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Knowledge, Perception, and Implementation of Oral Care in Patients with Head and Neck Cancer Before, During, and After Radiation Therapy

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Cancer Before, During, and After Radiation Therapy

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Abstract

The purpose of this study is to determine the extent of oral health education among head and neck cancer patients throughout various treatment periods and how this education influences their oral health practices, determine satisfaction with education and support based on initial symptoms as well as identify modifications to approaches to oral care education and further define a model for interprofessional practices to establish a role for speech-language pathologists in oral health education. A Qualtrics survey was distributed to gather information on oral care habits, determine habits, education, and satisfaction throughout radiation, completion of daily oral care, importance of oral health, and information specific to their cancer. The results indicate a relationship between number of oral symptoms and oral education satisfaction prior to treatment, as well as general trends of increased education leading to increased practices and satisfaction, a lack of awareness of the importance and health benefits of oral care, and patients with symptoms receiving less education than those without symptoms. Overall, patients with head and neck cancer experience a need for increased multidisciplinary communication and education.

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Contents

Chapter I

Introduction

Oral Care and Health

Oral care is an essential aspect of daily hygiene. In addition to improving the general health of the oral cavity, oral care reduces the risk of developing certain diseases. Mayo Clinic lists endocarditis, cardiovascular disease, diabetes and aspiration pneumonia as conditions negatively affected by improper oral health (Mayo Clinic, 2019). According to Colgate, more than 500 species of bacteria live in the mouth at any given time, and these bacteria accumulate and form dental plaque when oral care is neglected (Colgate Professional). By sustaining an effective oral care regimen, bacteria in the mouth can be controlled. Daily routines such as brushing and flossing minimize bacteria as well as subsequent dental plaque to prevent diseases such as cavities, tooth decay, and gum disease. Recommendations from Mayo Clinic for the general population include brushing the teeth twice a day with a soft-bristled brush and fluoride toothpaste, flossing daily, using mouthwash, limiting added sugars in a healthy diet, and avoiding tobacco to build a strong oral care routine (Mayo Clinic, 2019). Each individual must implement an effective oral healthcare routine in order to maintain health and wellness.

Importance of Oral Care Practice in Head and Neck Cancer

While maintaining adequate oral care is important to the general population, it is critical for those with head and neck cancer. Patients with head and neck cancer suffer from many short- and long-term side effects of radiation therapy, some of which can be prevented or lessened by implementing evidenced-based oral care. Devi and Singh (2014) described radiation-induced complications related to dental health in patients with head and neck cancer which include mucositis and xerostomia, otherwise known as dry mouth, in addition to the heightened risk of

dental caries and infection. Implementing a dental routine for individuals who suffer from radiation side effects may be difficult due to pain and discomfort. However, it is imperative to achieve proper oral hygiene to prevent the worsening of these side effects as well as other risks, such as aspiration pneumonia. Kawai, et al. (2017) reported many head and neck cancer patients had poor oral hygiene even before receiving treatment, and those individuals were more likely to develop aspiration pneumonia following treatment. Aspiration pneumonia can be a potentially fatal consequence for those with head and neck cancer, yet proper oral hygiene can help to prevent the disease. Overall, head and neck cancer patients are at a higher risk for poor oral health due to radiation-induced complications which could potentially lead to aspiration pneumonia as well as other disease processes.

Oral Care Perception, Education, and Practice

Inadequate oral care can lead to many complications, especially for those with head and neck cancer. Therefore, evidenced-based oral care education is imperative. Without proper oral care, radiation-induced side effects may present or worsen, in addition to increasing risk of disease processes, such as aspiration pneumonia. Despite the drastic implications improper oral care can have on individuals with head and neck cancer, there is little evidence regarding perceptions of the importance of oral care among head and neck cancer patients. Other disciplines have conducted research regarding perceptions of oral care among patients, including those with diabetes, cardiovascular disease, and spinal cord injuries (Eldarrat, 2011; Sanchez, et al., 2017; Sullivan, 2012). One study from the journal *Supportive Care in Cancer* researched patterns of dental care education and utilization among individuals with head and neck cancer (Epstein et al., 2018). The survey from Epstein et al. found that many head and neck cancer patients lacked proper oral care and expressed the need for knowledgeable health professionals

to be aware of the oral health complexities head and neck cancer patients face. Epstein's article revealed oral health education for head and neck cancer patients is inconsistent. One patient may receive frequent education from their dentist throughout treatment, while another may have only had dental health mentioned casually by their cancer team. Knowledge about the timing, provider, and frequency of oral health education is limited. Further investigation is also needed to explain how oral care education relates to the actual implementation of a recommended dental routine. By determining the various degrees of oral health education among head and neck cancer patients, a conclusion can be made about how to improve oral health education and practice.

Speech-Language Pathology and Oral Care Education

While oral care education is often provided by speech-language pathologists, minimal research has been conducted to explain the role of speech-language pathologists in oral care education. Although speech-language pathologists may not be considered oral health professionals, such as dentists, their services are influenced by oral health due to the effect of poor oral care on patients' risk of aspiration pneumonia as well as risk of reduced per oral nutrition and hydration. Speech-language pathologists provide services to patients with dysphagia and elevated risk of aspiration who especially benefit from proper oral health practices. Seedat and Penn (2016) examined the implementation of an oral care regimen in relation to dysphagia management and risk of aspiration pneumonia and found that individuals in compliance with their recommendations were at a lower risk of aspiration pneumonia. Since oral and dental care also relates to risk factors within a speech-language pathologist's scope of practice, ensuring patients maintain a proper oral health regimen is important. Therefore,

determining a role in oral health education for speech-language pathologists in the interdisciplinary setting, especially for head and neck cancer patients, is imperative.

The purpose of this study is to determine the extent of oral health education among head and neck cancer patients throughout various treatment periods and how this education influences their oral health practices, determine satisfaction with education and support based on initial symptoms as well as identify modifications to approaches to oral care education and further define a model for interprofessional practices to establish a role for speech-language pathologists in oral health education.

Chapter II

Literature Review

Oral Care and Health

Oral care is an aspect of daily life significant to the health and wellbeing of all

individuals. The American Dental Association suggests brushing teeth twice a day with fluoride

toothpaste, flossing once a day, seeing a dentist regularly, and eating a balanced diet to maintain

good oral hygiene (American Dental Association, n.d.). If these oral care practices are not

maintained, oral health can deteriorate and contribute to onset of disease. Poor oral health

places individuals at risk for various health conditions including cardiovascular disease,

pneumonia, or pregnancy complications.

When oral hygiene is neglected, dental plaque can form. If dental plaque is not restrained,

it spreads along the gumline allowing additional bacteria to infect the mouth. This can lead to

infections and diseases, the most dangerous of which is periodontal disease. The National

Institute of Health defines periodontal disease as an infection of the tissues that hold your teeth in

place caused by poor brushing and flossing habits which allows for the buildup of plaque

(National Institute of Health, 2018). Proper periodontal health is imperative, since gum disease

can have hazardous consequences for those who suffer from the preventable condition.

Periodontal health may be connected to some cancer diagnoses (Rajesh, et al., 2013). In addition,

periodontal disease can lead to cardiovascular disease, endocarditis, and even an increased risk

of heart attack. If someone has periodontal disease, bacteria can enter the circulatory system and

activate an inflammatory response which increases the risk of cardiovascular disease (Sanchez,

et al. 2017). Periodontal disease can increase the likelihood of a recurrent coronary event by

nearly 1.5 times (Sanchez, et al. 2017). Furthermore, the same bacteria growth can cause

endocarditis, an infection of the inner lining of the heart chambers and valves. One study found that those with poor oral health were especially susceptible to endocarditis following a tooth extraction (Lockhart, et al, 2010). When bacteria is accumulated in the mouth, the likelihood of cardiovascular disease or endocarditis is increased.

The lack of proper oral care has also been linked to pregnancy and birth complications. A systematic review from Agueda, Echeveria, and Manau (2008) indicated that pregnant women who were treated for periodontitis, or gum disease, had a lower incidence of adverse pregnancy outcomes such as preterm birth or low birth weight.

Aspiration pneumonia can be a potentially fatal diagnosis for older patients, especially those with difficulty swallowing, yet proper oral health can help to prevent the disease. According to a systematic review from Sjogren, et al. (2008), individuals who implemented proper oral hygiene routines experienced an absolute risk reduction, which indicated oral hygiene can play a role in reducing the risk of developing aspiration pneumonia (Sjogren et al., 2008).

The lack of proper oral care may influence survival rates in some older individuals. Maeda and Mori (2020) investigated the association between oral care and poor survival in geriatric patients admitted to acute care and found that patients with the poorest oral health at hospital admission had a decreased rate of survival. These were older adults with a mean age of 83.8 whose reasons for admission included infections, rehabilitation, surgery, or malignancies, among others. The study used the Oral Health Assessment Tool (OHAT), a comprehensive oral assessment tool which looked at the lips, tongue, gums and tissues, saliva, natural teeth, dentures, denture pain, and oral cleanliness. The OHAT rates each of those categories as either healthy, in need of changes, or unhealthy. The scores from each category are combined for a final score of

up to sixteen. The patients with an OHAT score greater than three were found to have higher mortality than those with OHAT scores two or below. The score of three or higher indicated poor oral health. Therefore, in a general, older adult population, poor oral health at time of admission was associated with in-hospital mortality (Maeda and Mori, 2020).

Aspiration pneumonia can be a common complication for those who suffer from dysphagia, and increased oral hygiene for this population also shows a reduction in cases. In fact, dysphagia and dependency on oral care were two factors significantly associated with aspiration pneumonia (Langmore, et al., 1998). According to a 2008 systematic review by Sjogren, et al., including fifteen articles which described the association between oral hygiene and pneumonia, implementing a specific, intensive oral care routine reduced the risk of aspiration pneumonia. The studies which implemented proper interventions showed an absolute risk reduction between 7% and 12%, which indicated that oral hygiene can play a role in reducing the risk for aspiration pneumonia (Sjogren, et al., 2008). Tongue-coating can occur when individuals do not brush their tongue as a part of their oral care regimen. Abe, et al (2008) shows that tongue-coating can be a risk indicator for aspiration pneumonia, especially in the elderly community. Aspiration pneumonia can be a potentially fatal disease, yet proper oral hygiene is a preventative measure. Therefore, it is important that individuals, as well as caretakers for those dependent on oral care, recognize the importance of oral care and which regimens to implement.

For those dependent on oral care, a study from Sorenson et al. (2013) had nursing home staff implement an intensified oral hygiene regimen which included a detailed tooth brushing procedure and the use of chlorhexidine .12% mouth rinse. For patients who suffer from dysphagia, when early dysphagia screenings are paired with this intensified oral hygiene by nursing staff, the incidence of x-ray verified pneumonia was significantly reduced (Sorensen et

al., 2013). By increasing oral hygiene for those with dysphagia, cough reflex sensitivity and swallowing reflex improved, while the risk of aspiration pneumonia decreased. The authors concluded that proper oral care, either by the patient themselves or nursing staff, can have a significant impact on the health and wellbeing of the elderly.

Perception, Knowledge, and Practice of Oral Care

Many individuals do not engage in proper oral care habits and may be unaware of the potentially dangerous consequences that come from a lack of oral hygiene. Thus, education is an important to ensure implementation of correct oral health care practices in the general population. Yet, many people only receive oral health education in childhood. Nakre and Harikiran (2013) studied the effectiveness of oral health education among children and found that oral health education improved the knowledge, attitude, and practice of a dental routine, especially when significant others, such as teachers or parents, were involved. This education was shown to be effective in changing the attitude of participants for up to 6 years. Therefore, oral health education is important because it is effective at changing the attitudes of those who receive it.

Although many people are aware of guidelines recommending proper oral hygiene, many Americans do not go to the dentist and suffer from tooth decay and gum disease. The Division of Oral Health from the Center for Disease Control and Prevention has a variety of oral health data which can be used to evaluate Americans' oral health. As of 2016, only 65.7% of those eighteen years of age or older had been to a dentist in the past year, up only one percent from the results of 2014. In addition, this resource also asked those aged sixty-five or older how many of them had lost teeth due to tooth decay or gum disease. As of 2016, 36.0% had lost six or more teeth

due to tooth decay or gum disease and 14.4% had lost all of their teeth (Center for Disease Control and Prevention, n.d.).

Other disciplines have conducted research regarding knowledge and practice of oral care. Sullivan (2012) reported that 59% of patients with spinal cord injuries perceived their mouth as healthy, yet 23% of those patients were in need of dental assistance. Many patients believed they had cavities even though none were present; however, many patients believed they did not have periodontal disease. Only 16% of participants believed they had periodontal disease when, in reality, over 75% had gum disease present (Sullivan, 2012). Therefore, many of these patients suffering from spinal cord injuries were not aware of their dental status, nor did they realize the importance of oral health.

Eldarrat (2011) evaluated diabetic patients' perception of oral health and found that diabetic patients did not have proper dental hygiene. Only 50% of participants brushed their teeth once a day, 66% never used dental floss, and only 14% of participants visited the dentist regularly. Furthermore, only 33% realized that diabetics were at an increased risk of oral diseases, such as periodontal disease. Overall, diabetic patients in this particular survey had poor understanding of the importance of oral health and did not have proper dental hygiene habits (Eldarrat, 2011).

Sanchez, et al. (2017) found that many patients with cardiovascular disease had poor dental health, yet they did not recognize the importance of oral health and its impact on their cardiovascular health. Of the twelve participants, nine said oral health was never discussed during their cardiac care, despite the fact that all twelve participants were receptive to cardiac nurses promoting oral health practices. Overall, many other disciplines have conducted research regarding the knowledge and practice of oral care. Furthermore, many individuals, including the

general population, caregivers who perform oral care, high-risk patients such as elderly, or those who with an underlying condition, fail to recognize the importance of oral hygiene and do not implement proper oral care regimens.

Roles of Oral Care Health Professionals

In 2000, the U.S. Surgeon General's report, *Oral Health in America*, raised awareness about the importance of good oral health as an integral component of general health and well-being (U.S. Public Health Service, 2000). The report highlighted the potential contribution of all healthcare professions to improve oral health, and the necessity for collaborative, interdisciplinary approaches to oral care. People with complex medical, physical, and psychological conditions are among the most underserved groups in receiving dental care. Consequently, these patients have the most significant oral health disparities of any group. The traditional dental care delivery system is not able to deliver adequate services to these people with "special needs" for a variety of reasons. New systems of care are evolving that better serve the needs of these groups by using interprofessional teams to reach these individuals and integrate oral health services into social, educational, and general health systems. In the 2000 U.S. Surgeon General's report *Oral Health in America,* it was noted that although there have been gains in oral health status for the population as a whole, they have not been evenly distributed across subpopulations. That report noted that health disparities exist among populations including racial and ethnic minorities, individuals with disabilities, elderly individuals, individuals with complicated medical and social conditions and situations, low income populations, and those living in rural areas (U.S. Public Health Service, 2000). Therefore, there are discrepancies and inconsistencies throughout the United States when it comes to oral health education. Many individuals who have complicated medical and social

situations may not receive the same level of education as those with better access to oral health education. However, a collaborative, interdisciplinary approach to oral care education will help bridge the gap in oral health education.

In 2011, the Institute of Medicine (IOM) released two independent reports, *Advancing Oral Health in America* (IOM 2011a) and *Improving Access to Oral Health Care for Vulnerable and Underserved Populations* (IOM 2011b). Although some improvements have been reported, vulnerable and underserved populations in the United States continue to suffer the burden and consequences of oral diseases. The report noted that people with disabilities and medical conditions are less likely to have seen a dentist in the past year than people without disabilities and medical conditions; that people with intellectual disabilities are more likely to have poor oral hygiene and periodontal disease and more likely to have caries than people without intellectual disabilities; that people with special needs face systematic barriers to oral health care, such as transportation barriers and cost; that dental care professionals are not trained to work with these individuals; and that dental offices are not physically suited for them to receive care.

Both reports underscored the pivotal role of multiple health care professionals in oral health promotion and disease prevention, the value of interprofessional team-based care to improve oral health, and the need for additional education and training of health professionals in oral health. Regardless of a patient's medical diagnoses, including but not limited to head and neck cancer, increased oral health education will benefit all individuals. An integrated, multidisciplinary approach would help ensure that patients receive the relevant, consistent oral care education they deserve.

Oral Care in Relation to SLP Scope of Practice

Although speech-language pathologists may not be as influential in the discussion of oral health as dentists or nurses, they are just as affected by proper oral care. Speech-language pathologists provide services to patients who have dysphagia or aspiration pneumonia, or simply patients who are planning to undergo radiation therapy should be seen by a speech-language pathologist for education related to the effect of radiation therapy on swallowing, strategies to improve outcomes, prophylactic swallowing exercises, and oral care education to prevent disease and infection. In the Scope of Practice in Speech-Language Pathology provided by the American Speech-Language-Hearing Association, educating individuals who are at risk for aspiration about oral hygiene techniques is listed under the examples for Prevention and Wellness programs designed to increase public awareness (ASHA, 2016). Speech pathologists are often involved in the treatment of children with special needs including intellectual disabilities, autism, and cerebral palsy who have challenges in receiving traditional oral care from dental professionals alone. In geriatric clients with dysphagia, or difficulty swallowing, proper oral care is crucial. Often, in these studies, individuals were in nursing homes or assisted living facilities in which they are not the ones doing their own oral hygiene. Instead, nurses are the ones providing oral care. For nursing home patients, intensive oral care, which included brushing a patient's teeth for approximately five minutes after each meal, was found to improve cough reflex sensitivity and helped to restore the swallowing reflex (Watando, et al., 2004).

Speech-language pathologists have the unique ability to realize the connections between poor oral care and conditions such as dysphagia and aspiration pneumonia. Therefore, they have the ability to educate their clients, as well as those who may be implementing oral care to others, of the proper oral hygiene recommendations and procedures.

Head and Neck Cancer Treatment and Oral Care

Oral care needs of patients with head and neck cancer are complex. According to Devi and Singh (2014), radiation induced complications specific to head and neck cancer patient's dental health can include mucositis, change in salivary composition, alteration of taste, various infections, with potential of developing dental caries, xerostomia, or malnutrition. Mucositis can especially affect the oral care routines of head and neck cancer patients. Mucositis is described by the Oral Cancer Foundation as the most debilitating side effect of cancer treatment, causing a range of symptoms including discomfort, increased redness, and painful sores in the mouth (Oral Cancer Foundation, n.d.). This condition may make it painful or uncomfortable to engage in a daily oral care routine, despite its importance. The risk of developing oral and dental disease rises as patients undergo therapy for cancer, and continues to develop even after therapy. Preventative and treatment regimens must be established to survey and address oral health, from pre-cancer evaluations to aggressive follow-up after completion of radiotherapy.

Carvalho, Medeiros-Filho, and Ferreira (2018) reviewed 54 articles which described oral care recommendations for individuals with cancer of all forms and found oral care should be addressed through oral and general assessment, professional oral care, and oral care at home. All three aspects were reviewed before, during, and after oncological treatment.

Before oncological treatment, there are multiple factors important to include in the assessment of the oral cavity. Some recommendations related to general health and were obtained through a patient medical history form or interview. Three studies requested information related to general medical history, another study inquired specifically about physical status, and three additional studies sought information specifically related to nutritional status. While patient medical history was deemed relevant across studies, greater emphasis was directed

toward oral health assessment. Six studies recommended a subjective assessment of patients' oral health, including an assessment of bleeding gums, dry mouth, or pain in the mouth. Ten studies recommended an objective oral assessment performed by a dentist to provide a comprehensive description of oral health. Four of the ten studies included panoramic and periapical radiography, known as dental x-rays, in the objective assessment.

The assessment of oral and general health continues during oncological treatment. One study recommended the assessment of complications such as mucositis, or mouth sores, herpes simplex, and low salivary flow. Three studies assessed the functionality of chewing, swallowing, and speech mechanisms throughout oncological treatment.

The functional assessment of chewing, swallowing, and speech was recommended again following treatment. One study recommended evaluations of alterations in tooth development for children who still have their baby teeth, or a mixture of baby and adult dentition. Generally, studies asked for evaluation of degree of oral complications, and follow up of resolution of oral complications.

Professional care is an important step in dental care before, during, and after care. Before care, five studies recommend receiving specific oral hygiene instructions from a dentist. Five studies suggested a thorough dental treatment of greater complexity be performed 10-21 days before treatment. Four additional studies recommended dentists perform a dental treatment specific to a patient's cancer and oral health needs 7-10 days prior to oncological treatment. One study suggested doing both dental treatments prior to oncological treatment. Recommended steps during the dental treatment included removal of bacterial biofilm retention factors in five studies, the topical application of fluoride in two studies, and one study recommended the polishing of present restorations as well as removal of sharp edges of teeth.

During treatment, the role of professional dentists changes. Professionals primarily provide instructions on how to maintain oral hygiene and oral health during treatment. Seven studies asked that dentists provide oral hygiene instructions to patients. Four studies implemented discussion of artificial saliva. Five studies required dentists advise the avoidance of substances that irritate or dry out the oral mucosa, including alcohol, tobacco, carbonated drinks, caffeine, and spicy or acidic foods. Additionally, patients with head and neck cancer were asked to avoid wearing removable dentures until treatment ceases in two studies. Also, in one study, dentists were asked to do emergency treatments if consent was given by an oncologist. Following treatment, the main role of dental professionals was to perform regular visits once every three months as recommended by six studies.

Oral care at home is also an important factor throughout oncological treatment. Prior to treatment, patients must brush at least three times a day using an ultra-soft brush, fluoride toothpaste with at least 1100 ppmF, and dental floss, as recommended by three studies. These three studies recommended this practice before, during, and after treatment. Six studies simply recommended that patients engage in oral hygiene practices. Three other studies suggested a .12% chlorhexidine mouthwash for individuals with difficulty controlling bacterial biofilm. One study recommended all patients use a .05% fluoride solution daily.

During treatment, patients must still brush three times a day with appropriate recommendations. In addition, six studies recommended the .12% chlorhexidine mouthwash, but now with the addition of patients without oral mucositis. In some cases, patients have low neutrophil and platelet counts which require cleaning the oral cavity with gauze moistened with the .12% chlorhexidine mouthwash, as recommended by six studies. One study recommended daily use of .05% fluoride solution and a topical application of fluoride. Two studies also

recommended lubrication and hydration of oral mucosa using artificial if patients have xerostomia, or dry mouth.

Following treatment, patients were still asked to brush three times a day with appropriate recommendations by three studies. Three studies continued to recommend .12% chlorhexidine mouthwash. Three studies also continued to recommend daily topical application of fluoride. Two studies recommend continuing lubrication if patients have xerostomia.

These recommendations for general, professional, and personal oral care during cancer treatment come from a 2018 systematic review by Carvalho, Medeiros-Filho, and Ferreira. This review included 54 articles which described oral care recommendations for individuals with cancer of all forms, not just head and neck cancer. All three aspects were reviewed before, during, and after oncological treatment.

Although these recommendations are put in place for patients with all cancers, more specific intervention is needed for those with head and neck cancers. A study from Samim et al. (2016) lists dental management guidelines with the goal of enhancing quality of life for head and neck cancer survivors. These recommendations are more specific for those with head and neck cancer, who may have more complex dental needs than other cancer patients.

Before cancer treatment, it is best practice for patients to have a pre-treatment assessment with a comprehensive examination and radiographs in order to identify and resolve pre-existing dental needs, such as advanced cavities or gum disease (Samim et al., 2016). In some cases, custom oral devices may be prescribed to minimize radiation exposure to oral structures which are unaffected by cancer. During treatment, it is essential for head and neck cancer patients to continue oral hygiene despite the discomfort, to reduce inflammation and infection. A follow up with a dentist or medical professional to manage symptoms associated with radiation is also

imperative. This symptom management may include the reduction of mucositis pain using topical anesthetics, as well as specific oral rinses or lip balms to help with dryness, among other treatments. In addition, it is recommended patients use fluoridated toothpaste, soft toothbrushes, lubrication of mouth and lips, and aqueous chlorhexidine .12% solution to prevent fungal and yeast overgrowth. Patient dental education is integral during treatment to promote optimal oral care and provide dietary instruction. Dietary instruction includes the avoidance of alcohol and tobacco use as well as proper nutrition which can negatively affect oral and general health. Following cancer treatment, dentists continue to promote fluoridated toothpaste, soft toothbrushes, and lubrication of mouth and lips. Furthermore, the dentists monitor, prevent, and manage oral complications which may arise from treatment such as mucositis, dry mouth, infections, cavities, or periodontal disease, among others. Overall, the guidelines specific to head and neck cancer found in Samim et al. (2016) contribute to better oral complication prevention and treatment to improve quality of life for head and neck cancer survivors.

Kawai et al. (2017), confirmed the need for proper oral hygiene for those with head and neck cancer. Many individuals had a dental exam before beginning treatment in which 63% of patients initially had poor oral hygiene, which was a moderate to severe case of dental plaque found by a dental hygienist. Following treatment, 35.6% of those patients still had poor oral hygiene. Those individuals with poor oral hygiene were more likely to develop aspiration pneumonia following treatment (Kawai, et al., 2017). Many guidelines and recommendations regarding oral health exist for those with head and neck cancer. It is important that the guidelines are followed to improve quality of life for these patients, as well as prevent complications such as aspiration pneumonia.

Patient Knowledge Versus Practice of Oral Care in Head and Neck Cancer

The quality of life for those with head and neck cancer is impacted by tumor and treatment factors, including the toxicities of treatment involving radiotherapy and chemoradiotherapy. Oral health affects head and neck cancer patients, because compromised oral function can affect nutrition and dietary intake. People with head and neck cancer need more support across a range of domains as compared to other cancers. In one study by Pateman et al. (2015), four men and two women were able to attend face-to-face interviews to examine the supportive care needs of cancer patients. They were between 50 and 72 years of age, some had chemoradiotherapy while others had surgery combined with radiotherapy. They were asked questions in three categories: oral health after treatment, dimensions of eating, and adapting to chronic side effects. Their concerns regarding eating included the embarrassment of social eating, adaptation to new ways of swallowing, as well as the need for constant conscious awareness of the movement of the lips and tongue. Patients reported adding moisture to their food and altering their diet to soft foods to avoid dysphagia. Those who participated in the Pateman et al. (2015) study were concerned about their oral health support. They wanted easier access to follow up specialists post-treatment. Traveling to a dental clinic separate from the hospital was a potential barrier for some clients. Patients also expressed a need for more general awareness of head and neck cancer to aid in early detection (Pateman et al., 2015). These concerns can help guide speech-language pathologists, doctors, and dentists alike to the needs of head and neck cancer patients.

Many cancer survivors lack the financial support, social support, or functional capacity to achieve optimal oral care. Epstein, et al. (2018) surveyed sixty-four participants following cancer treatment to provide insight into current practices and patterns of oral health in order to

identify specific recommendations for improvement. Patients were surveyed related to oral education, whether or not the patient was given oral preventative care instructions and who those were from, as well as oral care utilization, whether the patient followed through on the recommended dental practices, including who performed the evaluation, and what treatment was chosen. The participants were 64 individuals, with most being stage IV cancer patients with a median post-diagnosis time of three years. Therapy undergone by patients consisted of surgery (77%), radiotherapy (83.8%), and chemotherapy (58.1%). Education for these patients typically came from the patient's usual dentist, medical staff from the cancer center, or dental staff recommended by the cancer center. Patients were most satisfied with their pre-treatment dental care, and least satisfied with their care during cancer therapy. When patients were asked to use a 0-10 scale on how oral symptoms affected his/her quality of life, the median score was 9. The most common oral symptoms during their cancer treatments included dry mouth, difficulty swallowing, mucositis, oral pain and taste change. Only 34 of the 64 participants (53%) had a post-cancer dental evaluation. Some of these patients needed treatment for dental infections, dental extractions, or dental fillings among other oral health issues. Twenty-nine patients (45%) received swallowing evaluations and 23 patients (35%) received speech therapy. Patients also reported inability to identify providers and lack of communication between dental providers and other members of the cancer team as barriers to ideal oral health practices.

Despite current guidelines which provide recommendations for both pre and post treatment dental care, many patients did not receive this dental care. Only 72% received pre-cancer oral education, and only 54% reported a post-treatment dental evaluation. Potential barriers to oral health education include a lack of consistency and standardization in the education, the quality of the education, as well as the oral education provider. In addition, the

patient may not be receptive or the information did not resonate with them. The patients who did receive oral education were supposed to receive radiographs and dental cleanings from their dentists before their radiation began, but many did not. The community dentists must also be educated on the importance of supplemental fluoride and intense cleanings prior to initiation of treatment. Pre-treatment evaluations were done by the patient's usual dentists, while oral care education and monitoring was done by medical practitioners during cancer therapy. Many patients in the Epstein, et al. study did not receive post-treatment follow-up and these patients often needed dental extractions. Patients chose not to receive post-treatment dental care because of the inability to find appropriate dental providers, as well as lack of communication between dentists and the rest of the cancer team. Overall, the survey from Epstein, et al. found that many patients were not properly educated on oral health, and some even chose to forgo post-treatment dental care (Epstein, et al., 2018). Potential barriers to oral health education included a lack of consistency and standardization in the education, the quality of the education, or a lack of an oral education provider.

Role for SLPs in Interdisciplinary Oral Care Regimens in HNC

Many patients with head and neck cancer have an interdisciplinary team of doctors and specialists dedicated to their success during and after treatment. This approach is often used in head and neck cancer due its complexity. The benefits of multidisciplinary teams include better outcomes and satisfaction for clients, and more efficient use of resources and knowledge by the medical staff (HealthOne NSW). By utilizing this team, doctors and specialists do not need to scrounge for information for areas in which they are not proficient. Instead, this team allows multiple professions to learn from each other in order to build the most effective treatment for the patient. The interdisciplinary team for head and neck cancer is composed of surgeons,

medical and radiation oncologists, speech and occupational therapists, psychologists, and social workers (Badran, et al., 2018). However, dentists and nurses may not be privy to these conversations and treatments. Yet, these are the professionals most proficient in oral care requirements and regimens for the patients with head and neck cancer. The survey by Epstein, et al. (2018) expressed the need for knowledgeable health professionals who are aware of the complexities of the oral health needs of head and neck cancer patients and survivors. In an interdisciplinary team setting, the speech-language pathologists may be the oral health professional who recognizes the oral health needs and makes those among the priorities during head and neck cancer treatment. Since speech-language pathologists are seen more frequently than other oral health professionals, they have the unique ability to remind patients of oral care practices and address oral care concerns more often. Speech-language pathologists may have to educate other professionals, as well as the patient themselves, on the significance of proper oral health during this time.

Rationale for Current Study and Research Questions

The purpose of this study is to determine the extent of oral health education among head and neck cancer patients throughout various treatment periods. The oral health of those with head and neck cancer, especially elderly patients or those with dysphagia, is imperative to avoid potential complications. One of the most severe potential consequences which relates directly to the field of speech-language pathology is aspiration pneumonia. A systematic literature review of risk factors for aspiration pneumonia from Van der Maarel-Wierink, et al. (2017) contributed poor oral health, dysphagia, and age, among others, as significant risk factors for aspiration pneumonia. These three attributes, especially in addition to a head and neck cancer diagnosis, could promote the possibility of contracting a life-threatening disease. Therefore, proper oral

care can reduce the risk of aspiration pneumonia. Furthermore, Adachi, et al. (2002) found that once-a-month professional oral health care for nursing home residents reduced the prevalence of fevers and deaths related to aspiration pneumonia. 16.7% of those who did not receive professional oral care died from aspiration pneumonia, compared to 5.0% of those who received the oral care (Adachi, et al., 2002). This reduction in contraction of aspiration pneumonia can be contributed to the reduction of bacteria in the mouth provided by proper oral hygiene. One study from Ishikawa, et al. (2008) reiterated the correlation between poor oral health and contraction of aspiration pneumonia, and showed that weekly professional cleanings reduced oropharyngeal bacteria, which in turn helped to prevent aspiration pneumonia (Ishikawa, et al., 2016). Therefore, in order to reduce bacteria, proper oral hygiene is imperative. Since oral hygiene is especially difficult for those with head and neck cancer, proper education reiterates the importance of maintaining an effective routine. Patients must recognize that, despite uncomfortable radiation-induced side effects such as mucositis or dysphagia, oral hygiene reduces the risk of further complications with more dire consequences.

While research provides extensive recommendations for oral care practices in patients with head and neck cancer, there is a lack of specific evidence to guide medical and dental professionals in providing education. Due to the complex nature of head and neck cancer and the multidisciplinary care needed for patients with head and neck cancer, more information is necessary to guide health care teams and inform a protocol for oral care education. Although the survey from Epstein, et al. (2018) provided some data and percentages for respondents regarding oral hygiene practices and oral care education barriers for head and neck cancer patients, it did not delve into subgroups about types and timing of education. It is imperative as a part of our survey to delve deeper into the specificities of the education which these patients receive. This

knowledge will help to identify modifications that need to be made to oral care education, whether it is through interprofessional practice or provision of consistent education.

The research questions answered through the survey are as follows:

Research Question #1. What type of understanding do a group of head and neck cancer patients have about the importance and health benefits of oral care?

Research Question #2: Is there a difference in the Amount of Education provided based on the number of Professionals who provided initial Oral Health Education to patients with head or neck cancer?

Research Question #3: Is there a difference in the Satisfaction of Oral Health Education based on the number of Professionals who provided initial Oral Health Education to patients with head or neck cancer?

Research Question #4: Is there a relationship between the amount of initial oral health education provided and the amount of initial oral health practices by patients with head and neck cancer?

Research Question #5: Is there a difference in the amount of initial oral health education based on number of initial oral health symptoms?

Research Question #6: Is there a Relationship between the number of Oral Symptoms and Oral Health Education Satisfaction Before, During, and After Treatment for Head or Neck Cancer?

Research Question #7: Is there a Relationship between the number of Oral Symptoms and Satisfaction of Support for Oral Health Problems Before, During, and After Treatment for Head or Neck Cancer?

Chapter III

Methods

Study Design

This study was an online survey designed using Qualtrics software. Participants either took the survey from a computer or mobile device, or chose to complete a paper version of the survey. The full survey is included in Appendix A. The data from this survey was collected for up to one year, with the hope of thirty to fifty participants. The Eastern Illinois University (EIU) Institutional Review Board (IRB) granted approval for the study in October of 2020 (IRB 20-119).

Participants

Participants were recruited through Carle Foundation Hospital, Sarah Bush Lincoln Health Center, and Terre Haute Regional Hospital. Speech-language pathologists at the hospitals distributed flyers to patients over the age of 18 diagnosed with head and neck cancer who had completed radiation therapy within the past five years. Potential participants were given flyers which provided a URL and information about the online survey. Participants could also choose to complete a paper version of the survey. The link to the survey was also posted on Facebook groups related to head and neck cancer to allow for a broader range of participants. These groups included one HNC support group specific to SLPs and two for patients and their caregivers. The survey link was posted in the group as well as details about the survey. The survey link was also included in a copy of the Head & Neck Cancer Alliance Newsletter. Participants were made aware the survey was confidential and voluntary, although they could choose to be notified of results or put contact information if they were interested in participating in future studies. The vast majority of participants came via the Facebook groups rather than the hospitals.

The total number of participants who initially submitted a response on Qualtrics was 73, however only 16 were completed. Of the 16, only 5 respondents provided data for education, practices, symptoms, and satisfaction before, during and after treatment. The demographics of the 16 participants are as follows:

Table 1. Subject Background Description for 16 Respondents.						
Participant Name (Site of Cancer)	**Type and Severity of Cancer**	**Treatment of Cancer**	**5 year Habits Prior to Cancer**			**G-Tube**
			Brushing Teeth (T) or Dentures (D)	**Flossing**	**Visiting the Dentist**	
Base of Tongue (BOT) 1	Stage 4 Squamous Cell	Surgery and Radiation	T 1x/day	Rarely/ Not at All	Rarely/ Not at All	Before, During, and After
BOT 2	Stage 4 Squamous Cell	Chemotherapy and Radiation	T >1x/day	Rarely/ Not at All	>1x/year	During and After
Salivary Palate	Stage 4 Salivary Gland	Surgery and Radiation	T >1x/day	1x/day	>1x/year	Before
Larynx	Stage 4 Squamous Cell	Surgery and Radiation	D 1x/day	NR	>1x/year	Before, During, and After
BOT Larynx	Stage 4 Squamous Cell	Surgery and Radiation	D 2-3x/wk	NR	1x/year	Before, During and After
BOT 3	Stage 2 Squamous Cell	Surgery and Radiation	T >1x/day	Rarely/ Not at all	>1x/year	None
Larynx 2	Stage 4 Squamous Cell	Chemotherapy and Radiation	D 1x/day	NR	Rarely/ Not at All	During and After
Salivary 2	Stage 2 Parotid	Surgery and Radiation	T >1x/day	Rarely/ Not at All	Rarely/ Not at All	None
Salivary 3	Stage 3 Acinic Cell Carcinoma	Surgery, Chemotherapy, and Radiation	T >1x/day	2-3x/wk	Rarely/ Not at All	None
Larynx 3	Stage 3 Squamous Cell	Surgery, Chemotherapy, and Radiation	No Teeth or Dentures	NR	Rarely/ Not at All	Before, During and After
PalateSinus	Stage 3 Squamous Cell	Surgery, Chemotherapy, and Radiation	T >1x/day	1x/day	1x/year	None
Tongue 1	Stage 3 Squamous Cell	Chemotherapy and Radiation	T >1x/day	1x/day	1x/year	During and After
Tongue 2	Squamous Cell	Surgery, Chemotherapy, and Radiation	T 2-3x/wk	Rarely/ Not at all	Every Few Years	Before, During and After
Tonsil 1	Stage 4 Squamous Cell	Chemotherapy and Radiation	T 1x/day	2-3x/wk	>1x/year	During and After

Tonsil 2	Stage 4 Squamous Cell	Chemotherapy and Radiation	T 1x/day	2-3x/wk	>1x/year	None
Nasopharynx	Stage 4 Adenoid Cystic Carcinoma	Surgery and Radiation	T >1x/day	1x/day	>1x/year	NR

Of the sixteen participants, there was a range of sites, types, and severities of cancer, as well as treatment methods. The most common sites of cancer included Base of Tongue, Larynx, Salivary Gland, with three participants each. Nine patients had stage IV cancer, four patients had stage III and two had stage II cancer. The majority of patients had squamous cell cancer (12), but others included Adenoid Cystic Carcinoma, Salivary Gland, and Parotid. Treatments included surgery and radiation (7), chemotherapy and radiation (5), or a combination of the three (4).

Survey

The survey began with questions regarding informed consent and participation in the study. Questions relating to participants willingness to participate in future studies or receive the results from the current study are also included. Following informed consent, the survey had eight main sections. The sections, as well as information gathered in each section, are as follows:

1. **General Questions**: Questions 1-4 set the tone for the survey and asked questions about how they learned about the survey, whether they had teeth or dentures, and frequency of dentist visits prior to head and neck cancer diagnosis.

2. **Information about oral care habits:** Question 5 described the patients typical oral care habits in the five years prior to the diagnosis of head and neck cancer, including alcohol and tobacco use, consumption of sugary or starchy foods, as well as probiotic use are detailed in this section.

3. **Oral care habits throughout radiation therapy:** This section used a rating scale to answer questions related to oral care habits before, during, and after completing radiation therapy. Question 6 details how often patients completed various oral care practices

including brushing teeth, flossing teeth, or using mouthwash throughout each stage of radiation.

4. **Completion of daily oral care:** These questions determined whether oral care was done independently or with assistance, as well as living situations throughout therapy. Questions 7-10 ask about living situations and independent oral care while question 11 asks about g-tube use throughout treatment.

5. **Oral Care Health:** Question 12 asked participants how they felt about oral care statements regarding overall oral care importance, as well as the contribution of poor oral care to cardiovascular disease, pneumonia, and mucositis.

6. **Oral care education throughout radiation therapy:** In Questions 13 and 14, participants were asked which specialists the patients saw before, during and after therapy, as well as what education regarding oral care they received from those specialists.

7. **Oral care education satisfaction:** In Question 15, participants were asked how satisfied they were with various aspects of oral care education.

8. **Cancer:** Questions 16-24 determined the type, severity, and location of the cancer, provided dates of therapy initiation and termination, as well as further detail about radiation symptoms.

Data Analysis

To evaluate Research Question #1: "What type of understanding do a group of head and neck cancer patients have about the importance and health benefits of oral care?", the four parts of Question 12 were used which asked participants how they felt about oral care statements regarding overall oral care importance of oral care during and after radiation treatment, as well as

the contribution of poor oral care to cardiovascular disease, pneumonia, and mucositis. The percentage of participants who responded 'not at all, minimally, somewhat, or very much" was calculated. A mean total score (and standard deviation) was calculated for the 16 respondents across the four sub-items with each "very much" response= 3, "somewhat" = 2, "minimally" =1, and "not at all" = 0.

To evaluate Research Question #2: "Is there a difference in the Amount of Education provided based on the number of Professionals who provided initial Oral Health Education to patients with head or neck cancer?", a total score for the Amount of Education was calculated using the 16 oral education sub-topics in question #14. A total amount of education provided before, during, and after radiation treatment was calculated for the 5 participants who completed all parts of the survey. A total education score at the onset of cancer treatment before radiation was calculated for the 16 participants who completed the first part of the education question. Each subtopic received 0 if no professional discussed the topic with the patient, 1 if someone might have mentioned the topic or it was only a handout, 2 = some information was provided by a medical or dental professional, and 3=information about the topic was fully explained by a medical or dental professional. Since there were 16 sub-items with a 0-4 option, the maximum possible Amount of Oral Health Education score was 64 before, during or after radiation treatment. The Amount of Oral Health Education score was evaluated to determine if there was a difference between groups of patients who received Oral Health Education from 0, 1, 2 or 3+ professionals. Descriptive statistics of means and standard deviations for each group and a one-way ANOVA was used to determine if there was a significant difference between the groups.

To evaluate Research Question #3: "Is there a difference in the Satisfaction of Oral Health Education based on the number of Professionals who provided initial Oral Health

Education to patients with head or neck cancer?", three sub-items from survey question 15 were used. Portions of the question asked about the participant's satisfaction with oral health education provided by professionals before, during and after radiation treatment for head or neck cancer. Items were scored as 4= Very Satisfied, 3= Somewhat Satisfied, (a neutral response of 2 was not an option), 1= Somewhat Dissatisfied, and 0=Very Dissatisfied. The Satisfaction with Oral Health Education score was evaluated to determine if there was a difference between groups of patients who received Oral Health Education from 0, 1, 2 or 3+ professionals. Descriptive statistics of means and standard deviations for each group and a one-way ANOVA was used to determine if there was a significant difference between the groups.

To evaluate Research Question #4: "Is there a relationship between the amount of initial oral health education provided and the amount of initial oral health practices by patients with head and neck cancer?", the Oral Health Practices score was derived from participant responses to sub-items in survey question #6. Twelve of the 16 sub-items in question 6 reflected positive practices and 0-4 points were added to the score based on frequency of reported practice. Four of the sub-items were practices that would not be desirable for someone undergoing radiation and other treatment for head and neck cancer. Points were deducted based on reported frequency of practice of these items (use of foam swab without a mouthwash solution, use of lemon-glycerin swabs, use of oil-based lip balms, and use of alcohol-based mouthwashes). The maximum possible score for oral practices was 48 (12 positive practice items x 4 points each, and 0 points subtracted from the negative practice items). The relationship between the oral practices score and the oral health education score (described in research question #3) was evaluated using a Pearson correlation.

To evaluate Research Question #5 "Is there a difference in the amount of initial oral health education based on number of initial oral health symptoms?", survey question #46 was used. This question had 8 sub-items of oral health symptoms such as dry mouth, mouth pain, mouth bleeding, fungal infection, mouth sores, difficulty swallowing, pneumonia, and other mouth or throat infection. An option for no oral health symptoms was also included. A descriptive table was used to present the percentage of oral heal symptoms experienced by patients before, during and after cancer treatment. A table also showed the number of oral health symptoms initially and the amount of initial health symptoms. Two groups were formed, those with initial oral health symptoms and those without initial oral health symptoms and a t-test was used to analyze if there was a significant difference between these two groups in the amount of initial oral health education provided.

To evaluate Research Question #6 "Is there a Relationship between the number of Oral Symptoms and Oral Health Education Satisfaction Before, During, and After Treatment for Head or Neck Cancer?", survey question #46 was used. This question had 8 sub-items of oral health symptoms us as dry mouth, mouth pain, mouth bleeding, fungal infection, mouth sores, difficulty swallowing, pneumonia, and other mouth or throat infection. An option for no oral health symptoms was also included. A total score for oral health symptoms was calculated with one point for each reported difficulty before, during, or after radiation therapy for head or neck cancer. The maximum score for oral health symptoms was 8, if all 8 sub-items were experienced by the participant. A Spearman correlation was used to evaluate the relationship between the number of oral health symptoms and the oral health education satisfaction. The oral health education satisfaction score was described above in Research Question #3.

To evaluate Research Question #7, "Is there a Relationship between the number of Oral Symptoms and Satisfaction of Support for Oral Health Problems Before, During, and After Treatment for Head or Neck Cancer?", the satisfaction of support for oral health problems in survey question #15 was used. For the prompt about satisfaction of the support healthcare professionals provided when encountering oral health problems, participant responses were scored using a Likert Scale with the following choices: 4= Very Satisfied, 3= Somewhat Satisfied, (a neutral response of 2 was not an option), 1= Somewhat Dissatisfied, and 0=Very Dissatisfied. A Spearman correlation evaluated the relationship between Support for Oral Health Symptoms and the number of Oral Health Symptoms (described in research question #5 above) for 16 participants.

A detailed look at each of 5 participants' oral health problems, education provided, missed opportunities for education, and patient satisfaction with their oral health, oral health education, and oral health support before, during and after radiation treatment for head and neck cancer was conducted. These 5 participants answered all parts of detailed questions about education, symptoms and satisfaction at all three points in time of the cancer treatment process.

Chapter IV

Results

Importance and Health Benefits of Oral Care

For Research Question #1: "What type of understanding do a group of head and neck

cancer patients have about the importance and health benefits of oral care?", participants were

asked how they felt about oral care statements regarding overall oral care importance throughout

treatment, as well as how their oral care contributes to cardiovascular disease, pneumonia, and

mucositis. Table 2 notes the differences in participants' knowledge of the importance of oral care

related to specific conditions.

Table 2. Percentage of 16 Respondents' Degree of Knowledge and Importance of Oral Health Care by Patients Treated for Head and Neck Cancer.					
Item options	Oral care is important for individuals during and after undergoing radiation therapy for head and neck cancer % of Responses	Poor oral care can increase risk of mucositis (mouth sores) and infections during radiation therapy % of Responses	Poor oral care may increase risk of pneumonia for individuals with difficulty swallowing % of Responses	Poor oral care can contribute to cardiovascular disease % of Responses	Mean & SD of Total Score
Not at All			6%	13%	M= 9.06 SD=2.57 for 4 items, M= 2.25 per item which is "Somewhat"
Minimally		13%	38%	25%	
Somewhat	19%	25%	25%	19%	
Very Much	81%	63%	31%	44%	

Of the 16 respondents, 81% (n= 13) answered that oral care was very important.

However, when asked about individual practices, their understanding was limited. While these

patients knew that oral care is imperative for their care, approximately 40% of respondents had

minimal or no understanding of oral care's relationship to aspiration pneumonia or

cardiovascular disease. Patients were unaware of oral care's relationship to diseases and its ability to lessen the side effects of radiation.

Amount and Satisfaction of Oral Health Education based on Number of Professionals

Research questions 2 and 3 focused on the difference in the amount of education and patients' satisfaction in oral health education based on the number and type of professionals providing initial education. Participants were provided multiple education topics and asked which professionals, if any, provided education on the subject. Participants were later asked how satisfied they were with their initial education. As seen in Table 3, the number of professionals who provided initial oral health education were correlated with amount of initial education (p=.17) and satisfaction of initial education (p=.23).

Table 3. Mean (and standard deviation) of amount of initial oral health education and satisfaction with INITIAL health education based on the number of professionals who provided the education.		
Number of Professionals	**Amount of Initial Oral Health Education**	**Satisfaction with Initial Oral Health Education**
0 professionals (N=2)	4.50 (.71)	2.00 (1.41)
1 professional (N=8)	17.43 (8.30)	3.38 (1.06)
2 professionals (N=4)	23.50 (13.99)	3.25 (.50)
3+ professionals (N=2)	26.00 (11.31)	4.00 (.00)
Significance	One-Way ANOVA- Not Significant $F_{(3,11)}=1.99, p=.17$	One-Way ANOVA- Not Significant $F_{(3,12)}=1.64, p=.23$

Although there was no statistical significance between number of professionals and either amount or satisfaction of oral health education, there was still a relatively strong trend. Once more professionals were involved in oral health education, the amount of information provided increased. As a result, these patients were more satisfied with their education. Despite the meaningful pattern between patients who met with zero professionals and those who received

initial education from multiple professionals, there was not enough of a sample size to be statistically significant.

Table 4 examined the number of professionals who provided education before (m=1.36, SD=.89), during (m=1.13, SD=.72), and after (m=1.19, SD=1.23) cancer treatment. Patients who received education from two or more professionals steadily decreased from before treatment, when 37.5% (n=6) received education from multiple sources, to after treatment when only 25% (n=4) of participants received multiple avenues of communication.

Table 4. Number of Participants who were Provided Oral Health Education by 0-3+ Professionals Before, During, and After Cancer Treatment.			
	Initial Oral Health Education	**During Cancer Treatment Oral Health Education**	**After Cancer Treatment Oral Health Education**
0 professionals	2	3	5
1 professional	8	8	7
2 professionals	4	5	2
3+ professionals	2	0	2
Mean # of Professionals SD	1.38 (.89)	1.13 (.72)	1.19 (1.23)

Additionally, no patients received education from 3+ professionals during treatment, and 5 participants received no education from professionals following treatment. All in all, most participants were educated by 1 or 2 professionals throughout their time in cancer treatment.

As patients go through cancer treatment, oral health education and satisfaction can change. Table 5 indicated the satisfaction rate of participant's oral health education throughout treatment. As patients went through treatment, their mean satisfaction with their education dropped from a before treatment score of 3.25, or slightly higher than somewhat satisfied, to a during and after treatment score of 2.88, or slightly lower than somewhat satisfied.

Table 5. Number of Participants who were Very Dissatisfied, Somewhat Dissatisfied, Somewhat Satisfied, or Very Satisfied with Oral Health Education Before, During, and After Cancer Treatment.

	Initial Oral Health Education	During Cancer Treatment Oral Health Education	After Cancer Treatment Oral Health Education
Very Dissatisfied (0)	0	1	0
Somewhat Dissatisfied (1)	2	3	4
Somewhat Satisfied (3)	6	5	6
Very Satisfied (4)	8	7	6
Mean Satisfaction in Oral Health Education SD	3.25 (1.0) (slightly higher than somewhat satisfied)	2.88 (1.36) (slightly lower than somewhat satisfied)	2.88 (1.20) (slightly lower than somewhat satisfied)

Additionally, only one patient was very dissatisfied by any level of oral health education, with the dissatisfaction coming during cancer treatment. Overall, patients were generally satisfied with their oral health education, with the best results coming before treatment began.

Throughout cancer treatment, patients see a variety of professionals who have the opportunity to provide education. Table 6 details the types of specialists seen by 16 participants before, during, and after treatment, as well as which of these professionals provided education.

Table 6 Types of Specialists who Provided Education and Were Seen by 16 Participants with Head or Neck Cancer Before, During, and After Radiation Therapy and

	Before Radiation Therapy		During Radiation Therapy		After Radiation Therapy	
	Education	Seen	Education	Seen	Education	Seen
Speech-Language Pathologist	1 (16%)	6	1 (25%)	4	2 (50%)	4
ENT	1 (10%)	10	3 (60%)	5	2 (22%)	9
Cancer Center Doctor	9 (100%)	9	8 (80%)	10	5 (50%)	10
Cancer Center Nurse	3 (75%)	4	4 (66%)	6	3 (75%)	4
Cancer Center Dentist	4 (66%)	6	0	1	1 (50%)	2

Outside Dentist	3 (33%)	9	0	0	3 (60%)	5
Outside Hygienist	0	2	0	0	1 (20%)	5
Other	1 (100%)	1	1 (33%)	3	2 (66%)	3
TOTALS	**22**	**47**	**17**	**29**	**19**	**42**
	46% of Specialists Give Education		58% of Specialists Give Education		45% of Specialists Give Education	

Prior to radiation treatment, most patients saw an ENT, a cancer center doctor, an outside dentist, or a combination of the three. Only 10% (n=1) of ENTs and 33% of outside dentists (n=3) provided initial oral care education, while 100% of cancer center doctors (n=9) provided oral care education. During radiation therapy, the only specialist consistently seen was the cancer center doctor, with 80% (n=8) providing education. Additionally, 66% (n=4) of cancer center nurses seen during therapy provided education. After therapy, the majority of participants saw an ENT, a cancer center doctor, a dentist or hygienist, or a combination of the three. Only 22% (n=2) of ENTs and 20% (n=1) of hygienists provided oral health education, while 60% (n=3) of dentists and 50% (n=5) of cancer center doctors provided post-treatment oral health education.

For speech-language pathologists, only 6 participants saw a speech-language pathologist prior to treatment, with only 16% (n=1) of speech-language pathologists providing initial oral care education. During therapy, 4 participants saw a speech-language pathologist and 1 provided education. Following therapy, 4 participants saw a speech language pathologist and 2 provided education.

Initial Oral Health Education vs. Practices

For Research Question #4: "Is there a relationship between the amount of initial oral health education provided and the amount of initial oral health practices by patients with head and neck cancer?", patients were asked whether they participated in oral care health practices and whether or not they were educated on the aforementioned practices. Table 7 details the 14

oral health practices and compares the education provided and whether or not the education

influenced practices.

Table 7. Individual Practices' Amount of Initial Oral Health Education and Amount of Initial Oral Health Implementation Prior to Head and Neck Cancer Treatment		
Practice	**% Education** (Fully Explained or Some Education)	**% Practice** (1+/day)
Brush Your Teeth/Soaking Dentures	62.5%	81.25%
Brush Your Tongue	43.75%	43.75%
Floss	43.75%	31.25%
Mouthwash	75%	31.25%
Use mouth and/or lip moisturizer	50%	31.25%
Use Artificial Saliva	50%	0%
Use Flouride	31.25%	25%
Use Foam Swabs WITH a mouthwash solution INSTEAD OF brushing your teeth or cleaning your dentures	31.25%	0%
Saltwater/Baking Soda Mouth Rinses	56.25%	18.75%
Use a .12 chlorhexidine mouthwash	31.25%	0%
Use a "Magic Mouthwash" solution	31.25%	31.25%
Avoid Oil-Based Lip Balm	6.25%	12.5%
Avoid Sodium Lauryl Sulfate (SLS) in Toothpaste	0%	0%
Low-Level Therapy	0%	N/A

Table 7 points out the trends in education and practices in relation to each individual

practice. The majority of education was on brushing teeth (62.5%), using mouthwash (75%), use

of lip/mouth moisturizer (50%), use of artificial saliva (50%) and saltwater/baking soda mouth

rinses (56.25%). Notable topics that patients were not highly educated on included use of

fluoride (31.25%), mouth rinses or "magic mouthwash" (31.25%), and low-level laser therapy

(0%). For implementation of oral care practices, only brushing teeth increased from education to

practice (62.5% education to 81.25% practice).

Table 8. Individual Participant's Amount of Initial Oral Health Education and Amount of Initial Oral Health Practices at the Before Head and Neck Cancer Treatment.		
Participant Name (Site of Cancer)	**Initial Oral Health Education**	**Initial Oral Health Practices**
BOT1	9	14
BOT2	18	13
Salivary Palate	10	31
Larynx	18	20
BOTLarynx	4	21
BOT3	19	15
Larynx2	23	18
Salivary2	N/A	N/A
Salivary3	40	29
Larynx3	14	17
PalateSinus	34	22
Tongue1	32	24
Tongue2	11	16
Tonsil1	10	15
Tonsil2	5	19
Nasopharynx	30	22
	Pearson Correlation r= .41 (one-tailed significance p=.06)	

For each of the 16 participants, Table 8 compared their initial oral health education score

(max = 44) to their initial oral health practices score (max =48).

Some patients had similar levels of education and practices, whether low or high. For

example, BOT 1 had low education and practices while Nasopharynx had higher levels of both

education and practices. Salivary Palate, BOTLarynx, and Tonsil 2 had much lower education

scores than practices scores, which does not fit the general trend of an increased level of education leads to a higher level of practices.

Initial Oral Health Symptoms and Education

For Research Question #5: "Is there a difference in the amount of initial oral health education based on initial oral health symptoms?", patients were asked whether they experienced various oral symptoms prior to, during, and/or after head and neck cancer treatment. Of the 16 participants, 13 had at least one symptom prior to treatment, as detailed in Table 9.

Symptom	Before	During	After
Table 9. Description of Type of Oral Health Symptoms experienced by Patients with Head and Neck Cancer Before, During and After Cancer Treatment.			
Dry Mouth	(2/16) 13%	(10/16) 63%	(11/16) 67%
Mouth Pain	(2/16) 13%	(10/16) 63%	(5/16) 31%
Mouth Bleeding	(1/16) 6%	(3/16) 19%	(4/16) 25%
Mouth Sores	(2/16) 13%	(8/16) 50%	(8/16) 50%
Fungal Infection	(1/16) 6%	(4/16) 25%	(2/16) 13%
Difficulty Swallowing	(3/16) 19%	(12/16) 75%	(11/16) 67%
Pneumonia			(1/16) 6%
Other Mouth or Throat Infection		(1/16) 6%	(1/16) 6%
No Symptoms	(3/16) 19%	(2/16) 13%	(2/16) 13%
	11	48	43

Prior to cancer treatment, the most common symptoms included dry mouth, mouth pain, mouth sores, and difficulty swallowing. These four symptoms remained the most prevalent during cancer treatment, just at a higher rate. Dry mouth and mouth pain both rose from 2 participants prior to treatment to 10 participants during treatment. Mouth sores rose from 2 to 8 participants, while difficulty swallowing rose from 3 to 16. After treatment, mouth pain lowered, while dry mouth, mouth sores, and pneumonia remained similar.

Table 10 details each participants number of oral symptoms prior to treatment to the amount of education they were provided (max=44). When comparing the education levels of

those with oral care symptoms prior to treatment, there is no trend to suggest that increased oral

health symptoms leads to increased education. In some cases, such as BOT1 or BOTLarynx, the

opposite occurs and those with a high number of symptoms prior to treatment received among

the lowest initial oral health education. Table 11 looks at the mean amount of initial oral health

education for those who had no symptoms before compared to those who did have symptoms

prior to treatment.

Table 10. The Number of Oral Health Symptoms Head and Neck Cancer Patients were Experiencing at the Onset of Cancer Treatment and the Amount of Initial Oral Heal Education they Received.		
Participant Name (Site of Cancer)	**Number of Oral Symptoms Before Cancer Treatment**	**Initial Oral Health Education**
BOT1	3	9
BOT2	0	18
Salivary Palate	0	10
Larynx	0	18
BOTLarynx	2	4
BOT3	0	19
Larynx2	1	23
Salivary2	0	N/A
Salivary3	0	40 .
Larynx3	2	14
PalateSinus	1	34
Tongue1	0	32
Tongue2	1	11
Tonsil1	3	10
Tonsil2	0	5
Nasopharynx	0	30

Table 11. The Amount of Initial Oral Education Provided for a Group of Head and Neck Cancer Patients who had No Oral Health Symptoms Prior to Cancer Treatment compared to a Group of Patients who had One or More Oral Health Symptoms Prior to Cancer Treatment.

Groups Based on Initial Oral Health Symptoms	Mean (and Standard Deviation) of the Amount of Initial Oral Health Education
No Symptoms Before Number of Participants = 8	21.50 (SD 11.71)
One or More Oral Symptoms Before Number of Participants =7	15.00 (SD 10.20)
T-test Significance	Not significant F (13) =.288, p=.27

Although there was no statistical significance to suggest there is a difference in initial

oral care education for participants with or without symptoms prior to treatment, there is a

meaningful trend. Those who had no symptoms before (mean=21.50) had a higher amount of

education prior to cancer treatment than those who did experience symptoms (mean=15.00). In

some cases, key pieces of education related to the symptoms experienced prior to treatment was

not provided. For the seven subjects who did experience initial symptoms, Table 12 details the

extent of the symptoms, as well as which pieces of related key education were not provided.

Table 12. Comparison of key education provided or not provided for the seven subjects who experienced initial symptoms prior to radiation therapy.

Participant Name(Site of Cancer)	Oral Symptoms Before Cancer Treatment	Related Key Education Provided	Related Key Education Not Provided
BOT1	3 – Mouth Pain, Mouth Bleeding, Mouth Sores	9 Saltwater and baking soda rinses (some)	Brush teeth (maybe) Brush tongue (none) Floss teeth (none) Mouthwash (maybe) Lip moisturizer (maybe) Fluoride (none) Avoid oil-based lip balm (none) Avoid alcohol-based mouthwash (maybe) Low-level laser therapy (none)

BOTLarynx	2- Fungal Infection, Difficulty Swallowing	4 Mouthwash (some)	Brush teeth (none) Brush tongue (none) Artificial saliva (none) Fluoride (none)
Larynx2 - dentures	1 - Difficulty Swallowing	23 Mouthwash (fully explained) Artificial saliva (fully explained) Fluoride (fully explained)	Brush tongue (maybe) Denture care (maybe)
Larynx3 – edentulous and no dentures	2 – Dry Mouth, Difficulty Swallowing	14 Mouthwash (some) Lip moisturizer (some) Brush tongue (some)	Artificial saliva (none) Fluoride (none) Avoid alcohol-based mouthwash (maybe)
PalateSinus	1 – mouth pain	34 Brush teeth (fully explained) Brush tongue (fully explained) Mouthwash (fully explained) Floss teeth (fully explained) Fluoride (some) Saltwater and baking soda rinses (fully explained) Avoid alcohol-based mouthwash (fully explained)	Avoid oil-based lip balm (maybe)
Tongue2	1 – dry mouth	11 Brush teeth (fully explained)	Brush tongue (none) Mouthwash (none) Lip moisturizer (none) Artificial saliva (none) Fluoride (maybe) Avoid alcohol-based mouthwash (none)
Tonsil1	2 – Mouth Pain, Mouth Bleeding	10 Brush teeth (some) Floss teeth (some) Mouthwash (some) Lip moisturizer (some)	Brush tongue (none) Artificial saliva (none) Fluoride (none) Saltwater and baking soda rinses (none) Avoid oil-based lip balm (none) Avoid alcohol-based mouthwash (none) Low-level laser therapy (none)

When evaluating key education strategies relating to patient's initial oral care symptoms prior to head and neck cancer treatment, many strategies were not provided. In the case of a participant such as BOT1, nine pieces of key education which would have helped reduce the symptoms of mouth pain, mouth bleeding, or mouth sores was not provided prior to beginning treatment. Even if only one symptom was experienced, such as Tongue2, six pieces of key education were not provided by educators. Only PalateSinus had a majority of key education strategies provided to them to alleviate their pre-treatment symptoms.

Oral Symptoms, Oral Health Education Satisfaction and Support for Oral Health Problems

For Research Questions 6 and 7, patients were asked about their satisfaction with their oral care education as well as their support for oral health problems experienced throughout treatment. Tables 13 and 14 detail the participant's satisfaction with oral care education and support for oral health problems, respectively, throughout treatment.

Table 13. Participants' satisfaction with oral care education throughout head and neck cancer treatment			
	Before Treatment	**During Treatment**	**After Treatment**
Dissatisfied/Very Dissatisfied	18.75% (n=3)	25% (n=4)	25% (n=4)
Satisfied/Very Satisfied	81.25% (n=13)	75% (n=12)	75% (n=12)

Table 14. Participants' satisfaction with support for oral health problems throughout head and neck cancer treatment.			
	Before Treatment	**During Treatment**	**After Treatment**
Dissatisfied/Very Dissatisfied	12.5% (n=2)	18.75% (n=3)	31.25% (n=5)
Satisfied/Very Satisfied	81.25% (n=13)	81.25% (n=13)	68.75% (n=11)

Overall, participants were satisfied with their oral care education and support for

problems throughout treatment. The most dissatisfaction came following treatment with support

for oral health problems, with 31.25% (n=5) patients experiencing dissatisfaction.

Tables 15-17 correlate the oral care education satisfaction and support for oral health

problems scores to number of oral care symptoms before, during, and after treatment. The

correlation between number of oral symptoms and oral education satisfaction before cancer

treatment was statistically significant (r=-.59, p=.008). Although this correlation was the only

statistically significant correlation, there was still a general trend that increased number of oral

symptoms led to lower levels of satisfaction for both oral education and oral health problems was

found.

Table 15. Individual Participant's Number of Initial Oral Symptoms, Initial Oral Education Satisfaction, and Initial Satisfaction of Support for Oral Health Problems Before Head and Neck Cancer Treatment.			
Participant Name (Site of Cancer)	**Number of Oral Symptoms Before Cancer Treatment**	**Oral Education Satisfaction Before Cancer Treatment**	**Satisfaction Support for Oral Health Problems Before Cancer Treatment**
		(0=Very Dissatisfied, 1 = Somewhat Dissatisfied, 3=Somewhat Satisfied, 4=Very Satisfied)	
BOT1	3 - Mouth Pain, Mouth Bleeding, Mouth Sores	1	3
BOT2	0	4	4
Salivary Palate	0	3	0
Larynx	0	4	4
BOTLarynx	2 - Fungal Infection, Difficulty Swallowing	1	3
BOT3	0	4	4
Larynx2	1 - Difficulty Swallowing	3	3
Salivary2	0	4	4
Salivary3	0	4	4
Larynx3	2 - Dry Mouth, Difficulty Swallowing	3	3
PalateSinus	1 - Mouth Pain	4	4
Tongue1	0	4	N/A
Tongue2	1 - Dry Mouth	4	0

Tonsil1	2- Mouth Pain, Mouth Bleeding	1	3
Tonsil2	0	4	3
Nasopharynx	0	3	3
Correlation/Significance	Mean = .75	Spearman Correlation with number of symptoms r = -.59** (one-tailed significance p=.008**)	Spearman Correlation with number of symptoms r = -.40 (one-tailed significance p=.07)

Table 16. Individual Participant's Number of Initial Oral Symptoms, Initial Oral Education Satisfaction, and Initial Satisfaction of Support for Oral Health Problems During Head and Neck Cancer Treatment.

Participant Name (Site of Cancer)	Number of Oral Symptoms During Cancer Treatment	Oral Education Satisfaction During Cancer Treatment	Satisfaction Support for Oral Health Problems During Cancer Treatment
		(0=Very Dissatisfied, 1 = Somewhat Dissatisfied, 3=Somewhat Satisfied, 4=Very Satisfied)	
BOT1	3 - Dry Mouth, Mouth Pain, Difficulty Swallowing	3	3
BOT2	4 - Mouth Pain, Mouth Sores, Fungal Infection, Difficulty Swallowing	4	4
Salivary Palate	4 - Dry Mouth, Mouth Pain, Difficulty Swallowing, Other Infection	1	0
Larynx	0	4	4
BOTLarynx	4 - Dry Mouth, Mouth Pain, Fungal Infection, Difficulty	1	3
BOT3	3 - Dry Mouth, Mouth Pain, Difficulty Swallowing	4	4
Larynx2	3 - Dry Mouth, Mouth Sores, Difficulty Swallowing	3	3
Salivary2	2 – Dry Mouth, Mouth Pain	4	4
Salivary3	5 - Dry Mouth, Mouth Pain, Mouth Bleeding, Mouth Sores, Difficulty Swallowing	4	4
Larynx3	4 - Dry Mouth, Mouth Pain, Mouth Sores, Difficulty Swallowing	3	3
PalateSinus	5 - Dry Mouth, Mouth Pain, Mouth Bleeding, Mouth Sores, Difficulty Swallowing	4	4
Tongue1	2- Fungal Infection, Difficulty Swallowing	4	4
Tongue2	5 – Dry Mouth, Mouth Pain, Mouth Sores, Fungal Infection, Difficulty Swallowing	0	0

Tonsil1	4 - Dry Mouth, Mouth Sores, Mouth Bleeding, Difficulty Swallowing	3	3
Tonsil2	2 - Mouth Pain, Mouth Sores.	1	1
Nasopharynx	0	3	3
Correlation/ Significance	Mean = 3.125	Spearman Correlation with number of symptoms r = -.17 (one-tailed significance p=.26)	Spearman Correlation with number of symptoms r = -.14 (one-tailed significance p=.31)

Table 17. Individual Participant's Number of Initial Oral Symptoms, Initial Oral Education Satisfaction, and Initial Satisfaction of Support for Oral Health Problems After Head and Neck Cancer Treatment.

Participant Name (Site of Cancer)	Number of Oral Symptoms After Cancer Treatment	Oral Education Satisfaction After Cancer Treatment	Satisfaction Support for Oral Health Problems After Cancer Treatment
		(0=Very Dissatisfied, 1 =Somewhat Dissatisfied, 3=Somewhat Satisfied, 4=Very Satisfied)	
BOT1	3 - Dry Mouth, Mouth Pain, Difficulty Swallowing	3	3
BOT2	3 - Dry Mouth, Mouth Sores, Difficulty Swallowing	4	0
Salivary Palate	3 - Dry Mouth, Mouth Bleeding, Difficulty Swallowing	1	0
Larynx	0	4	4
BOTLarynx	4 - Dry Mouth, Mouth Bleeding, Fungal Infection, Difficulty Swallowing	1	3
BOT3	0	3	4
Larynx2	3 – Dry Mouth, Mouth Sores, Difficulty Swallowing	3	1
Salivary2	1 - Dry Mouth	4	4
Salivary3	5 – Dry Mouth, Mouth Pain, Mouth Bleeding, Mouth Sores, Difficulty Swallowing	4	4
Larynx3	3 - Dry Mouth, Mouth Pain, Mouth Sores	3	3
PalateSinus	5 - Dry Mouth, Mouth Pain, Mouth Bleeding, Mouth Sores, Difficulty Swallowing	4	4
Tongue1	3 - Dry Mouth, Mouth Pain, Mouth Sores	4	4
Tongue2	5 - Dry Mouth, Mouth Pain, Mouth Sores, Fungal Infection, Difficulty Swallowing	1	0
Tonsil1	3 - Mouth Sores, Difficulty Swallowing, Other Infection	3	3

	4 - Dry Mouth, Mouth Pain, Mouth Sores, Difficulty Swallowing		
Tonsil2		1	1
Nasopharynx	0	3	3
Correlation/ Significance	Mean = 2.81	Spearman Correlation with number of symptoms r = -.21 (one-tailed significance p=.22)	Spearman Correlation with number of symptoms r = -.24 (one-tailed significance p=.19)

Chapter V

Discussion

Summary of Results

Importance and Benefit of Oral Care

Participants were asked how they felt about oral care statements regarding overall oral care importance throughout treatment, as well as how their oral care contributes to other complications such as cardiovascular disease, pneumonia, or mucositis. While a majority of participants believed that oral care was important (81%), approximately 40% of respondents had minimal or no understanding of oral care's relationship to aspiration pneumonia or cardiovascular disease. Participants were "somewhat" aware of the importance and health benefits of oral care as it related to specific conditions; therefore, further education is imperative.

Similarly, other disciplines also found that patients had limited awareness of the importance of oral health and lacked proper hygiene habits, including spinal cord injuries, cardiovascular disease and diabetes (Sullivan, 2012; Eldarrat, 2011; Sanchez et al., 2017). This limited awareness indicates additional education can be beneficial for all individuals in their future oral health practices. The provision of oral health education can also influence patients' perceptions. One study from Devadas Nakre & Harikiran (2013) found that oral health education programs can change the knowledge and attitudes of participants, even after a follow-up period of up to 6 years. Additionally, utilization in dental services increased following their oral education program. In the current study, many patients knew the importance of oral care, but their perception of oral care practices relating to specific conditions was low. Nevertheless, health care providers can have an impact on patient's practices. Patients have been found to respond to recommendations by health care providers regarding pre-treatment dental evaluations

(Epstein, et al., 2018). Further education can affect the knowledge and attitudes, as well as practices of patients. The current study found that patients were only somewhat aware of the importance of oral care as it relates to conditions such as aspiration pneumonia or cardiovascular disease, despite the knowledge that oral care is important. However, if patients are exposed to education regarding these conditions and are willing to respond to recommendations by educators, further education has the power to considerably impact a patient's oral care practices.

Initial Oral Health Education vs Practices

For 14 individual practices, participants were asked about the amount of education (Fully explained or some education) they received on the topic as well as how often they implemented (1 or more times per day) the practice. Notable topics lacking education included use of fluoride, mouth rinses or "magic mouthwash", and low-level laser therapy. The only positive practice to have a higher amount of implementation (81.25%) than education (62.5%) was brushing your teeth/soaking your dentures. Notably, of those who reported not brushing their teeth daily, one participant had no teeth or dentures while the other two indicated they had only brushed their teeth 2-3x/wk during the five years prior. Oil-based lip balm also had higher implementation (12.5%), than education (6.25%), despite its negative impact. Some practices were not highly implemented, despite education received on the topic. However, some of the decreases such as use of artificial saliva, saltwater mouth rinses, and magic mouthwash solution, could be due to the fact that patients were not yet experiencing the side effects which would require implementation of the practices (e.g., they had not experienced dry mouth so they did not have to use artificial saliva).

Generally, a higher level of initial oral health education led to higher implementation of practices. The Pearson correlation between initial oral health education and initial oral health

practices r=.41 (one-tailed significance p=.06) was moderate and approached significance. Although there was a trend, three patients had much lower education scores than practices scores, which did not fit the pattern. Consequently, the correlation was moderate and approaching significance, but remained not statistically significant.

Other studies have also found connections between oral health education and practices. Devadas Nakre & Harikiran, 2013 found that oral health education in a range of sample sizes was effective in improving oral health related practices. Their study also evaluated various forms of educating, including instruction, demonstration and lectures.

Initial Oral Health Symptoms and Education

Of the 16 participants, the most prevalent symptoms throughout all stages of radiation treatment included dry mouth, mouth pain, mouth sores, and difficulty swallowing. When comparing these initial symptoms and others to the level of education provided prior to treatment, there is a noticeable lack of education provided to those experiencing symptoms. When patients had no symptoms prior to treatment, they received a higher level of education (21.50) than those who were experiencing symptoms (15.00). Despite the fact that these patients were already experiencing painful oral care symptoms which may worsen during and following treatment, they are not receiving the education they need to correct their behavior. The correlation between education and symptoms was not evident (p=.27), but there was still an impactful trend. Alarmingly, patients who required more education in order to curb their pre-existing symptoms and prevent additional symptoms were not receiving the education. In fact, key pieces of education directly related to the patients symptoms were not provided for many patients. Only one patient out of the seven who experienced initial symptoms had a majority of key education strategies provided to them to help alleviate their pre-treatment symptoms. The

other six patients had a wide range of symptoms and received little to no education on how to relieve their symptoms, in some cases missing up to nine key strategies.

Other studies have found many oral complications impact oral care and could be relieved by education. According to Epstein et al., 2018, of 70 patients who completed the survey, 52 or 74.2% reported experiencing oral complications, yet only 47 reported notifying their cancer team of the issues. If health care providers are unaware of the symptoms that patients are facing, they are unable to provide the key education strategies which could help alleviate their symptoms. In order to reduce symptoms, key education strategies can be implemented. Dental prevention must include regular daily fluoride applications and patients should be instructed in daily atraumatic tooth brushing, bland oral rinses, flossing and fluoride gel applications, as well as management of mucositis (Samim et al., 2016). To minimize the severity of oral problems, the studies emphasize daily oral care, treatment of xerostomia with saliva substitute and hydration, and low-level laser therapy, nystatin, acyclovir, respectively, for the prevention and treatment of oral mucositis, oral candidiasis, and infection by herpes simplex virus. (Carvalho et al., 2017). Therefore, key education strategies are imperative in order to help alleviate a patient's symptoms, yet healthcare providers can not help patients if they are unaware of the symptoms they are experiencing.

Oral Symptoms, Oral Health Education Satisfaction and Support for Oral Health Problems

Generally, satisfaction in both education and support decreased as treatment progressed. Prior to treatment, 81.25% of patients were satisfied with both their oral care education and support for oral health problems. Following treatment, these numbers fell to 75% and 68.75%, respectively. Oral health symptoms also increased as treatment progressed as well. Therefore, there was a pattern between the satisfaction in oral health education and support for oral health

problems decreasing as symptoms increasing. The correlation between number of oral symptoms and oral education satisfaction before cancer treatment was statistically significant (r=-.59, p=.008). The correlation between satisfaction with support for oral health problems and number of symptoms before treatment was approaching significance as well (r=-.40, p=.07). Therefore, if a participant experienced increased number of oral symptoms prior to cancer treatment, they had lower satisfaction in their oral education and support for oral health problems.

Epstein et al., 2001 found that reduction in side effects of treatment may be the best means of reducing psychosocial morbidity in the long-term survivor. Furthermore, general life satisfaction improved with time after treatment and was related to pain, difficulty with speech and dysphagia. All in all, relieving a patient's symptoms through dental education can influence their lives in the long-term.

Although the current study did not find correlations with oral symptoms and oral education satisfaction or satisfaction with support during or after treatment, meaningful trends were still found. Increased number of oral symptoms generally led to lower levels of satisfaction with oral education and satisfaction in support for oral health problems. However, some patients remained very satisfied with their education and support throughout all treatment periods despite having multiple symptoms during and after treatment. One possible explanation for their satisfaction could be that these patients did not recognize the connection between their oral habits and the symptoms they were experiencing.

According to Epstein et al., 2018, 20.6% being either "dissatisfied" or "completely dissatisfied" with their dental or oral care during therapy. The current study found that during treatment 25% of treatments were "dissatisfied" or "very dissatisfied" with oral care education while 18.75% of patients were dissatisfied with support for oral health problems. Although these

two studies looked at different types of satisfaction during radiation therapy, both studies found that some patients experience dissatisfaction with oral care.

Amount and Satisfaction of Oral Health Education based on Number of Professionals

The current study found that more professionals must be involved in providing oral care education. Participants were asked about the education provided on multiple topics as well as how satisfied they were with their initial education. Generally, the mean educational scores rose considerably from when no professionals were involved to when three or more professionals were involved. The same upward trend can be found when looking at satisfaction with oral health education, which also increased as additional professionals were involved. While there was no significance found between the number of professionals and the amount of education (p=.17) or satisfaction (p=.23), there is a meaningful pattern. The lack of statistical significance may be due to the small sample size. However, the trend is encouraging. The amount of education and satisfaction with education generally increases as the number of professionals providing education increases.

Other studies have found connections between education or satisfaction and practices of oral health education. Epstein et al., 2018 indicates that clients were receiving insufficient or no oral care as part of their treatment, often caused by inadequate dental service, inability to identify a provider, and lack of communication between dental providers and cancer treatment. Therefore, the provision of oral care education is inconsistent and inadequate, which may lead to a lack of implementation if patients are unaware of the consequences of improper oral care habits. Even though cancer patients may be inclined to discontinue oral hygiene due to discomfort, the avoidance of basic hygiene results in increased microbial loads, gingival/oral

inflammation and risk of infections (Samim et al., 2016). Thus, maintenance of oral hygiene should be encouraged.

The current study also found a considerable gap between specialists seen throughout radiation therapy compared to those who provided education. Patients need multiple professionals providing education to ensure proper education as well as increased satisfaction. This interdisciplinary team can be built of a multitude of professionals, including SLPs as well as ENTs, cancer doctors, nurses, dentists and hygienists. The current study found that around half of the specialists seen throughout education were providing education (46% prior, 58% during, 45% after), with the majority of education coming from cancer center doctors and nurses as well as dentists. Epstein et al., (2018) found that 72.6% of participants received dental education prior to cancer therapy, with the most education being provided by dental providers followed by medical staff from the cancer center. Both studies found that the majority of oral health education came from cancer center medical staff as well as dentists.

Although some patients did receive education from cancer center staff or dentists, the need for more interprofessional communication, education, and practice can be found throughout an abundance of literature (Epstein et al., 2018; Nakre & Harikiran 2013; Carvalho, et al., 2017; Samim et al., 2016; Epstein et al., 2001; Epstein et al., 2020). Ensuring that multiple professionals are involved in providing education can allow for education to remain consistent and relevant to symptoms. Oral and dental care is impacted by the patient's initial oral and dental status, as well as the specific cancer location, type and its treatment; thus, close communication between the dental professional and the oncology team is required for appropriate therapy (Samim et al., 2016). Therefore, ensuring a multidisciplinary approach to education is imperative. When education is not provided consistently, patients may not be willing to prioritize

oral care. According to Epstein et al., 2018, the frequency of post-treatment follow-up was low and need for post-treatment extractions were high indicating the patient's need for post-treatment care. Overall, an increased need for interprofessional communication and education can influence a patient's amount of education, as well as their satisfaction with education.

Clinical Implications

Patients with head and neck cancer are seen by speech-language pathologists, who have an opportunity to play a role in interdisciplinary education. According to Epstein, et al., 2018, 33% of patients sought rehab from an SLP for speech and 42% for swallowing. In our current study, 37% of patients saw a speech-language pathologist prior to radiation therapy, as well as 25% during and after radiation. Therefore, speech-language pathologists have an opportunity to provide education, yet more interprofessional practice is needed in order for educators to give relevant, accurate information (Epstein et al., 2018; Samim et al., 2016; U.S. Public Health Service, 2000; IOM 2011a; IOM 2011b).

If speech-language pathologists are aware of the oral care education strategies that are beneficial for head and neck cancer patients, they can provide relevant education based on patient's potential complications. Oral and dental care is impacted by the patient's initial oral and dental status, as well as the specific cancer location, type and its treatment; thus, close communication between the dental professional and the oncology team is required for appropriate therapy (Samim, et al., 2016). As a part of a multidisciplinary oncology team, speech-language pathologists need to be aware of what kinds of education must be provided based on patients oral and dental status as well as cancer status. In order to do so, speech-language pathologists themselves must be educated on how to provide the most relevant and comprehensive education. ASHA's Scope of Practice lists educating individuals who are at risk

for aspiration pneumonia oral hygiene techniques as part of a prevention and wellness program, but does not detail what these techniques may be (ASHA, 2016). Therefore, speech-language pathologists can benefit from their own education on how to provide the best quality oral care advice to those with head and neck cancer. Multiple studies have found the need for additional oral care education regarding basic oral care information, such as use of fluoridated toothpaste and soft toothbrushes, lubrication of mouth and lips, and use aqueous chlorhexidine .12% solution but especially in regards to fluoride and treatment for xerostomia (dry mouth) (Epstein et al., 2018) (Nakre & Harikiran, 2013) (Carvalho et al., 2017) (Samim et al., 2016) (Epstein et al., 2001) (Epstein et al., 2020). Once speech-language pathologists are aware of the recommendations they should be suggesting for those with head and neck cancer, these patients will begin to receive the relevant and comprehensive education they need more consistently.

Overall, findings demonstrate the need for a more coordinated and enhanced multidisciplinary approach relating to oral supportive care in the head and neck cancer patient population. (Epstein et al., 2018). Additionally, speech-language pathologists can advocate for patient support related to oral care symptoms to ensure the best care for patients as well as the least risk for aspiration pneumonia. Devadas Nakre & Harikiran (2013) has found that providing education can improve patient's perception of oral care for a follow up period of up to six years. Speech-language pathologists can play a role in providing this oral supportive care for head and neck cancer patients going forward.

Limitations and Future Research Needed on Topic

Further research on oral care education in regards to head and neck cancer is needed in order to provide patients with consistent, quality education from an interdisciplinary team of professionals. One limitation of this study was a small sample size of 16 participants. Of the

initial 73 respondents, only 16 provide sufficient data for analysis and 5 were fully completed. A larger study with a further variety of participants would allow for more comprehensive data regarding knowledge, perception, and implementation of oral care.

The current study provided a glance into the lack of education received by head and neck cancer; however, additional research is needed to develop a comprehensive multidisciplinary education approach. Future studies could also include the perspective of the professionals providing oral health education and their knowledge and perceptions of their role within multidisciplinary education. In addition, research which examines the role of caregivers or significant others could be pursued, as education has been found to be more effective when significant others were involved (Nakre & Harikiran, 2013). Furthermore, patients could face barriers to oral health education. Many factors could be influencing an individual's ability to receive oral care education, including poor access to dental care, lack of transportation or lack of financial support (IOM 2011a, IOM 2011b). Research regarding the barriers to oral health care could provide an opportunity to improve access to education to prevent oral health complications. In addition to barriers, research could also focus on the modalities of education to discover whether written or spoken education leads to higher amounts of retention. These modalities could vary depending on preferences and ways of learning, as well as age and other characteristics. All in all, future research is needed in order to evaluate the effectiveness of a multidisciplinary systematic oral health education program on the oral health practices of patients with head and neck cancer.

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Appendix A

Oral Care Education and Practices in Head and Neck Cancer Survey

Informed Consent: We are interested in understanding how you were provided <u>education</u> about oral care (e.g., brushing your teeth, using mouthwash, etc.) by your healthcare team after you were diagnosed with head and neck cancer. We are also interested in <u>your oral care routine/habits</u> before and after you were diagnosed with head and neck cancer. This information will help us research ways to improve oral care education for patients with head and neck cancer. For this study, you will complete a survey about your experience. Your responses will be kept confidential. If you choose to provide personal information to be contacted with the results of the study and/or to be contacted for future studies, personal identifiers on any hard copies will be removed and kept in a separate location from other survey information provided. SEPSEP

The survey should take you around 20-30 minutes to complete. Your participation in this research is voluntary. You have the right to withdraw at any point during the study without being penalized. If you would like to request materials explaining current research related to oral health and hygiene as a benefit of participating in this study, please feel free to contact the Principal Investigator. The Principal Investigator of this study, Lynne Barcus, can be contacted at lnbarcus@eiu.edu or 217-549-0407. We are hoping for at least 20-30 individuals who have completed radiation therapy for head and neck cancer within the past year to complete this survey.

By clicking the button below, you acknowledge:

      Your participation in the study is voluntary

      You are 18 years of age

      You are aware that you may choose to terminate your participation at any time, for any reason, without being penalized

            -I consent, begin the study

            -I do not consent, I do not wish to participate

Are you willing to be contacted for future studies?

      Yes

      No

If yes, please provide any or all of the following:

      Name

      Email

      Phone Number

Would you like to receive the results of the study?

      Yes

      No

If yes, please provide any or all of the following:

      Name

      Email

      Phone Number

Q1 Where did you hear about this survey?

- Sarah Bush Lincoln Health Center
- Terre Haute Regional Hospital
- Carle Foundation Hospital

- Facebook
- Other (please specify) _____

Q2 Do you wear dentures?

- Yes
- No

Q3 Do you have teeth?

- Yes
- No

The following questions relate to information about your oral care habits:

O4 Which best describes the frequency of your <u>visits to the dentist</u> during the **5 years prior to** your diagnosis of head and neck cancer?

- · 0= rarely/not at all
- · 1= every two to three years
- · 2= typically once per year
- · 3= more than once per year

Q5: The following questions involve participation in daily habits:

Do you...	In the Past	Rarely/Not at all	2-3 times/week	Once a day	More than once a day
Drink alcohol?					
Use tobacco?					
Eat sugary foods (e.g. candy, desserts, soda, etc.)?					
Eat starchy foods (e.g. bread, pastries, etc.)					
Eat yogurt?					

The following questions relate to information about your <u>oral care habits</u> during three different time periods (e.g., **before** you started radiation therapy, **during** radiation therapy, and **after** you completed radiation therapy)

Q6 Please use the following rating scale for the questions below: 0= I do not know 1 = rarely/notat all 2= two or three times per week 3 = typically once per day 4= more than once per day

	Before you started radiation therapy?	**During** the weeks you were undergoing radiation therapy?	**After** you completed radiation therapy?
How often did you **brush your teeth or soak/brush dentures**			
How often did you **brush your tongue**			
How often did you **floss**			
How often did you **use mouthwash**			
How often did you **use mouth and/or lip moisturizer**			
How often did you **use artificial saliva**			
How often did you **use fluoride**			

How often did you use foam swabs *without* a mouthwash solution ___instead of___ brushing your teeth or cleaning your dentures			
How often did you use foam swabs *with* a mouthwash solution ___instead of___ brushing your teeth or cleaning your dentures			
How often did you **use lemon-glycerin swabs**			
How often did you **use saltwater and baking soda mouth rinses**			
How often did you **use .12 chlorhexidine mouthwash**			
How often did you **use a "magic mouthwash" solution**			
How often did you **use oil-based lip balms**			

How often did you **avoid Sodium Lauryl Sulfate (SLS) in toothpaste**			
How often did you **use alcohol-based mouthwashes**			

Q7 Did you complete daily oral care independently during radiation therapy or did a care provider give assistance?

- · Independently
- · Assistance from a care provider

Q8 Do you currently complete daily oral care independently?

- · Yes
- · No

Q9 What was your living situation during radiation therapy?

- · Home by yourself
- · Home with spouse or family
- · Assisted living
- · Skilled nursing facility

Q10 What is your current living situation after radiation therapy?

- · Home by yourself
- · Home with spouse or family
- · Assisted living
- · Skilled nursing facility

Q11 Did you use a G-tube for any of your nutrition and hydration before, during, or after radiation therapy (**select all that apply**)?

- · Before undergoing radiation therapy
- · During radiation therapy
- · After undergoing radiation therapy

Q12: Please indicate the degree to which you agree with general statements about oral care

	Not at All	Minimal/Undecided	Somewhat	Very Much
Oral care is important for individuals during and after undergoing radiation therapy for head and neck cancer				
Poor oral care can contribute to cardiovascular disease				
Poor oral care may increase risk of pneumonia for individuals with difficulty swallowing				
Poor oral care can increase risk of mucositis (mouth sores) and infections during radiation therapy				

Q13 The following questions ask about different specialists relating to oral care education:

	Dentist outside of cancer center	Dental Hygienist outside of cancer center	Cancer center dentist	Cancer center nurse	Cancer center radiation doctor	Ear nose and throat doctor (ENT)	Speech Language pathologist	other
Which specialist(s) did you see BEFORE radiation therapy								
Who talked to you about oral care BEFORE radiation therapy								
Which specialist(s) did you see DURING radiation therapy								
Who talked to you about oral care DURING radiation therapy								
Which specialists did you see AFTER								

radiation therapy								
Who talked to you about oral care AFTER radiation therapy								

Q 14: Please use the following rating scale for the questions below:

0= no medical or dental professional discussed this with me

1= someone might have mentioned this or it was only in a handout

2= some information was provided by a medical or dental professional

3= information was fully explained by a medical or dental professional

Did a medical or dental professional:	Before you started radiation therapy?	During the weeks you were undergoing radiation therapy?	After you completed radiation therapy?
Talk to you about getting a **dental examination?**			
Talk to you about **brushing your teeth?**			
Talk to you about **brushing your tongue?**			
Talk to you about **flossing your teeth?**			
Talk to you about **using mouthwash?**			

Talk to you about **mouth and lip moisturizer?**			
Talk to you about **artificial saliva?**			
Talk to you about **using fluoride?**			
Talk to you about **not using lemon-glycerin swabs?**			
Talk to you about **saltwater and baking soda rinses?**			
Talk to you about **"magic mouthwash" compound solutions?**			
Talk to you about **avoiding oil-based lip balms?**			
Talk to you about **avoiding sodium lauryl sulfate (SLS) in toothpaste?**			
Talk to you about **avoiding alcohol-based mouthwashes?**			

Talk to you about **low-level laser therapy?**			
Talk to you about **caring for your dentures?**			

Q 15: How satisfied were you with the following:

	Completely Satisfied	Somewhat satisfied	Somewhat dissatisfied	Completely dissatisfied
Your own oral health				
BEFORE treatment				
DURING treatment				
AFTER treatment				
Oral Care Education provided to you				
BEFORE treatment				
DURING treatment				
AFTER treatment				
The support healthcare professionals provided when encountering oral health problems				
BEFORE treatment				
DURING treatment AFTER treatment				

Q16 check any of the following symptoms which apply:

- Dry Mouth
- Mouth Pain
- Mouth Bleeding
- Mouth sores
- Fungal infection
- Difficulty swallowing
- Pneumonia
- Other mouth or throat infection
- I did not have any symptoms

Q17 What was your primary cancer diagnosis?

- · Adenocarcinoma
- · Squamous Cell Cancer
- · Salivary Gland Tumor
- · Mucoepidermoid Carcinoma
- · Basal Cell Cancer
- · Other (please specify)

Q18 What stage was the tumor when you began radiation therapy?

- · Stage 1
- · Stage 2
- · Stage 3
- · Stage 4
- · Don't know

Q19 When were you diagnosed with head and neck cancer? (MM/DD/YYYY)

Q20 Where was the location of the cancer (select all that apply)?

- · Lip
- · Tongue
- · Cheek
- · Roof of mouth
- · Gum
- · Throat
- · Base of tongue
- · Larynx (voice box)
- · Nasopharynx
- · Sinus
- · Tonsil
- · Salivary gland

Q21 What types of therapy(s) did you have for head and neck cancer (select all that apply)?

- · Surgery
- · Radiation therapy

- ·   Chemotherapy
- ·   Don't know
- ·   Other (please specify)

Q22 What date did you complete radiation therapy? (MM/YYYY)

Q23 What is your present cancer status?

- ·   Cured/remission
- ·   Evidence of cancer
- ·   Recurrence of cancer
- ·   Don't know/unsure

Q24 Have you had cancer anywhere else in your body?

- ·   Yes
- ·   No

Appendix B

Select Individual Results by Topic

Appendix Table 2.1. Comparison of Education Topics to Practices Response by 5 participants before, during and after cancer treatment for Head or Neck Cancer.						
	BEFORE RADIATION		**DURING RADIATION**		**AFTER RADIATION**	
	EDUCATION (#14)	PRACTICES (#6)	EDUCATION (#14)	PRACTICES (#6)	EDUCATION (#14)	PRACTICES (#6)
Specific Positive Practices and Education Topics Question 6 and 14	a. BOT 1 (3) b.BOT2 (4) c.BOT3 (9) d.Larynx (6) e.Nasophar (20)	BOT 1 BOT2 BOT3 Larynx Nasophar	BOT 1 BOT2 BOT3 Larynx Nasophar	BOT 1 BOT2 BOT3 Larynx Nasophar	BOT 1 BOT2 BOT3 Larynx Nasophar	BOT 1 BOT2 BOT3 Larynx Nasop
Dental Examination	a. Some b. Explained c. Explained d. Explained e. Explained	N/A	a. None b. Explained c. None d. Explained e. Maybe	N/A	a. None b. Explained c. None d. Explained e. Maybe	N/A
Brush your Teeth	a. Maybe b. Explained c. Explained d. Explained e. Explained	a.1x/day b.>1x/day c.>1x/day d.1x/day e.>1x/day	a. None b. Explained c. Explained d. Explained e. Maybe	a.. Rarely b.. 2-3x/wk c.. >1x/day d.. 1x/day e.. Rarely	a. None b. Explained c. None d. Explained e. Maybe	a.. Rarely b.. 1x/day c.. >1x/day d.. 1x/day e.. Rarely
Brush your Tongue	a. No b. No c. Explained d. Explained e. Explained	a.IDK b. Rarely c. Rarely d. 1x/day e.>1x/day	a. None b. None c. Explained d. Explained e. Maybe	a.. IDK b.. >1x/day c.. Rarely d.. 1x/day e.. Rarely	a. None b. None c. None d. Explained e. Maybe	a.. IDK b.. Rarely c.. Rarely d.. 1x/day e.. Rarely
Floss	A. No b. No c. No d. Explained e. Explained	a.Rarely b. Rarely c. Rarely D. 1x/day e. 1x/day	a. None b. None c. None d. Fully e. Maybe	a.. IDK b.. Rarely c.. Rarely d.. 1x/day e.. IDK	a. None b. Explained c. None d. Explained e. Maybe	a.. IDK b.. >1x/day c.. Rarely d.. 1x/day e.. IDK
Use mouth and/or lip moisturizer	a. Maybe b. No c. Explained d. Explained e. Explained	a.2-3x/wk b. Rarely c. Rarely d. Rarely e. 1x/day	a. None b. None c. Fully d. Fully e. Maybe	a.. 1x/day b.. >1x/day c.. Rarely d.. Rarely e.. >1x/day	a. None b. Explained c. None d. Explained e. Maybe	a.. 2-3x/wk b.. >1x/day c.. Rarely d.. Rarely e.. >1x/day
Use artificial saliva	a. Maybe b. Explained c. None d. None e. Explained	a. Rarely b. Rarely c. Rarely d. Rarely e. Rarely	a. None b. Explained c. None d. None e. Maybe	a.. IDK b.. Rarely c.. Rarely d.. Rarely e.. IDK	a None b. Explained c. None d. None e. Maybe	a.. IDK b.. >1x/day c.. Rarely d.. Rarely e.. IDK
Use fluoride	a. None b. Explained c. Some d. None e. Explained	a. Rarely b. IDK c. Rarely d. Rarely e. Rarely	a. None b. Explained c. Explained d. None e. None	a.. IDK b.. IDK c.. Rarely d.. Rarely e.. IDK	a. None b. Explained c. Maybe d. None e. None	a.. IDK b.. >1x/day c.. Rarely d.. Rarely e.. IDK
Foam swabs *with* a mouthwash solution *instead of* brushing your teeth or cleaning your dentures	N/A	a. Rarely b. Rarely c. Rarely d. Rarely e. Rarely	N/A	a.. >1x/day b.. Rarely C.. Rarely d.. Rarely e.. IDK	N/A	a.. 1x/day b.. Rarely c.. Rarely d.. Rarely e.. IDK
Saltwater/baking soda mouth rinses	a. Maybe b. None c. Some d. None e. Explained	a..Rarely b. Rarely c. Rarely d. Rarely e. Rarely	a. None b. None c. Fully d. None e. Maybe	a.. >1x/day b.. >1x/day c.. >1x/day d.. Rarely e.. 2-3x/wk	a. None b. None c. None d. None e. Maybe	a.. 1x/day b.. Rarely c.. >1x/day d.. Rarely e.. 1x/day

Use a .12 chlorhexidine mouthwash	a. None b. None c. None d. None e. None	a. Rarely b. IDK c. Rarely d. Rarely e. Rarely	a. None b. None c. None d. None e. None	a.. >1x/day b.. IDK c.. Rarely d.. Rarely e.. IDK	a. None b. None c. None d. None e. None	a.. 2-3x/wk b.. IDK c.. Rarely d.. Rarely e.. IDK
Use a "magic mouthwash" solution	a. None b. None c. None d. None e. None	a. Rarely b. Rarely c. Rarely d. Rarely e. Rarely	a. None b. None c. None d. None e. None	a.. Rarely b.. Rarely c.. Rarely d.. Rarely e.. IDK	a. None b. None c. None d. None e. None	a.. Rarely b.. Rarely c.. Rarely d.. Rarely e.. IDK
Low-level laser therapy	a. None B .None c. None d. None e. None	N/A	a.None b. None c. None d. None e. None	N/A	a.. None b. None c. None d. None e. None	N/A
Avoid Sodium Lauryl Sulfate (SLS) in toothpaste	a. None b. None c. None d. None e. None	a. IDK b. IDK c. Rarely d. Rarely e. Rarely	a. None b. None c. None d. None e. None	a.. IDK b.. IDK c.. Rarely d.. Rarely e.. IDK	a. None b. None c. None d. None e. None	a.. IDK b.. IDK c.. Rarely d.. Rarely e.. IDK

Individual Analysis of symptoms, education, and practices before, during, and after treatment for 5 participants.

Appendix Table 2.1 compares Education Topics provided to practices by 5 participants before, during and after cancer treatment for Head or Neck Cancer. The 5 tables below give a detailed look at each of these 5 participants' oral health problems, education provided, missed opportunities for education, and patient satisfaction with their oral health, oral health education, and oral health support.

Table 2.2 BOT 1, Stage 4 SCC, Surgery and Radiation Therapy, Cured/Remission				
Symptoms Before	Total Education Score/Total Practice Score	Related Key Education Provided	Related Key Education Not Provided	Patient satisfaction
Mouth pain, mouth bleeding, mouth sores *G-tube	9/10	Saltwater and baking soda rinses (some)	Brush teeth (maybe) Brush tongue (none) Mouthwash (maybe) Lip moisturizer (maybe) Avoid alcohol-based mouthwashes (maybe, but pt used 2-3x/wk) Fluoride (none) Low-level laser therapy (none)	Oral health: somewhat satisfied Education: somewhat dissatisfied Support for oral health problems: somewhat satisfied

Symptoms During	Total Education Score/Total Practice Score	Related Key Education Provided	Related Key Education Not Provided	Patient satisfaction
Dry mouth, mouth pain, *difficulty swallowing *G-tube	2/19	Saltwater and baking soda rinses (some)	Brush teeth (none) Brush tongue (none) Mouthwash (none) Lip moisturizer (none) Artificial saliva (none) Fluoride (none) Avoid alcohol-based mouthwashes (none) Low-level laser therapy (none)	Oral health: somewhat satisfied Education: somewhat satisfied Support for oral health problems: somewhat satisfied
Symptoms After	**Total Education Score/Total Practice Score**	**Related Key Education Provided**	**Related Key Education Not Provided**	**Patient satisfaction**
Dry mouth, mouth pain, *difficulty swallowing *G-tube	2/14		Brush teeth (none) Brush tongue (none) Mouthwash (none) Lip moisturizer (none) Artificial saliva (none) Fluoride (none) Saltwater and baking soda rinses (none) Low-level laser therapy (none)	Oral health: somewhat satisfied Education: somewhat satisfied Support for oral health problems: somewhat satisfied
*seen by SLP before and after radiation therapy				

Table 2.3 BOT 2, Stage 4 SCC, Radiation Therapy and Chemo Therapy, Cured/Remission				
Symptoms Before	Total Education Score/Total Practice Score	Related Key Education Provided	Related Key Education Not Provided	Patient satisfaction
None reported PO intake	18/8	Brush teeth (fully explained) Lip moisturizer (fully explained) Artificial saliva (fully explained) Saltwater and baking soda rinses (fully explained) Avoid alcohol-based mouthwashes (fully explained)	Mouthwash (none) Brush tongue (none) Floss teeth (none) Fluoride (none) Avoid oil-based lip balms (none, and pt used 2-3x/wk) Low-level laser therapy (none)	Oral health: somewhat dissatisfied Education: very satisfied Support for oral health problems: very satisfied

Symptoms During	Total Education Score/Total Practice Score	Related Key Education Provided	Related Key Education Not Provided	Patient satisfaction
Mouth pain, mouth sores, fungal infection, *difficulty swallowing *G-tube	18/13	Brush teeth (fully explained) Lip moisturizer (fully explained) Artificial saliva (fully explained) Saltwater and baking soda rinses (fully explained) Avoid alcoholbased mouthwashes (fully explained)	Mouthwash (none) Brush tongue (none) Floss teeth (none) Fluoride (none) Avoid oil-based lip balms (none, and pt used >1x/day) Low-level laser therapy (none) Pt also reported using mouth swab without mouthwash or solution instead of brushing teeth.	Oral health: very dissatisfied Education: very satisfied Support for oral health problems: very satisfied
Symptoms After	**Total Education Score/Total Practice Score**	**Related Key Education Provided**	**Related Key Education Not Provided**	**Patient satisfaction**
Dry mouth, mouth sores, *difficulty swallowing *G-tube	24/21	Brush teeth (fully explained) Floss teeth (fully explained) Mouthwash (fully explained) Lip moisturizer (fully explained) Artificial saliva (fully explained) Fluoride (fully explained)	Saltwater and baking soda rinses (none) Avoid oil-based lip balms (none, and pt used >1x/day) Low-level laser therapy (none)	Oral health: very dissatisfied Education: very satisfied Support for oral health problems: very dissatisfied
*seen by SLP before, during, and after radiation therapy				

Table 2.4 Larynx, Stage 4 SCC, Surgery and Radiation Therapy, Cured/Remission (Dentures)				
Symptoms Before	**Total Education Score/Total Practice Score**	**Related Key Education Provided**	**Related Key Education Not Provided**	**Patient satisfaction**
None reported *G-tube	18/14			Oral health: very satisfied Education: very satisfied Support for oral health problems: very satisfied

Symptoms During	Total Education Score/Total Practice Score	Related Key Education Provided	Related Key Education Not Provided	Patient satisfaction
None reported *G-tube	18/14			Oral health: very satisfied Education: very satisfied Support for oral health problems: very satisfied
Symptoms After	Total Education Score/Total Practice Score	Related Key Education Provided	Related Key Education Not Provided	Patient satisfaction
None reported *G-tube	18/14			Oral health: very satisfied Education: very satisfied Support for oral health problems: very satisfied
*Not seen by a speech-language pathologist				

Table 2.5 BOT 3, Stage 2 SCC, Surgery and Radiation Therapy, Unsure if Cured				
Symptoms Before	Total Education Score/Total Practice Score	Related Key Education Provided	Related Key Education Not Provided	Patient satisfaction
None reported PO Intake	19/11	Brush teeth (fully explained) Brush tongue (fully explained) Mouthwash (fully explained) Saltwater and baking soda rinses (fully explained)	Floss teeth (none) Lip moisturizer (none) Fluoride (none) Avoid oil-based lip balm (none) Avoid alcohol-based mouthwash (none)	Oral health: very satisfied Education: very satisfied Support for oral health problems: very satisfied
Symptoms During	Total Education Score/Total Practice Score	Related Key Education Provided	Related Key Education Not Provided	Patient satisfaction
Dry mouth, mouth pain, *difficulty swallowing PO Intake	18/14	Brush teeth (fully explained) Mouthwash (fully explained) Brush tongue (fully explained) Artificial saliva (fully explained) Saltwater and baking soda rinses (fully explained)	Floss teeth (none) Lip moisturizer (none) Fluoride (none) Avoid oil-based lip balm (none) Avoid alcohol-based mouthwash (none) Low-level laser therapy (none)	Oral health: very satisfied Education: very satisfied Support for oral health problems: very satisfied

Symptoms After	Total Education Score/Total Practice Score	Related Key Education Provided	Related Key Education Not Provided	Patient satisfaction
None reported

PO Intake | 1/14 | | | Oral health: very satisfied
Education: somewhat satisfied
Support for oral health problems: very satisfied |
| *seen by speech-language pathologist during radiation therapy | | | | |

Table 2.6 Nasopharynx, Stage 4, Adenoid Cystic Carcinoma, Surgery and Radiation Therapy, Cured/Remission				
Symptoms Before	Total Education Score/Total Practice Score	Related Key Education Provided	Related Key Education Not Provided	Patient satisfaction
None reported

No g-tube reported | 30/17 | | | Oral health: somewhat dissatisfied
Education: somewhat satisfied
Support for oral health problems: somewhat satisfied |
| Symptoms During | Total Education Score/Total Practice Score | Related Key Education Provided | Related Key Education Not Provided | Patient satisfaction |
| None reported

No g-tube reported | 9/3 | | | Oral health: somewhat dissatisfied
Education: somewhat satisfied
Support for oral health problems: somewhat satisfied |
| Symptoms After | Total Education Score/Total Practice Score | Related Key Education Provided | Related Key Education Not Provided | Patient satisfaction |
| None reported

No g-tube reported | 9/6 | | | Oral health: somewhat dissatisfied
Education: somewhat satisfied
Support for oral health problems: somewhat satisfied |
| seen by speech-language pathologist after radiation therapy | | | | |