subject of this</td>
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manuscript has/have been cleared through the Premarket Notification (510(k)) process/approved through a Premarket Approval application for the indications studied.

The device(s) that is/are the subject of this manuscript has/have been cleared through the Premarket Notification (510(k)) process/approved through a Premarket Approval application for [state the specific indication on a separate page and attach], but not for the indications that were reported.

The device(s) that is/are the subject of this manuscript is/are being evaluated as part of an ongoing FDA-approved investigational protocol (DE) for [state the intended use on a separate page and attach].

The device(s) that is/are the subject of this manuscript is/are exempt from FDA regulations because [state reason on a separate page and attach].

The device(s) that is/are the subject of this manuscript is/are not FDA-approved and is/are not-commercially available in the United States.

The device(s) that is/are the subject of this manuscript is/are not intended for human use.

The legal/regulatory status of the device(s) that is/are subject of this manuscript is/are not known by the author(s).

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Resubmissions

| | When resubmitting a manuscript for further consideration, provide an itemized accounting of how the manuscript was changed in response to the original set of evaluations. Also, a highlighted or marked-up (Track Changes) copy should be submitted showing all of the changes made throughout the manuscript. |
| | Both a clean and marked-up copy of the manuscript files that were revised are required at submission. |

I have reviewed this Checklist and have complied with its requirements.

Claire M. Dolislager

5/15/22

Type in name above

Type in date above
Appendix C.3.2
Submitted Manuscript Cover Letter

Leighton Chan, MD, MPH, FACRM
Allen W. Heinemann, PhD, ABPP, FACRM
Editors in Chief
Archives of Physical Medicine and Rehabilitation
May 15, 2022

Dear Dr. Chan and Dr. Heinemann,

Enclosed you will find our article submission, entitled A Comprehensive Prehabilitative Model of Care for Head and Neck Cancer Survivors: A Scoping Review. The idea for this project was born out of an everyday practice dilemma. Some cancer populations have robust prehabilitation programs, and for the people in our community, it seems to work well. But for head and neck cancer survivors, their care is fragmented and patients are often blindsided by how much cancer treatment affects their lives. It should not be a surprise when we, their care team, know the sequelae of cancer treatment are well documented. In the context of a larger knowledge translation project, this scoping review was conducted to explore the existing evidence on comprehensive prehabilitation in head and neck cancer populations. Is fragmented care for head and neck cancer survivors common? What are their needs? As occupational therapists, what is our role on their care team according to the evidence? These are some of the questions we sought to answer.

In this scoping review, there was overwhelming support for prehabilitation as a model of care in oncology in general, and more importantly here, in head and neck cancer populations specifically. A number of unmet supportive care needs were identified across studies, particularly pertaining to information about their treatment, secondary disease prevention, skilled therapy services, and intervention for returning to work. Few but high quality studies support and described the role of occupational therapy pertaining to driving, radiotherapy mask anxiety, and work.

We believe this article aligns well with the mission, scope, and readership of your journal. Like us, we anticipate your readers will be excited to understand the depth and breadth of the needs of this population, and to learn about evidence-based approaches that may prevent or minimize the severity of chronic illness. Indeed, this scoping review highlights the hope for head and neck cancer survivors at large to enjoy greater quality of life, meaningful participation in daily living, and better health.

The corresponding author for our project is Claire Dolislager, and she may be contacted by email at claire.dolislager@gmail.com or phone at (616) 355-3996. We confirm this article has not been published elsewhere, nor is it under consideration for publication in another journal. The individual named in the Acknowledgements has consented to be so named. All authors have approved the manuscript and are in agreement with submission to the Archives of Physical Medicine and Rehabilitation.
Thank you kindly for your time and consideration,

Claire Dolislager, Katie Polo, and Teresa Wickboldt
### Appendix C.3.3

**PRISMA-ScR Checklist**

#### Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

<table>
<thead>
<tr>
<th>SECTION</th>
<th>ITEM</th>
<th>PRISMA-ScR CHECKLIST ITEM</th>
<th>REPORTED ON PAGE #</th>
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<tbody>
<tr>
<td>TITLE</td>
<td>Title</td>
<td>Identify the report as a scoping review.</td>
<td>1</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>Structured summary</td>
<td>Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.</td>
<td>1</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>Rationale</td>
<td>Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Objectives</td>
<td>Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.</td>
<td>3</td>
</tr>
<tr>
<td>METHODS</td>
<td>Protocol and registration</td>
<td>Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.</td>
<td>N/A</td>
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<td></td>
<td>Eligibility criteria</td>
<td>Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Information sources*</td>
<td>Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.</td>
<td>5-7</td>
</tr>
<tr>
<td></td>
<td>Search</td>
<td>Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.</td>
<td>5-7</td>
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<td></td>
<td>Selection of sources of evidence†</td>
<td>State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.</td>
<td>5-6</td>
</tr>
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<td></td>
<td>Data charting process‡</td>
<td>Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.</td>
<td>7-8</td>
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<td>Data items</td>
<td>List and define all variables for which data were sought</td>
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## PRISMA-ScR CHECKLIST ITEM

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<td>RESULTS</td>
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<td>If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).</td>
<td>N/A</td>
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<tr>
<td>RESULTS</td>
<td>13</td>
<td>Describe the methods of handling and summarizing the data that were charted.</td>
<td>8</td>
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<tr>
<td>RESULTS</td>
<td>14</td>
<td>Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.</td>
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<td>RESULTS</td>
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<td>For each source of evidence, present characteristics for which data were charted and provide the citations.</td>
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<td>RESULTS</td>
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<td>For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.</td>
<td>8</td>
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<tr>
<td>RESULTS</td>
<td>18</td>
<td>Summarize and/or present the charting results as they relate to the review questions and objectives.</td>
<td>8-19</td>
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## DISCUSSION

| DISCUSSION | 19   | Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups. | 19-21 |
| DISCUSSION | 20   | Discuss the limitations of the scoping review process. | 21 |
| DISCUSSION | 21   | Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps. | 22 |

## FUNDING

| FUNDING | 22   | Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review. | 22 |

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where sources of evidence (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.
† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with information sources (see first footnote).
‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.
§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

### ICMJE DISCLOSURE FORM

**Date:** 5/15/2022  
**Your Name:** Claire M. Dolislager  
**Manuscript Title:** A Comprehensive Prehabilitative Model of Care for Head and Neck Cancer Survivors: A Scoping Review  
**Manuscript Number (if known):** Click or tap here to enter text.

In the interest of transparency, we ask you to disclose all relationships/activities/interests listed below that are related to the content of your manuscript. “Related” means any relation with for-profit or not-for-profit third parties whose interests may be affected by the content of the manuscript. Disclosure represents a commitment to transparency and does not necessarily indicate a bias. If you are in doubt about whether to list a relationship/activity/interest, it is preferable that you do so.

The author’s relationships/activities/interests should be defined broadly. For example, if your manuscript pertains to the epidemiology of hypertension, you should declare all relationships with manufacturers of antihypertensive medication, even if that medication is not mentioned in the manuscript.

In item #1 below, report all support for the work reported in this manuscript without time limit. For all other items, the time frame for disclosure is the past 36 months.

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**Time frame: past 36 months**
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Please place an “X” next to the following statement to indicate your agreement:

I certify that I have answered every question and have not altered the wording of any of the questions on this form.
Appendix C.3.5

Article Submission Clinical Highlights

A Comprehensive Prehabilitative Model of Care for Head and Neck Cancer Survivors: A Scoping Review

Highlights

- Head and neck cancer survivors have many unmet supportive care needs
- Prehabilitation in head and neck cancer populations is supported by research
- Prehabilitation can improve quality of life and overall wellness
- Increased occupational therapy services may help address unmet needs