THE PERSPECTIVE OF INDIVIDUALS WITH HEAD AND NECK CANCER ON DYSPHAGIA TREATMENT IN THE UNITED STATES

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ABSTRACT

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Dysphagia, or difficulty swallowing, is a common consequence of head and neck cancer (HNC) and its associated treatments. Speech-language pathologists (SLPs) often play an integral role in the rehabilitation of swallowing difficulties for people with HNC. In clinical speech pathology, it is of utmost importance to base treatment decisions on high-quality evidence. One key tenant of evidence-based practice that is often overlooked is the client perspective. To date, limited research has explored the perspectives of individuals with HNC who have received treatment for dysphagia, especially HNC survivors living in the United States (U.S.). To close this gap, the aim of this project is to establish an increased comprehension of the perspectives of individuals with HNC who have been treated for dysphagia. Specifically, the project explores participant perceptions of which elements of dysphagia care led to positive clinical experiences and which elements created barriers to positive experiences. Six individuals participated in individual, semi-structured interviews to share their experiences with HNC and dysphagia treatment. Using interpretative phenomenological analysis, the interview data were coded and analyzed. A set of themes emerged from the recurrent and substantiated ideas within the data. The ability to participate in dysphagia therapy was limited by the physical effects of cancer treatments. Swallowing difficulties caused the participants to experience psychological and emotional reactions. Participants revealed that they had no concerns with accessing treatment financially. However, several individuals were not provided with a speech therapy referral until significant swallowing difficulties developed. Generally, the participants found value in their dysphagia treatments and faced no difficulty accessing speech therapy once they were referred.

Future research directions and clinical implications were provided to improve patient-centered care for individuals with HNC and dysphagia.

This study is dedicated to individuals with head and neck cancer and their loved ones.

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CHAPTER I: INTRODUCTION

Swallowing issues are a common consequence of head and neck cancer (HNC) and its associated treatments (e.g., chemotherapy). Dysphagia can be acute, but it is more likely to endure long-term for those with HNC. As a result, individuals with HNC may continue to seek treatment for dysphagia long after their cancer treatments conclude (Cousins et al., 2012). A speech-language pathologist (SLP) most commonly serves to rehabilitate dysphagia and often plays an integral role in the treatment of individuals with HNC.

Across all areas of speech pathology, including the treatment of people with HNC, clinical interactions must be driven by evidence-based practice (EBP; Greenwell & Walsh, 2021; Limoncello & Ness, 2013; Roberts et al., 2020). To implement high quality EBP, clinicians must incorporate client values and perspectives into assessment and treatment decisions. Unfortunately, limited research has explored the perspectives of individuals with HNC who have received treatment for dysphagia. The research base pertaining to HNC survivors living in the United States is especially underdeveloped. In order to begin closing this gap, this study will investigate the perspectives of people with HNC regarding their experiences as clients receiving dysphagia treatment.

Overview of Head & Neck Cancer: Prevalence, Incidence and Causes.

The seventh most common cancer globally is head and neck cancer. More than 1.1 million people worldwide are diagnosed with HNC each year (Mody et al., 2021). In 2020, approximately 66,000 people were diagnosed with HNC in the U.S. (Siegel, 2020). HNC includes malignant tumors present in the oral cavity, pharynx, larynx, nasopharynx, nasal cavity, paranasal sinus, and hypopharynx (American Speech-Language-Hearing Association, n.d.;

American Cancer Society, 2016). One or more anatomical structures may be impacted by the tumors, which vary in size and type on a case-by-case basis (Mody et al., 2021).

Many etiologies of HNC are known. Some causes include infections (e.g., human papillomavirus), tobacco use, radiation exposure, and occupational exposure (Hashim et al., 2019). The demographics of the HNC population have changed considerably in recent years. In previous decades, tobacco use was the leading cause of HNC (Wyss et al., 2013). Today, fewer individuals are being diagnosed with HNC from tobacco use because the amount of people who use tobacco has decreased considerably (Wyss et al., 2013). For this reason and many others (e.g., improved preventative screenings), cases of cancer have decreased overall. In contrast, the incidence of oropharyngeal cancers has increased. This increase is attributable to the rise of human papillomavirus (HPV) (Chaturvedi et al., 2011). HPV is a group of at least 100 various infections transmitted through skin-to-skin contact, which are predominately transmitted sexually (Bansal et al., 2016). Some of these infections can lead to cancer (e.g., oropharyngeal cancer).

The incidence of HPV is variable across different countries; however, it primarily impacts nations with developed economies (Chaturvedi et al., 2013). According to a report by the Centers for Disease Control (2022), roughly 43,000 individuals in the U.S. have HPV infections, making HPV the most common sexually transmitted infection. Each year, approximately fourteen million new cases of HPV emerge in the U.S. (Centers for Disease Control, 2022). Individuals with HNC caused by HPV are commonly younger than those with HNC caused by other etiologies. With the change of demographics, the population impacted by HNC is younger than in the past. In 2018, 50% of people in the U.S. diagnosed with sexually transmitted infections were between the ages of 15 and 24 (Kreisel, 2021). Generally, this younger population is more likely to have a better prognosis when diagnosed with HNC.

Individuals with a type of cancer called squamous cell carcinoma of the head and neck who test positive for HPV have better chances of survival compared to those who test negative for HPV (Callaway, 2011). Ultimately, an increased number of individuals with HNC survive to experience the long-term effects today when compared to the past. These demographic changes will likely require medical professionals to change the ways in which rehabilitation services are delivered to long-term HNC survivors.

Treatment for HNC

The primary goal of treatment for HNC is to remove all cancerous cells from the individual's body to save their life. Commonly, a group of healthcare professionals provide a multimodal treatment approach including a combination of radiation, chemotherapy, and/or surgery (Ringash, 2015; Wells & King, 2017). Secondary to survival, professionals attempt to maximize the individual's quality of life posttreatment (Hansen et al., 2018; Mehanna et al., 2010).

An individual's access to services, their age, the type of cancer treatments they receive, the location of their tumor, and the size of their tumor can impact their prognosis following cancer treatments (Hansen et al., 2018; Wells & King, 2017). Nonetheless, medical advancements have expanded the treatment options available to individuals with HNC, leading to more successful treatment outcomes (Ringash, 2015). Thus, an increased number of individuals are surviving HNC compared to previous decades (Hajdú et al., 2019; van der Molen et al., 2009). In fact, nearly half of the individuals diagnosed with HNC are expected to live at least five years after their diagnosis (Brockbank et al., 2015). With the increased rate of survival, more individuals live to experience the immediate and long-term effects of cancer and the associated treatment. Given that the population of people who live for many years after having

HNC is increasing, there is an urgent need for researchers to develop interventions that are informed by and in alignment with client perspectives.

As a result of cancer treatments, side effects commonly develop and lessen the quality of life for this population (Banda et al., 2021; Holloway et al., 2005). These side effects often endure for years, and many persist through the remainder of an individual's life. Medical advancements have minimized certain side effects of treatments; however, many problems are unavoidable and commonly persist beyond treatment. Chronic effects can create emotional, physical, and social challenges (Dornan et al., 2021; Ganzer et al., 2015).

Dysphagia: Definition, Causes, Effects and Treatment

Given its role in the process of eating, swallowing is a crucial human biological function. Moreover, eating and drinking are essential components of the psychological, physical, and social domains of living (Dornan et al., 2021; Nund et al., 2014a).

The following structures are used for swallowing: the esophagus, pharynx, larynx, oropharynx, and oral cavity. A minimum of thirty muscles and nerves are coordinated when an individual swallows (Matsuo & Palmer, 2008). A breakdown in any of these structures, nerves, or reflexes may lead to dysphagia. In the U.S., an estimated 3-4% of adults experience swallowing problems each year (Bhattacharyya, 2014; Cho et al., 2015). In addition, dysphagia can lead to aspiration of materials. When materials (e.g., food, saliva) are aspirated into the lungs, an individual is placed at a higher risk of developing aspiration pneumonia, which is an infection of the lungs. Individuals with aspiration pneumonia are at an elevated risk for health-related complications and death (Gupte et al., 2022). Other life-threatening potential consequences of dysphagia include dehydration, malnutrition, and weight loss (Brockbank et al., 2015; Nund et al., 2015).

Due to the complexity of the swallowing function, dysphagia develops secondary to numerous health conditions. Head and neck cancer, strokes, medications, heart failure, and chronic obstructive pulmonary disease are a few of the medical conditions that might lead to dysphagia (Bhattacharyya, 2014). Individuals may experience oral pharyngeal or esophageal dysphagia depending on the anatomical location where the difficulty swallowing manifests. Neurological disorders (e.g., Parkinson disease) commonly lead to oropharyngeal dysphagia (Kwan & Lee, 2019). Difficulties with esophageal motility, structural abnormalities, and inflammation may cause esophageal dysphagia.

Regardless of etiology, dysphagia has been linked to numerous health consequences and lifestyle changes. A reduced quality of life is strongly correlated with dysphagia (Nguyen et al., 2005; Maurer et al., 2011). Dysphagia can cause fatigue, a lack of nutrition, and dehydration (Wilson et al., 2011). Other eating-related difficulties experienced by people with dysphagia include pain, loss of taste, change in taste, xerostomia (i.e., dry mouth), swelling, and burning (Patterson et al., 2015).

Difficulty with eating food, drinking socially, and enjoying meals is strongly associated with difficulties in the emotional and social areas of life (Banda et al., 2021; Nund et al., 2014a). In a study by Pezdirec et al. (2019) approximately 3 out of 4 individuals with HNC experienced negative social implications caused by their swallowing difficulties. In a study by Dornan et al. (2021), individuals with chronic dysphagia and HNC reported experiencing social isolation, which can lead to emotional and psychological challenges.

HNC & Dysphagia

As many as 90% of individuals with HNC face challenges with drinking and eating following treatment (Chan et al., 2019; Crowder et al., 2018). These difficulties may persist for months after cancer treatment is completed. Ranta et al. (2021) found that nearly half of the participants with HNC continued to experience dysphagia one year after finishing chemotherapy or radiation treatments. Other related long-term effects that commonly develop following the treatment for HNC include altered eating patterns, decreased oral consumption, and changed social interactions (Brockbank et al., 2015).

There are many reasons why individuals may develop dysphagia from HNC and its treatment. In the swallowing process, both voluntary and involuntary movements are combined to move food from the mouth to the stomach. Swallowing involves the intricate and complex coordination of nerves and muscles occurring in the oral cavity, pharynx, larynx, and esophagus. Several cranial nerves, including the trigeminal nerve, facial nerve, glossopharyngeal nerve, vagus nerve, and hypoglossal nerve, enable the swallowing function (Florie et al., 2021). A tumor that causes damage to a structure or obstruction within the pharynx, larynx, oral cavity may cause difficulty swallowing (Pauloski, 2008). Additionally, if a tumor damages a cranial nerve involved in swallowing, dysphagia may arise (Florie et al., 2021; Hansen et al., 2018). If an individual with HNC requires surgery to remove tissues associated with swallowing, the altered structures that exist post-surgery may not allow for safe swallowing (Pauloski, 2008). Other cancer treatments using radiation and chemotherapy are known to frequently disturb swallowing functions temporarily and long term due to the damage caused to the nerves and muscles involved in swallowing (Banda et al., 2021; Thankappan et al., 2018).

SLP Role in Dysphagia Treatment

A multi-disciplinary team composed of the patient's physicians, nutritionists, therapists, surgeons, nurses, and social workers collaborate to alleviate the symptoms of HNC and the side effects of its treatment. SLPs play a critical role in these teams, helping clients to manage the eating and swallowing symptoms commonly associated with HNC. Services may be provided before, during, and after their cancer treatment depending on the client's needs (Hansen et al., 2018). Patients may receive speech therapy at a separate facility or may receive their treatments at an interdisciplinary healthcare facility.

After an individual receives an HNC diagnosis, an SLP can provide a range of services prior to receiving radiation, chemotherapy, or surgical treatments (Hansen et al., 2018; Krisciunas et al., 2012). The clinician will likely obtain a baseline measure of an individual's abilities in the areas of swallowing, communication, speech, and cognition (Hansen et al., 2018). The SLP may then counsel the patient to prepare them for upcoming symptoms that may result from medical cancer treatments (e.g., difficulty swallowing). Early, proactive speech therapy reduces the side effects of radiation and chemotherapy (Hansen et al., 2018; Wall et al., 2016). Therefore, to lessen the impact of complications and maximally preserve the swallow function, SLPs commonly introduce preventative exercises to improve postoperative and posttreatment swallowing abilities. The immediate and long-term complications of HNC may be minimized through preventative speech therapy.

Following cancer treatments, SLPs may work to improve an individual's swallowing abilities. Every course of treatment begins with a thorough assessment to determine how best to improve a client's swallowing abilities and maximize the extent to which they can return to pre-cancer eating behavior while at the same time minimizing the dysphagia-related health risks they are exposed to. Common treatment options include:

- Swallowing strategies including postural changes (e.g., chin tuck), swallow maneuvers (e.g., effortful swallow), or behavioral strategies (e.g., taking multiple swallows) may promote safe swallowing abilities (Hansen et al., 2018; Krekeler et al., 2020).
- Swallowing exercises to improve an individual's range of motion, muscle strength, and blood flow related to swallowing (Krisciunas et al., 2012; Logemann, 1998).
- Limiting oral intake to foods and drinks of certain consistencies. Depending on their abilities, some clients may not be able to safely swallow non-modified foods and may benefit from eating pureed foods or drinking thickened liquids (Krekeler et al., 2020).
- Recommending a feeding tube for clients who struggle to take in enough nourishment orally (Patterson et al., 2015).
- Ongoing swallowing assessments to determine the most appropriate clinical recommendations.

Qualitative Studies of HNC and Dysphagia

One avenue for investigating clients' perspectives is through qualitative research studies that enable SLPs to develop better understandings of patient perspectives and beliefs. Clinicians can use this information to inform the development of patient-centered approaches to intervention.

The majority of the studies conducted on HNC and dysphagia provide quantitative data about the presence of certain acute and chronic effects of cancer and its associated treatments. A limited number of qualitative studies exist that explore the ideas, thoughts, feelings, and experiences of individuals with HNC and dysphagia.

In an Australia-based study, Patterson et al., (2015) conducted 24 interviews across two phases along with naturalistic observations to gain qualitative information about swallowing difficulties from the perspectives of participants with HNC. The themes that emerged from this study suggested that swallowing difficulties worsen after diagnosis, continue to intensify during and soon after treatment, and then begin to improve approximately six months after treatment ends. Findings suggested that an individual's swallowing abilities are unlikely to be fully restored after treatment.

In a study by Checklin et al. (2020), the researchers interviewed eight individuals with HNC who received dysphagia treatment at a private, nonprofit healthcare clinic in Australia. The participants shared information during semi-structured interviews about which factors improved their treatment experiences and a variety of themes emerged. The participants reported the importance of having an involved support system, assurance from their healthcare team, access to treatment, access to correct information, and self-motivation/resilience. Another theme displayed the continued shock and changes experienced by some of the participants.

Dawson et al. (2019) conducted a qualitative study aimed to understand the experiences of individuals with HNC between one and two weeks after reconstructive facial surgery by completing fifteen semi-structured interviews. The first overarching theme that emerged from the data was that participants experienced challenges they could not anticipate prior to surgery. Following surgery, participants reported that they felt that they looked and functioned differently compared to before their operations. The participants had to adjust to this new version of themselves and felt unprepared to manage the wide array of changes and difficulties they experienced following surgery. The second main theme found that patients experienced support and connection when healthcare professionals prioritized their humanity and looked beyond their physical changes caused by HNC.

In a study based in the United Kingdom, Govender et al. (2017) used 13 semi-structured interviews to learn about the thoughts of individuals with HNC on what factors improve and diminish adherence to dysphagia exercises. The themes indicated that inadequate understanding of swallowing and the purpose of swallowing exercises posed barriers for the participants. Other prominent barriers to adherence included forgetting to complete exercises, being overwhelmed with information, and experiencing fatigue or pain. Factors that were reported to improve patient adherence included receiving support from family members and the clinician, developing an understanding of how to complete the exercises, and remaining motivated to avoid negative consequences (e.g., further swallowing difficulties). Regularly completing the exercises in a routine and receiving reinforcement were noted to be key in maintaining swallowing adherence.

A qualitative study was conducted by Nund et al. (2014b) to gain the perspectives of individuals who have received radiation treatment for HNC. 24 participants were asked about the daily impact of their dysphagia symptoms in individual interviews. The uncovered themes suggested that dysphagia following HNC alters an individual's thoughts surrounding food and generally impacts individuals physically, emotionally, and personally. The same authors conducted another study using semi-structured interviews with 24 participants to gain their thoughts on dysphagia services following radiation treatment for HNC (Nund et al., 2014a). The participants wished for access to ongoing services to deal with their lasting dysphagia. They desired support as they experienced a broad array of changes (e.g., emotional changes).

United States Healthcare System vs Other Countries

The qualitative literature available on dysphagia management for individuals with HNC is based almost entirely in the European Union and Australia. Clear differences exist between the healthcare systems of the United States (U.S.) and those of Australia and the European Union. The features of a healthcare system may impact the quality, amount, and kind of medical treatment the population receives. Specifically, the affordability and accessibility of healthcare can significantly impact the health of the people in a country.

In the U.S., healthcare coverage is primarily available to purchase from private insurance companies. Most commonly, employers in the U.S. will voluntarily provide their employees with insurance (De Lew et al., 1992; Krishnananthan, 2018). Public insurance programs (i.e., Medicare and Medicaid) are only available to individuals 65 and older, individuals with disabilities, or individuals near or below the federal poverty limit. The U.S. has the largest proportion of uninsured individuals compared to other member countries of the Organisation for Economic Co-operation and Development (OECD; Lorenzoni et al., 2014); nearly 50 million individuals are without coverage.

In contrast to the U.S., most wealthy countries have a public insurance option available to all citizens. For example, all citizens of Australia, Canada, Belgium, and France are candidates to receive public healthcare insurance that is funded through taxes (Dixit & Sambasivan, 2018). Such systems can create more universal and affordable access to healthcare guaranteed for all members of a nation (Dixit & Sambasivan, 2018). Citizens of these countries are afforded the opportunity to purchase additional private healthcare (Dixit & Sambasivan, 2018).

The cost of health care services also differs across the countries in which most HNC/dysphagia research has been conducted. Healthcare spending in the U.S. is the highest of any OECD member country. The U.S. spent approximately $12,319 per capita on healthcare expenditure. The second highest spending country was Germany, where $7383 per capita is designated to healthcare. Romania, a member of the European Union, spent the least on healthcare at $2052 per capita (OECD, 2022b). In summary, healthcare spending in the U.S. is about two to six times more than healthcare spending in Australia and the European Union. Lorenzoni et al. (2014) noted that the highest healthcare spending is due to elevated price levels of healthcare services when compared to other countries.

The U.S. has higher poverty rates than Australia and the majority of countries in the European Union (e.g., Ireland; OECD, 2022c). Additionally, income inequality is greater in the U.S. than Australia and most countries in the European Union (OECD, 2022a). This statistic indicates that income is more unevenly divided amongst societal groups in the U.S. population compared to the other countries.

The insurance systems, healthcare prices, and general socioeconomic structures of the U.S. on one hand and other wealthy nations on the other are markedly different from one another. Thus, qualitative studies about the dysphagia services provided to people with HNC in Australia and the European Union may reveal very little about the perspectives of individuals receiving healthcare in the U.S.

Evidence-Based Practice in Dysphagia Care

According to a position statement by the American Speech-Language-Hearing Association (2005), “The term evidence-based practice refers to an approach in which current, high-quality research evidence is integrated with practitioner expertise and client preferences and values into the process of making clinical decisions." To provide the highest quality treatment possible, SLPs must engage in evidence-based practice (Greenwell & Walsh, 2021).

ASHA's model of EBP is a balanced triangle where all components receive equal weight (ASHA, 2005). However, the client's perspective is the component of EBP that is most neglected in many clinical cases (Lawton et al., 2018). More recently, researchers have begun to emphasize that clinicians must conceptualize client values and perspectives as a vital component of EBP (Greenwell & Walsh, 2021; Siminoff, 2013). Incorporating the patient's perspective increases motivation and promotes lasting treatment outcomes (Greenwell & Walsh., 2021).

Within the field of dysphagia care, SLPs may suggest that clients modify their eating and swallowing habits, implement new strategies to promote safe swallowing, stick to a particular diet, or engage in exercises to improve swallow function in the therapy room and between treatment sessions. However, across many diagnoses, including HNC, the adherence rate is variable among the patient population (Mortensen et al., 2015). In a study by Shinn and others (2013), only 13% of participants fully adhered to the SLP's guidance. More than half of the participants with HNC never attempted to complete the swallowing exercises prescribed to them in speech therapy. When individuals display a lack of adherence to these approaches, the treatments may be completely or partially unsuccessful (Wells & King, 2017). Moreover, low adherence leads to a higher risk of aspiration (Krekeler et al., 2020).

Strategies for increasing adherence are available to clinicians. One highly effective way to inspire a client's willingness to stick to recommendations involves orienting to their wants, needs, and perspectives when designing therapeutic programs. A clinician whose approach to intervention is informed by a client's perspective as well as their own medical expertise is likely to foster treatment adherence and increase the extent to which patients follow clinical recommendations (Chakrabarti, 2014).

Critical Gap

The literature base used by dysphagia care professionals is dominated by studies that focus on the ‘external evidence’ arm of the EBP triangle. Very few investigators have sought to better understand the ideas, opinions, and narratives of those affected by HNC and dysphagia.

The healthcare systems in the U.S. and the other mentioned countries are fundamentally different. HNC survivors who receive dysphagia services in the United States are thus likely to hold different values and perspectives and to have different experiences as consumers of SLP services. However, the few studies that contribute qualitative information about the perspectives of those with HNC and dysphagia were conducted in the European Union and Australia. No studies oriented to the perspectives of people with HNC who received dysphagia treatment in the U.S. currently exist.

One way SLPs can access information about the client perspective is through qualitative research designed to interpret the lived experiences of a specified group. By gaining information about the patient’s perspectives and using their considerations to guide treatment, clinicians will be better able to provide meaningful, relevant services to clients, which will in turn increase the likelihood that clients will adhere to treatment. Clinicians can utilize the resulting information as a framework or beginning point that can be built upon by incorporating the needs, abilities, and perspectives of individual clients with HNC and dysphagia. This work is intended for clinicians to use in combination with evidence-based resources and individual client reports.

Two research questions were investigated in this study:

1. Which factors lead to positive clinical experiences for individuals with HNC who have been treated for dysphagia by an SLP in the United States?
2. What factors create barriers to positive clinical experiences for individuals with HNC who have been treated for dysphagia by an SLP in the United States?

Research Strategy

One qualitative research method that can allow researchers to better understand the experiences of individuals with HNC is interpretative phenomenological analysis (IPA; Smith, 2019). IPA can be utilized to learn about the perspectives of individuals who have lived through specific experiences (Smith & Osborn, 2015). Phenomenology thus allows the researcher to gain insider information about the feelings and ideas of the participants.

The process of collecting data typically involves the use of semi-structured interviews (Miller et al., 2018; Smith, 2019). The researcher starts the interview by building rapport with the participant, which may help the individual share their story or perspective. Then, the researcher uses an interview guide to structure a discussion related to the interviewee's perspective on and understanding of a given experience (Smith, 2003). This method allows the researcher to maintain flexibility and enables them to ask follow-up questions. The interview will proceed organically and often resemble an informal conversation (Smith, 2003).

With this approach, the researcher focuses on finding meaning within the data rather than dispelling their preconceived notion (Pietkiewicz & Smith, 2014). Despite careful considerations, the interviewer must still recognize that bias will be a factor in all research interactions.

Following data collection, the researchers use the data to conduct in-depth qualitative analyses and identify emergent themes. Rather than simply stating the commonalities found, the researchers must attempt to gain a rich understanding of the experiences described. All participating researchers share the themes that were identified in their analysis. Then, the ideas are combined, and a set of themes are determined. The researchers then return to the interview data to examine if the themes can be substantiated.

Interpretative Phenomenological Analysis in Communication Sciences

In the field of communication sciences, IPA is one established method for gaining the perspectives and experiences of individuals with a specific difficulty or disorder and their caregivers. Phenomenological studies have been conducted with participants who have aphasia, hearing loss, Parkinson disease, and stuttering, as well as with other individuals with impacted communication abilities.

Aphasia

Brown et al. (2010) explored the life experiences of 25 people with aphasia (PWA) through semi-structured interviews in an attempt to move away from traditional “deficit” models of aphasiology and better understand what it means to live successfully. Although each participant’s experiences were unique, four themes emerged. The main themes of living successfully with aphasia included doing as much as possible to increase feelings of fulfillment and usefulness, developing strong, meaningful relationships to increase support and socialization, maintaining a positive way of life with a positive attitude and acceptance of the situation, and the necessity of communication both verbally and as an essential aspect of the other themes (Brown et al., 2010). Brown et al. (2012), analyzing the same topic, conducted qualitative meta-analysis of three studies highlighting the lived experiences of 25 PWA, 24 family members, and 25 SLPs to reveal both overarching, shared themes and subtle differences in understandings of living successfully with aphasia. The authors generated themes after conducting extensive qualitative meta-synthesis of the completed studies. The themes included participation in meaningful activities, the necessity of meaningful relationships to foster love and acceptance, creating a network of support for both PWA and their family members, communicating needs effectively across multiple modalities, maintaining positive attitudes and speech amid adversity, fostering opportunities to promote independence for PWA, and finding acceptance and perseverance in the midst of an aphasia diagnosis overtime.

In the acute care setting, Foster and colleagues (2016) explored the management of aphasia using interviews with 14 Australian SLPs and an interpretative phenomenological methodology. The interviews revealed several themes and a guiding construct that this may be the first experience PWA have with the profession of speech pathology. The themes included ensuring the accurate screening and assessment of PWA to provide structured conversation and next steps, maintaining a strong sense of advocacy for PWA in the acute setting, providing education and emotional support to PWA and their families, differences in therapeutic intervention and goal setting across settings, and the effects of differing referral process on successful treatment of PWA (Foster et al., 2016).

More recently, Strong et al. (2018) used IPA to explore the lived experiences of three individuals with aphasia who each participated in an identity-focused project about their life. The themes demonstrated that the participants maintained a positive perspective on their identities, an enjoyment in sharing one’s story, and a new empowerment of their communication abilities.

Hearing Loss

In 2013, Hilton et al. used IPA to conduct semi-structured interviews to gain the perspectives of eleven participants with sequential cochlear implants. The participants provided overwhelmingly positive responses about their choice to receive a sequential hearing aid. The main themes included careful consideration of and fluctuating emotional commitment and adjustment to a second implant, improved happiness, confidence, and social lives with two cochlear implants, finding connection, inclusion, and integration in the hearing world, identifying deafness as a valued part of self, experiencing a bicultural identity as both a hearing and deaf individual, and feeling different in a hearing world due to looks, isolation, frustration at not fitting in, and prejudice (Hilton et al., 2013).

In 2017, Edmondson engaged in an IPA to better understand the experiences of six adolescents with hearing loss in an educational setting. Six superordinate themes were identified among the participants, including the building of relationships to increase social acceptance, finding strong support from teachers and family members, and maintaining confidence. Within these superordinate themes, several subthemes were determined to explain barriers and facilitators to positive school experiences. These included developing effective coping strategies and receiving sufficient support, difficulty processing with hearing and radio aids in certain environments, the positive impact of good teachers and adapted schoolwork, and establishing confidence with hearing loss as a part of self (Edmondson, 2017).

Schmulian and Lind (2020) explored the perspectives of ten individuals who parent children with permanent hearing loss using an interpretative phenomenological framework. The data resulted in five themes including difficulty contextualizing a diagnosis and its accompanying disabling issues early on, experiencing loss of socialization and milestone experiences, immediate acceptance of and struggle with the disability at time of diagnosis, unique individual experiences based on familial makeup, and the appreciation of audiologists as effective guides through information sharing and emotional debriefing (Schmulian & Lind, 2020). Talewar and colleagues (2022) used IPA to understand the experiences of four women with Meniere’s disease and the impact the disease makes on the participants’ lives. Data from semi-structured interviews with the participants revealed the following themes: “You have no control whatsoever,” “Meniere’s takes your life away completely,” and “You get on with life” (Talewar et al., 2022).

Parkinson Disease

In 2005, Bramley and Eatough utilized an IPA methodology and three semi-structured interviews with one participant to better understand the experiences of individuals with Parkinson’s disease. The two overarching themes that surfaced from the data included a disconnect between mind and body facilitated by oscillating periods of movement and medication, and the ability to both differentiate the disease from one’s “true self” and incorporate it into one’s self-concept (Bramley & Eatough, 2005). IPA was used by Giles and Miyasaki (2009), who interviewed three family groups connected to individuals with Parkinson Disease to understand their thoughts and beliefs surrounding their healthcare services. One theme shared by the participants was a lack of information about their diagnosis and treatments. Another theme emphasized the difficulty participants had with obtaining government funded care, leaving them to seek private home health. A study was conducted by Shahmoon et al. (2019) to learn how Deep Brain Stimulation treatment impacts the lives of individuals with Parkinson Disease. From interview data based on a sample of ten individuals with Parkinson’s disease, two superordinate themes emerged. First, participants experienced a significant amount of healing and relief from their symptoms which was either tempered by feelings of fear and disappointment or enhanced by strong social support. Second, many patients experienced a new interpretation of their living condition, both attempting to live more and do more things, and accepting the need for assistance while fearing regression (Shahmoon et al., 2019). In a study by Stephenson et al. (2022), four individuals with Parkinson disease were interviewed using IPA to better understand their daily responsibilities, challenges, and unmet needs. The data revealed four main themes. First, all participants experienced some kind of pre-diagnosis denial of symptoms through rationalization. Second, individuals experienced a post-diagnosis loss of current sense of self, resulting in dark thoughts and uncertainty about the future. Third, many participants took agency over their diagnosis by searching symptoms and treatment options online while subsequently resenting their choices and the healthcare professionals that diagnosed them. Finally, participants experienced a loss of pre-morbid identity due to stereotypical images of individuals with Parkinson's disease but ultimately accepted new versions of themselves with different goals (Stephenson et al., 2022).

Stuttering

Numerous studies have been conducted in the area of fluency using phenomenology to gain the perspectives of people who stutter (PWS). In 2013, Bricker-Katz et al. explored the impact stuttering has on an individual's work life using IPA. Through the analysis of semi-structured interviews with nine PWS, several superordinate themes arose. These included the pervasive influence of stuttering at work and the need for constant vigilance, reduced self-confidence and concerns over social integration, universal communication issues and frustration, and issues experiencing occupational advancement due to increased verbal demands and being overlooked (Bricker-Katz et al., 2013).

Tichenor and Yaruss (2018) used a phenomenological approach to investigate the self-perceptions of stuttering that PWS may possess. Using data from 13 participants, several main themes were highlighted. These included the anticipation of stuttering through both action and non-action responses, the loss of both motor-linguistic and cognitive conversational control of speech, variability of numerous aspects like stress, strategies, thoughts, and location that change across time and place, intertwined physical, emotional, and cognitive experiences, action and non-action management techniques, and building and maintaining relationships with listeners through positive active strategies (Tichenor & Yaruss, 2018).

In a study by Young and colleagues (2022), the researchers conducted semi-structured interviews with 12 participants and used IPA to gain perspectives of PWS on the topic of self-disclosure statements. Superordinate themes discussed in the article included the cognitive relief experienced as reduced anxiety and increased focus, increased self-empowerment through greater self-acceptance and confidence in educating others, increased social connection through greater listener engagement and emotional intimacy, and the ability to personalize disclosure statements and implement them as needed with practice (Young et al., 2022). Self-disclosure statements were found to create a positive impact on the lives of the participants who stutter.

In 2023, Daniels and colleagues conducted semi-structured interviews with seven PWS to understand the perspectives of bisexual, gay, and lesbian individuals who stutter and their experiences with communication. The main themes found in this study include the importance of shared social identity and visibility in fostering affirmation, the effects of oppressive social expectations on identity concealment and isolation, the negative and complex effects of not being affirmed for who one is, and the intersectionality of stuttering with gay, lesbian, and bisexual identities (Daniels et al., 2023).

CHAPTER II: METHODOLOGY

Participants

To meet the eligibility requirements for the study, the participants were required to be at least eighteen years old and have a diagnosis of head or neck cancer. Participants must have received a minimum of six treatment sessions for dysphagia from a certified SLPs in the U.S. Additionally, the participants were required to comprehend questions and form verbal descriptions of their treatment experiences within a virtual interview. To recruit the participants, the researchers posted virtual flyers on groups and social media forums designated for people with HNC. Additionally, the researchers posted flyers in groups and forums with audiences of SLPs. When connecting with SLPs, the researchers provided them with a virtual flyer to post in locations where their patients with HNC might see them. After seeing a flyer, interested individuals had the opportunity to contact the researchers using the information on the flyer.

Following Institutional Review Board approval, six individuals expressed interest in the study and were recruited to participate. All participants independently contacted the researchers through email to express their interest in the study and consented to participation in the study by means of the BGSU IRB approved informed consent document.

At the beginning of the interviews, participants were asked demographic questions (e.g., gender, age). The participants had the option to answer or choose not to respond to the questions. From the provided responses, one participant was a female, and five participants were male. Participant ages ranged from 56 to 83 years old, with an average age of approximately 68 years old. Three participants were diagnosed with HNC located exclusively in the tongue. One participant had malignant tumors in the tonsils and lymph nodes. Another individual had HNC located in the pharynx and tongue. Lastly, one participant was diagnosed with HNC in the tongue and lymph nodes.

One participant reportedly received a partial glossectomy, a surgery to remove the malignant tumor on a portion of the participant's tongue. This participant displayed limited speech intelligibility. Because of this, the researchers had a difficult time comprehending the participant's message during the interview and during transcription. To ensure that this participant's intended message was not distorted or misrepresented, member checking (see the results section for an explanation of this process) was completed to ensure that the notions presented in the themes were representative of the information provided by this participant. The speech of the remaining participants was intelligible. However, member checking was completed with all participants. If any of the themes were misaligned with any of the participants' perspectives, they had an opportunity to provide feedback on the results to the researchers. Then, the researchers adjusted the results based on any feedback provided through member checking.

The purpose of this study is to explore the experiences of individuals with head and neck cancer and dysphagia through the following research questions:

- What factors lead to positive clinical experiences for individuals with HNC who have been treated for dysphagia by an SLP in the United States?
- What factors create barriers to positive clinical experiences for individuals with HNC who have been treated for dysphagia by an SLP in the United States?

Table 1

Participant Information

Participant	**Pseudonym**	**Age**	**Gender**	**Diagnosis Year**	**Cancer Info**
1	Felix	67	Male	2020	Tongue
2	Daniel	69	Male	2015	Tongue
3	Ivan	58	Male	2018	Tonsil and lymph nodes
4	Jack	83	Male	1997	Tongue + lymph nodes
5	Alice	76	Female	1998	Tongue
6	Lucas	56	Male	2021	Tongue, pharynx

Consent

When participants emailed the researchers to express interest in participating, the researchers provided them with a copy of the informed consent form to review. This document was approved for use by the Institutional Review Board at Bowling Green State University. Before beginning an interview with a participant, the researcher read the consent form aloud and displayed the form on the computer screen. Then, each participant provided consent prior to answering any questions. The researcher reiterated to each participant that they had the right to withdraw involvement from the study or skip questions at any time.

Procedure

To gather data, interviews were conducted using Zoom video communications software. Each participant attended one individual interview where they answered questions about their treatment experiences (Checklin et al., 2020; Dawson et al., 2019; Patterson et al., 2015). Prior to the interview, the participants received a copy of the questions to allow them time to prepare their responses and reflect on their experiences (Nund et al., 2014). Interviews occurred privately using a secure virtual meeting platform (Checklin et al., 2020). Compared to in-person interviews, virtual interviews are evidenced to be equally effective (Cabaroglu et al., 2010; Deakin & Wakefield, 2013). Interviews lasted as long as necessary for the interviewer to gain an understanding of the individual's experiences (Plexico & Burrus, 2012). On average, interviews lasted approximately 55 minutes.

All interviews were conducted by the primary author (LC). The questions were in-depth, open-ended, and semi-structured (Bricker-Katz et al., 2013; Bramley & Eatough, 2005; Giles & Miyasaki, 2009; Habermann, 1996; Klompas & Ross, 2004; Lowe & Nobriga, 2021; Nund et al., 2014; Pietkiewicz & Smith, 2014; Plexico & Burrus, 2012). An interview guide with original, predetermined questions was used by the interviewer to flexibly shape the interview (Bricker-Katz et al., 2013; Habermann, 1996; Huws & Jones, 2015; Klompas & Ross, 2004; Patterson et al., 2015; Pietkiewicz & Smith, 2014).

Follow-up questions were asked based on participant responses to ensure rich explanations and to clarify the researcher's interpretations (Klompas & Ross, 2004; Lowe & Nobriga, 2021; Tichenor & Yaruss, 2018). With participant permission, the interviews were audio recorded for later verbatim transcription and analysis (Checklin et al., 2020; Huws & Jones, 2015; Nund et al., 2014; Plexio & Burrus, 2012). The process of recruitment continued until the same themes emerged repeatedly and until no novel themes developed from conducting additional interviews. Thus, saturation was achieved (Plexico et al., 2010; Tichenor & Yaruss, 2018).

Data Analysis

An interpretive phenomenological approach (IPA) was implemented as this study is focused on gaining the perspectives of individuals who share a particular experience (Huws & Jones, 2015; Plexico et al., 2010; Tichenor & Yaruss, 2018). IPA allows participants to share their experiences while researchers strive to understand the individual in their specified context (Smith, 2003).

Verbatim transcripts of the interviews were created and reviewed (Tichenor & Yaruss, 2018). The researchers (LC and BA) independently familiarized themselves with the interview data by repeatedly reviewing the transcripts (Bricker-Katz et al., 2013; Huws & Jones, 2015; Nund et al., 2014; Plexico & Burrus, 2012; Smith & Osborn, 2004). To extract the data, the researchers independently used open line-by-line coding (Bricker-Katz et al., 2013; Huws & Jones, 2010; Moloney & Walshe, 2018).

Connections between codes were identified and an axial code was created for each category of associated open codes (Bricker-Katz et al., 2013; Huws & Jones, 2010). The axial codes from both researchers were compared and combined (Maloney & Walshe, 2017). Schemas were created to categorize major themes, ideas embedded within themes, and connections between themes (Bramley & Eatough, 2005; Bricker-Katz et al., 2013; Huws & Jones, 2015; Plexico & Burrus, 2012).

To confirm that the schemes were portrayed within the data, the researchers reviewed the data again (Bramley & Eatough, 2005; Huws & Jones, 2015; Smith & Osborn, 2004). The schemas were adapted as appropriate to ensure that the findings were prevalent within the data (Bramley & Eatough, 2005; Huws & Jones, 2015).

Rigor

The researchers sought to maximize the extent to which the findings were grounded in the interview data. To achieve this objective, a number of procedures were implemented. As the primary analyst, I (LC) kept written notes and a journal from the beginning of the research project. As I narrowed in on areas for examination, did background reading for the project, developed questions, conducted and analyzed interviews, I recorded in writing what my perceptions, opinions and questions about the data were.

Both primary analysts (LC and BA) met regularly and communicated via email. Both primary analysts kept detailed notes about their views as they became familiar with the data and started to develop schemata to describe the data. Our interpretations of each theme and the connections between themes were written down (Bramley & Eatough, 2005, Smith & Osborn, 2004). The decisions we made and our justifications for arriving at certain positions were also recorded in writing. The various preliminary taxonomies for arranging and connecting codes were recorded in writing.

Taken together, these written records provide a transparent overview of how we gathered and analyzed the data. This audit trail allowed us to ensure that we were following our planned procedures, and in instances where we had to deviate, the written record provided reasons for changing plans. Moreover, the audit trail provided comprehensive documentation on how our understanding of the data changed over time and information on how we arrived at our conclusions. We referred to the audit trail throughout the research process to ensure that we were proceeding with sufficient rigor.

Independent Analysis and Peer Debriefing

The two primary analysts (LC and BA) reviewed and analyzed the interview transcripts independently of one another. Once both analysts had completed these separate, independent processes, a joint schema was developed.

Member Checking

Each participant was contacted to complete member checking, where they were asked to confirm or deny the interpretations and findings (Bramley & Eatough, 2005; Nund et al., 2014). All participants confirmed that our analysis was reasonable and aligned with their perceptions.

Lamination

Lamination was conducted by a third-party individual who is skilled in qualitative research. This individual reviewed the transcripts and determined if the schemas were grounded in the data (Bramley & Eatough, 2005; Huws & Jones, 2015). The processes of member checking and lamination concluded that the findings of the study aligned with the perspectives of the participants and were reasonable representations of the information portrayed in the interviews. Following all revisions, direct quotes were chosen to substantiate each theme (Bramley & Eatough, 2005).

CHAPTER III: RESULTS

Five primary themes surfaced from the participant responses collected during the individualized interviews. The themes include:

1. The effects of cancer treatments reduce clients' capacity to participate in dysphagia therapy.
2. Changes in swallowing abilities give rise to a range of emotional and psychological reactions.
3. Participants received timely care when SLPs were part of their care teams.
4. Participants experienced no barriers to financially accessing treatment.
5. SLPs provide valuable services to HNC participants with dysphagia.

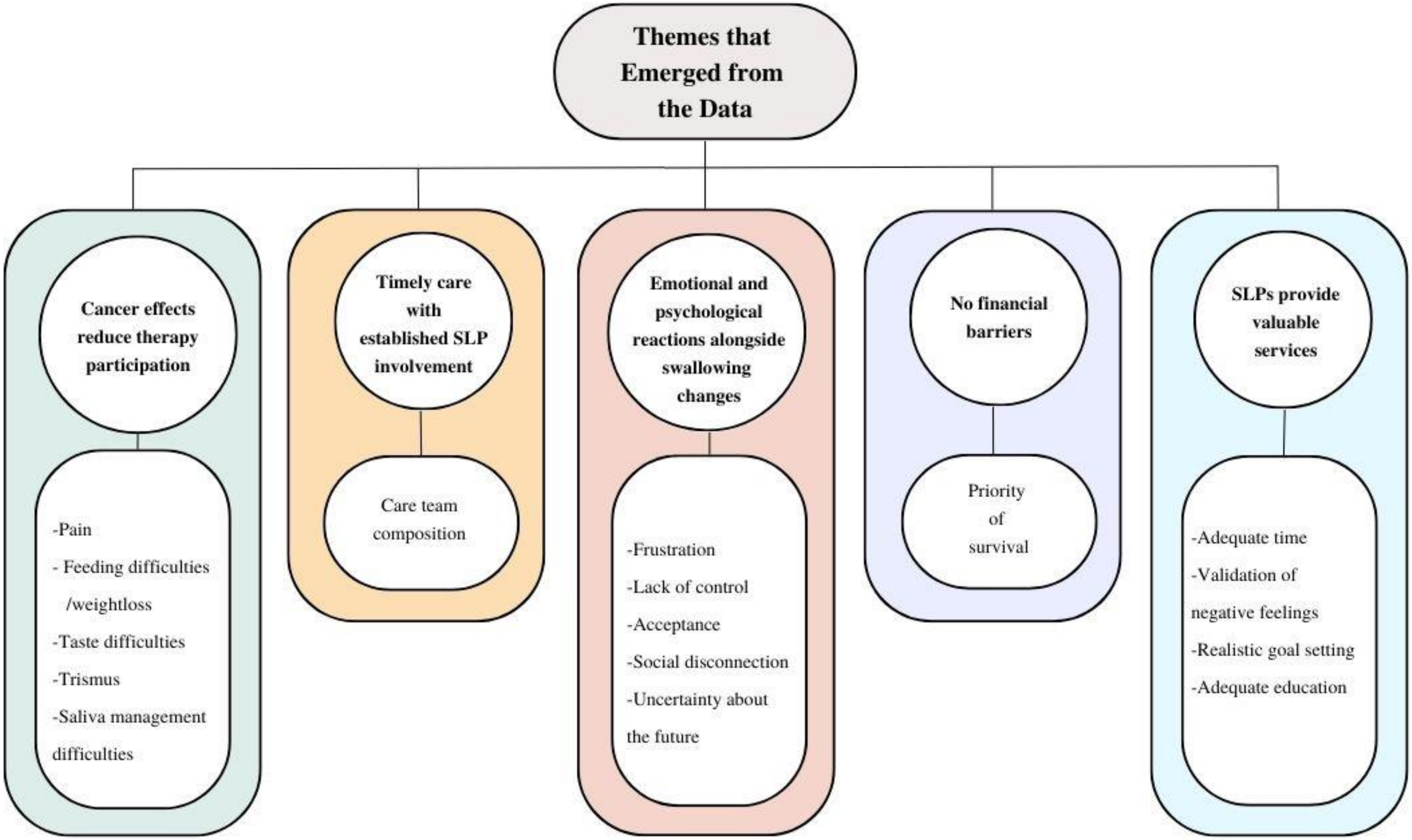

Figure 1: Themes that Emerged from the Data

Theme 1: The Effects of Cancer Treatments Reduce the Clients' Capacity to Participate in Dysphagia Therapy

"Radiation felt like I hit a freaking wall or got ran over by bus. So, by July, I could no longer eat. I couldn't taste...it was lost. I had burns all over my neck. I started using magic mouth wash and lidocaine and some other stuff to numb my throat just so that I could swallow the pills."

Lucas

Many of the reported difficulties emerged within the period of time that participants received cancer treatments. These effects would either present for a short period of time (i.e., acute effects) or would be long-lasting (i.e., chronic effects). In addition to any effects that developed during treatment, effects of cancer treatments could appear weeks, months, or years after the cancer was treated. Participants had numerous responsibilities, including attending speech therapy, while withstanding the physical effects the treatments placed on their bodies. As can be seen from the difficulties detailed below, the side effects of cancer treatment tended to affect structures in the oral cavity, and processes related to swallowing. Cancer treatments thus indirectly compromised the participants' abilities to fully participate in dysphagia therapy.

Physical Capacities

All six participants stated that the physical demands of cancer treatments amounted to barriers for them as they pursued dysphagia treatment. The majority of patients discussed experiencing multiple physical effects as a result of chemotherapy, radiation, and/or surgery.

"I've had no sign of reoccurrence of cancer, but the treatment just created a myriad of problems that I continue to have to deal with."

Daniel

Pain Caused by Various Complications

Three of the six participants experienced pain as an effect of their cancer treatments. The pain these individuals experienced seemed to be incomparable to ordinary pain experienced in daily life (e.g., headaches). This pain was drastic and intolerable to the participants who described the feeling.

"My throat and my mouth hurt so bad when I woke up… especially right during treatment. Two days after treatment started, I went to the hospital. Just ungodly pain."

Lucas

"The swallowing several weeks into the radiation therapy was the most painful thing I've ever experienced. I was taking all of the narcotics they would give me right on schedule, and I'm a person that typically shies away from taking any kind of medication for anything.

Daniel

One participant experienced a burning sensation in his mouth, which is referred to as glossodynia.

"I have something called I think the layman's terms of it is called Burning Mouth syndrome and it hasn't gone away either. It has gotten maybe a little bit better with some things, but even with mild foods, some spice or something is still off. I can't tolerate spice with whatever it is exactly, I don't know, but I usually have water around to have when I have anything to eat."

Lucas

One participant explained that he developed mouth sores while receiving chemotherapy and radiation treatments.

"My entire mouth was just one huge sore."

Daniel

Following chemotherapy or radiation, two individuals developed significant burns on their necks, leading to significant pain.

"I had burns all over my neck."

Lucas

"I had really bad like second degree burns on my neck from the radiation."

Felix

Feeding Difficulties and Weight Loss

One participant encountered difficulty in obtaining adequate nutrition to preserve their bodyweight. For this participant, their dysphagia or associated pain impeded their ability to eat or drink.

"It was just so painful to try to get this volume of liquid down and to keep my weight up."

Daniel

Significant weight loss during radiation or chemotherapy was reported by two other participants.

"I lost I mean I was probably thirty pounds overweight when I started. I lost ten pounds in the seven weeks of treatment, and then I lost twenty-two pounds in the following six weeks."

Felix

"It got to the point where if he (the radiation oncologist) wasn't watching, I'd be trying to get on the scale with my shoes. I'd keep my wallet, my cell phones, and keys in my pocket…stupid stuff to try not to go down another pound."

Lucas

Three participants reported that they required percutaneous endoscopic gastronomy (PEG) tubes, feeding tubes that deliver nutritional support directly to the stomach, in order to meet nutrition needs. One of the three individuals utilized a PEG tube during the time of his cancer treatments. After this individual's radiation and chemotherapy ended, he worked with SLPs to regain the ability to receive his nutrition orally. Then, the individual had his feeding tube removed within one year. The remaining two participants who utilized feeding tubes ate orally until at least two years after their cancer treatments had ended. The coordination of muscles and nerves required for swallowing diminished for these two individuals overtime requiring them both to need PEG tubes. Following the placement of a PEG tube, one participant continued to seek speech therapy in an attempt to improve his swallowing abilities and remove the PEG tube, however this treatment was reportedly ineffective for him. The other participant did not seek further speech therapy following the placement of the PEG tube.

"I can't put anything in my mouth anymore. I am on a feeding tube permanently."

Alice

Difficulties with Taste

Four of the six participants discussed changes in their ability to taste resulting from cancer treatments. For two of the individuals, their taste was significantly limited compared to their taste prior to their chemotherapy or radiation.

"I probably have ten, fifteen percent of the taste I had before."

Daniel

"I have two issues with I guess with my mouth. One is the dysphagia, and the other is, I absolutely have no taste buds."

Felix

For two individuals, their sensation of taste had altered. This experience likely changed the way they experienced foods.

"Food was terrible tasting and then as time progressed my taste kind of flopped, so what would be sour you chew on one side would then be sweet on the other."

Ivan

"I could taste like a chain link fence kind of feeling…just metal."

Daniel

Trismus

A common experience amongst the participants was trismus, or the difficulty with opening one's mouth. Four of the participants worked on trismus during speech therapy to loosen their jaw and help coordinate or strengthen the muscles required for jaw opening.

"*I was having a problem. I was losing the ability to open my mouth. I had not regained it.*"

Lucas

"First off, I could not get my mouth open. So, I had to work it so I could eat. I couldn't put anything in my mouth."

Alice

"Residual like jaw issues, so I can't think of the medical term where you can't open your jaw that well anymore because of the radiation and your ability to open your jaw is diminished. So, we worked on that a lot as well."

Ivan

Along with trismus, one individual reported difficulty with mastication. This individual had difficulty chewing food and properly preparing a bolus for each swallow. This symptom significantly limited the foods the individual was able to swallow.

"I can't eat at a restaurant now; you know typically there's nothing on the menu because I can't chew it."

Daniel

Difficulties with Saliva Management

Three participants discussed difficulties with managing or effectively producing saliva. During radiation, one participant experienced damage to his salivary glands. This participant experienced xerostomia or oral dryness caused by salivary gland dysfunction.

"I had no saliva."

Lucas

In contrast, two participants reported difficulty managing the saliva or mucous present in their oral cavities. The participants were unable to swallow their oral secretions, which required them to expectorate the saliva or mucous.

"I just needed to start eating and get rid of the little red solo cup that I carried around and drooled into for like five or six months."

Ivan

"We were having to get up a couple of times a night and change the bed linens because I wasn't swallowing it. Swallowing the mucosis became progressively more and more and more painful. So, I was spitting it out in my sleep and we were getting cups of it."

Daniel

Theme 2: Changes in Swallowing Abilities Give Rise to a Range of Emotional and Psychological Reactions

"Even in talking to you, I was a little surprised, but it's still a little sensitive and a little emotion invoking."

Lucas

Five of the six participants discussed the mental and emotional difficulties associated with experiencing dysphagia, HNC, and the associated treatments. The emotions described included frustration, acceptance, feeling a lack of control, feelings of being socially disconnected, and feeling unsure about the future.

Frustration

One participant reported significant frustration with his loss of effective swallowing abilities.

"You've lost one of your most basic functions that worked as a child. You're born with the ability to suckle and to swallow... those are just normal things. And now, suddenly, as an adult, you've lost basic function. Losing that basic function is incredibly frustrating."

Ivan

Feelings of Lack of Control

Two of the six participants noted feeling a lack of control. One participant discussed a general lack of control that developed when he began radiation to treat the HNC.

“This is the first time in your life that you haven’t had any control over anything.”

Felix

Another participant described feeling this loss of control when one of his basic physical functions became impacted.

“I couldn't even control my own saliva.”

Ivan

Acceptance

One individual’s swallowing function did not improve despite intensive dysphagia treatments. The participant described holding onto hope that he would regain the ability to eat food orally. However, his continued swallowing difficulties led the participant to require a PEG tube indefinitely. When the treatment proved ineffective for this participant, he eventually experienced acceptance.

“One day we finally had to say the vital stim didn’t work and I just had to accept the fact that it did not work.”

Jack

Feelings of Social Disconnection

Two individual reported difficulty maintaining social aspects of life due to swallowing difficulties. The participants discussed how food is a prominent component or central aspect of social interactions or life in general. Dysphagia reportedly impacted these individuals’ social lives, likely impacting their connections and interactions with others.

“I don't think you realize how food impacts the various areas of your life other than like you said just survival, because you can survive without it. I mean, I've been fine that way but the social, the going out, the taste, the habits...the whole nine yards is difficult.”

Ivan

“You know I was just embarrassed and felt like everybody was looking at me. Because I mean eating is one of the great pleasures of life.”

Jack

Feeling Unsure About the Future

Three of the six participants described how they viewed the future differently after developing and being treated for cancer. These changes were commonly linked to the idea that they continued to experience consequences of treatments long after the treatments have ended, and they could develop new effects at any time thereafter.

“There's still a reasonable chance for reoccurrence…this is now part of me for perpetuity.”

Daniel

“Having ended up in the hospital twice with absolutely no idea of how I got there…I would tell you now that I absolutely expect to die of aspiration pneumonia someday.”

Daniel

"I mean I never ever got and or expected to get back to where I was."

Felix

Theme 3: Participants Received Timely Care when SLPs were Part of Their Care Teams

"Well to us, that's unconscionable how speech pathology cannot be included or is not included as a key part of your team doing treatment and following treatment for head and neck cancer."

Daniel

Once participants were referred to SLPs, all six reported receiving ready access to speech therapy sessions. However, the access to initial speech therapy referrals varied widely amongst this sample. Some participants had speech therapy as a built-in service within their care plan and others had to seek speech-therapy services from external healthcare facilities. Other participants had to self-advocate for a solution to swallowing difficulties that arose following cancer treatments.

Participants mentioned that it was easy to receive speech therapy access if it was a service automatically built into their care plan. Oftentimes, these participants received their oncologic services and speech pathology services within the same healthcare system. Within these systems, some of the participants received their care from an interdisciplinary team where professionals from different disciplines (e.g., oncologist and SLP) collaborate to provide care to a patient. These participants were satisfied receiving speech therapy soon after they were diagnosed with HNC.

"[SLPs] really have been kind of the leaders of the team so I think it's really a very important and very critical part of the treatment and should be viewed that way. But maybe it not always is.

At [HOSPITAL] because of their holistic approach I think that my speech pathologists have had a stronger voice in the process maybe."

Daniel

For other participants, speech pathology was not included in their care until after the beginning of cancer treatments. For these individuals, no preliminary education or proactive swallowing interventions were provided from speech therapists. In a few cases, participants were not referred to a speech pathologist until swallowing difficulties arose months or years after their cancer treatments ended. These participants felt that they did not receive speech therapy as early as they would have liked throughout treatment. This participant contacted his physicians to address his swallowing difficulties that were unaddressed until he could no longer eat or manage his airway. Once this participant sought an evaluation of his swallowing mechanism, a referral to a speech therapist was initiated. During the interview, this participant discussed that beginning speech therapy sooner may have maximized his swallowing functions and ability to maintain his airway.

"The time I started (cancer treatment), I think they were trying to wait and see if I would be able to manage my airway on my own. As time progressed, I wish they would have started that sooner."

Ivan

Another individual experienced three occurrences of aspiration pneumonia and cooccurring swallowing difficulties without receiving a speech therapy referral. After this individual's fourth hospitalization for aspiration pneumonia, a physician initiated an order for speech therapy.

"Nobody referred me to a speech pathologist."

Jack

Similarly, another individual had to advocate for themselves to receive speech therapy services by repeatedly raising their concerns.

"You really have to push for your oncologist to give you access."

Felix

Another participant shared that he finds integrated teams to be more likely to provide a referral for speech pathology compared to professionals providing care independently.

"I saw this guy with head and neck cancer was not seen someplace with an integrated team and so when the surgeon finished, there was no referral to a speech pathologist… if you don't go to some place that has an integrated team for your treatment, that's very common."

Daniel

Theme 4: Participants Experienced No Barriers to Financially Accessing Treatment

"To learn to be able to eat and speak again and to maintain my airway I couldn't put a price tag on it."

Ivan

Six of the six participants reported that financial factors did not impact their access to swallowing intervention. In fact, this seemed to be a low priority for many of the participants because they were primarily focused on survival. Zero participants reported concerns or difficulties with insurance that arose from their treatments for dysphagia.

"You go into it knowing that you have to do it. You can't be thinking about spending a bunch of money. You're going to do what you have to do to get through if you know you're just trying to survive."

Felix

"Money considerations were never really a part of my treatment."

Jack

Theme 5: SLPs Provide Valuable Services to HNC Patients with Dysphagia

"She exceeded my goals. She exceeded my expectations."

Lucas

Generally, all six participants viewed the dysphagia treatment they received as valuable, despite varying treatment outcomes. Participants associated receiving time to interact with the SLP, validation of negative feelings, realistic goal setting, adequate education with positive experiences or treatment outcomes.

The majority of participants benefited from having adequate time to ask questions and exchange information with the speech-language pathologist during therapy.

"She was very patient. I never felt rushed. She took her time and spent as much time as I needed. I know she had other people because she was busy, but I never felt rushed."

Alice

"The SLP is very, very, very good about not pushing too much at you but answering every question. You never felt rushed."

Felix

Participants discussed the role of the SLP in setting realistic goals and managing preexisting expectations. Two participants discussed the importance of maintaining a sense of hope that they would improve. However, these participants mentioned that they had to appropriately adjust their expectations throughout treatment.

Several participants discussed receiving education or counseling from an SLP. This information was commonly explaining the importance of completing speech therapy exercises and helping them understand the various effects that may persist following cancer treatments.

"But the goal was to learn about what was happening, and then subsequently, it's been about fending off what is probably still going to happen."

Lucas

Five of the six patients reported that their goals were achieved in speech therapy.

“I probably got back to where they expected that I get back to but they did not get back to where I hoped I would get back to.”

Felix

CHAPTER IV. DISCUSSION

To the best of my knowledge, there is no qualitative literature aimed at exploring the speech pathology treatment experiences of individuals with a variety of HNC diagnoses and dysphagia treated within various healthcare systems in the U.S. Similar studies have been conducted in the European Union and Australia. These systems and the U.S. healthcare system differ based on an array of factors, including the availability of medical treatments, the accessibility of health insurance, and the cost of healthcare. Experiences reported within one healthcare system may differ from experiences associated with receiving treatment in a different healthcare system.

A handful of qualitative studies have served to explore the perspectives of individuals with HNC and dysphagia. More broadly, numerous studies exist to provide information about HNC and dysphagia separately. In this section, comparisons of this study to existent research studies will be discussed. Additionally, clinical implications, study limitations, and future research suggestions will be discussed.

The objective of this study was to better understand the perspectives of individuals with HNC on their experiences with dysphagia treatment provided by U.S.-based SLPs. Two proposed research questions were investigated in this study. Findings from this study can provide patient-centered insight to clinicians serving individuals with HNC and dysphagia.

Research Question 1: What Factors Lead to Positive Clinical Experiences for Individuals With HNC Who Have Been Treated for Dysphagia by An SLP in the United States?

The participants discussed how physical effects of cancer treatments impacted their ability to participate in dysphagia treatments. The physical symptoms that developed for this cohort of individuals included various pain-inducing complications (e.g., burns in the oral cavity), weight loss, difficulties with taste, trismus, and difficulties with saliva management. Participant cohorts from comparable studies reported many of the same symptoms reported in this study. Similar to the experiences reported within this study, individuals with HNC and dysphagia reported extreme, severe pain in several other studies (Checklin et al., 2020; Govender et al., 2017; Patterson et al., 2015). In two studies, researchers reported that the experience of pain hinders the participants' abilities to fully participate in swallowing treatments (Checklin et al., 2020; Govender et al., 2017). Weight loss also was noted as a physical symptom for the participants of three similar studies (Checklin et al., 2020; Nund et al., 2014a; Nund et al., 2014b). Along with this cohort of participants, individuals in two other studies reported altered taste sensations (Checklin et al., 2020; Nund et al., 2014b). Three additional studies highlighted trismus as a prominent symptom, which often impacts the participants' abilities to masticate and control oral boluses (Checklin et al., 2020; Nund et al., 2014b; Patterson et al., 2015).

Emotional and psychological reactions occurred after the onset of dysphagia for many individuals within this study. Some psychological experiences of participants in this study were reflective of participant experiences reported in other studies. The feeling of frustration was a common experience for individuals with HNC and dysphagia in three other articles as well as in this study (Dawson et al., 2019; Nund et al., 2014b; Patterson et al., 2015). The participants in both this study and others described a feeling of acceptance at a point in time following cancer treatments (Nund et al., 2014a; Nund et al., 2014b). Another common prevalent feeling amongst participants in this study and others was the feeling of social disconnection due to altered eating abilities. Individuals with HNC in another study described the negative social implications (e.g., lifestyle changes, isolation from others) they experience as a result of their swallowing difficulties (Patterson et al., 2015). Finally, the uncertainty of the future regarding one's health was a comparable feeling amongst individuals in this study and others (Checklin et al., 2020; Dawson et al., 2019).

Research Question 2: What Factors Created Barriers to Positive Clinical Experiences for Individuals With HNC Who Have Been Treated for Dysphagia by An SLP in the United States?

The individuals in this study received timely care when SLPs were automatically included in their integrated care teams. However, some participants in this study did not receive a referral for speech therapy services until after developing dysphagia and the associated complications (e.g., aspiration pneumonia). In a study by Lowe and Nobriga (2021), semi-structured interviews were conducted with 18 individuals with HNC who resided in a rural area. When asked about access, less than half of the participants (i.e., 8 of the 18 participants) were seen by an SLP while receiving cancer treatments. In comparison to this study, three of the six participants received delayed speech pathology referrals while the others had ready access to SLP referrals during or before cancer treatments. A direct comparison between this study and the study utilizing only rural participants is complex as the location of all individuals in this study is unknown. In this study, two participants shared that they received treatment within large, metropolitan cities within the U.S. None of the participants specifically mentioned living or receiving treatment in a rural setting in the current study. In another article, all participants with HNC felt the initiation time of their speech pathology services was suitable (Checklin et al., 2020). The variability in the results of all three studies demonstrates that referrals to speech pathology services for individuals with HNC are inconsistent among different healthcare providers.

Ideally, all clients with HNC should be referred to SLP services as soon after their initial diagnosis as possible. Conducting instrumental swallowing evaluations on individuals with HNC prior to their cancer treatments can provide important information about clients' pre-cancer treatment abilities (Starmer et al., 2011). Studies such as the one conducted by Hutcheson and colleagues (2013) illustrate the value of prophylactic swallowing therapy before cancer intervention begins. In this retrospective study conducted with individuals with HNC located in the pharynx, the authors aimed to better understand how adherence to preventative dysphagia interventions impacted the participants' abilities to intake food orally following radiation treatments. The findings demonstrated that individuals who exercised and continued eating orally utilized alternative nutrition (e.g., feeding tubes) the least and ate a regular diet longer. Of course, only clients who are referred to SLPs in a timely fashion will derive benefits from pre-treatment swallowing services.

Financial access appears to vary across individuals with HNC in the U.S. In the same study as discussed above by Lowe and Nobriga (2021), participants reported that the costs associated with cancer treatments impacted them financially. Specifically, these participants discussed difficulty keeping up with paying their bills (Lowe & Nobriga, 2021). However, the participants in the present study expressed no financial barriers as a component of their experience. One of the differences between these participant cohorts is the urban and metropolitan makeup of the groups. The participants who mentioned financial barriers all resided in rural areas, which may contribute to the differences in these findings.

When asked about the valuable aspects of their experiences with dysphagia therapy, the participants described a variety of elements. The most prominent components that added value to their treatments included that SLPs were patient, ensured goals were realistic, participated in managing participant expectations, and provided adequate education or counseling. Recommendations from another study were similar in that the participants benefited from receiving adequate time in speech therapy, which is reflective of patience displayed by SLPs (Dawson et al., 2019). Participants in both studies made positive connections between positive treatment experiences and being provided with adequate time.

Another shared perspective between the experiences of these participant groups was finding importance in patient education throughout dysphagia treatments (Dawson et al., 2019). Checklin and colleagues (2020) found that participants with HNC also alluded to the benefit of being adequately educated and informed by their SLPs when receiving dysphagia treatments. Finally, participants in this study found difficulty with managing expectations of their abilities during and after receiving cancer interventions. Similarly, participants in another study discussed the evolving expectations they experienced through their journeys with cancer and during survivorship (Nund et al., 2014a).

Across many of these articles, participants mentioned how SLPs play a role in addressing their psychological needs in addition to their physical needs (Checklin et al., 2020; Dawson et al., 2019; Nund et al., 2014a). It was recommended in two other articles that SLPs take a comprehensive or holistic approach to dysphagia care to address psychological and physical needs present for individuals with HNC (Checklin et al., 2014; Nund et al., 2014b).

Limitations and Future Directions

Although this study provides valuable insight into the treatment experiences and thoughts of these participants, some changes and additions could be made to further explore the perspectives of individuals with HNC and dysphagia. The data presented are only representative of the six individuals who participated in this study. The extent to which the findings of this study reflect the experiences of other individuals with HNC and dysphagia is unknown. Findings from this study are intended to serve as a starting point for SLPs providing services to the HNC population. The information shared from the interviews conducted in this study is intended to serve as a resource to be utilized in tandem with other evidence-based resources, individualized information about clients, and clinical expertise. When interpreting the results of this study, several limitations should be considered. These limitations can be addressed by conducting future replications or contributing novel studies adding to this area of study.

When recruiting participants for the study, the prerequisites included being at least eighteen years old, being able to answer questions, having a history of HNC and dysphasia, and having experience working with a U.S.-based SLP for at least six sessions. These conditions did not ensure certain numbers of people were represented across various ethnicities, sexes, and types of cancer. When asked demographic questions, participants voluntarily disclosed the sex with which they identify. Five of the participants identified as males and one participant identified as a female, creating a sex bias. The inclusion of more participants who are female could provide a more well-rounded representation of individuals with HNC.

All individuals who participated in this study were Caucasian. Therefore, there is no representation of people of color within this sample of participants. We know that systemic racism influences how people of color experience the healthcare system and has a deleterious effect on the ability of people of color to access appropriate services (Boynton-Jarret et al., 2021; Feagin & Bennefield, 2014). Future studies should include participants representing a variety of ethnicities and races. Recording and analyzing the perspectives of people who are impacted by systems of oppression such as racism will help SLPs develop a better understanding of the facilitators and barriers that clients from different backgrounds encounter when they receive dysphagia services.

The socioeconomic statuses of the participants in this study are unknown. None of the participants in this study reported any financial barriers preventing them from accessing care. It is thus highly likely that the sample was inadvertently composed of people with a fair amount of financial stability and access to resources. It is almost certain that people with less money and access to resources would have reported more difficulty in obtaining resources. A future line of research could investigate how the socioeconomic statuses of individuals with HNC impacts their abilities to access treatments for dysphagia.

Another factor to consider is the range of cancer diagnoses represented by the participants in this study. The participants in this study had cancer located in the tongue, lymph nodes, tonsils, and pharynx. Individuals with malignant tumors in the pharynx, nasal cavity, and paranasal sinus were not included in this study. The extent to which the experiences of an individual with one location of HNC track those of others with different tumor locations is unknown. To better represent a larger population of individuals with HNC in future studies, having more representation of individuals with various locations of tumors could be beneficial. Generally, replicating this study to represent a larger number of individuals would provide the rich data necessary to better inform patient-centered dysphagia treatments.

Participants were not provided with an incentive for their engagement in this study. Those who participated willfully volunteered their time and effort. Some participants expressed that they wanted to “help other people with head and neck cancer.” One participant mentioned that he wanted to participate in this study to give back to the speech pathology profession as he had very positive experiences with his dysphagia treatment. Given this rationale, the participants may have been more inclined to volunteer for this study if they had positive experiences in dysphagia treatment. To develop a broader and deeper understanding of how clients experience and evaluate SLP services, future studies should attempt to recruit clients who are not as positive about the treatments they received. By focusing on service ‘failures’, researchers could develop further insights about how to ensure treatment better aligns with client values and perspectives.

This study was completed with participants who were in the phase of cancer remission sharing their experiences in hindsight. In future directions of this study, gaining the experiences of individuals with HNC in the U.S. before and during their cancer interventions could provide rich insights into the immediate needs and desires of individuals with HNC and dysphagia.

Another significant factor that varied within this group of participants was the timeliness of their speech pathology referral. Further investigation of the experiences of individuals who received referrals before undergoing treatment compared to after their cancer treatments have ended could provide valuable insight into the most effective time to provide speech pathology referrals.

Clinical Implications

The interviews and analysis conducted for this study provide practicing clinicians with several clinical implications. These insights are based on data provided by people with HNC who received dysphagia services. While it is not possible to generalize from one qualitative study to all people with HNC, qualitative studies can provide access to one set of perspectives that provide initial background information and common issues clinicians can consider. SLPs who work with clients in this population should consider the findings presented here and in other similar qualitative studies when treating clients. Thinking about how other clients have experienced swallowing services can help orient SLPs to the values and perspectives of a given person in their case load.

Clinicians should be aware that their clients with head and neck cancer may develop treatment side effects that affect swallowing, and regularly check in with clients and other medical professionals about treatment progression and complications. Regular and open communication with clients about their ability to stick to a program and about whether or not recommendations are exacerbating side effects is extremely valuable; one recommendation made by a participant in this study was to complete frequent check-ins and reminders with the patient to promote participant adherence. Since clients in this population are likely to have difficulty adhering to treatment, it is essential that SLPs build partnerships with clients so that clients play a leading role in determining the plan of care. Moreover, SLPs should focus on educating clients about the reasoning behind recommendations. To ensure that information is accessible to this group of individuals, SLPs can provide recommendations or information in multiple modalities. Then, clinicians can provide verbal explanations for the participants while giving them access to the information in other settings.

One way to maximize the effectiveness of treatments for individuals with compounding difficulties is to address the specific needs and barriers of each person with HNC. Prioritizing the treatment of symptoms most significantly impacting an individual’s life may facilitate improved experiences for these individuals.

It is important to set manageable goals for individuals with HNC and dysphagia. When prescribing treatment recommendations, it is important that the individual can feasibly adhere to the recommendations while managing any co-occurring physical or psychological difficulties that arise. Determining a minimum exercise goal for a participant could be a way to motivate participants to adhere to treatments. Further, clinicians should try to set up treatment regimens that account for the side effects clients experience. If elements of a plan of care become difficult to implement or appear to be aggravating cancer treatment side effects, clinicians should modify their approach. SLPs should regularly consult with other team members such as dietitians, pharmacists, doctors, and others to determine how best to address the negative consequences of cancer treatments. The expertise of other professionals may help to alleviate side effects and promote client participation in dysphagia therapy.

Unsurprisingly, participants reported that changes to swallowing and eating abilities had emotional and social impacts. SLPs should be equipped to consider and assist with both psychological and physiological concerns regarding dysphagia. This finding underscores the need for SLPs to provide basic counseling services to clients. Simple practices that can promote well-being include regularly asking about clients' mental health, conducting brief and appropriate quality of life assessments related to swallowing such as the Swallowing Quality of Life Measure (SWAL-QOL), encouraging behavioral activation (i.e., encouraging clients to think about and actually engage in activities that they enjoy), and creating environments in which clients feel listened to and have their feelings validated (Kanter et al., 2010; McHorney et al., 2000). SLPs should investigate what mental health resources are available to them in the particular settings where they work and refer clients who report difficulties coping with and adapting to their illnesses to other professionals such as counselors.

One common experience in this study was that participants were not aware of the role SLPs take in dysphagia management. Additionally, the individuals who received delayed referrals were treated by numerous healthcare professionals who reportedly did not recommend speech therapy services for these individuals. This suggests that at local, regional, national, and international levels, SLPs and thier professional bodies should advocate for the establishment of protocols that ensure that all individuals with HNC are referred to SLPs upon diagnosis. Policies of this kind could reduce the effects of dysphagia and related symptoms during and after cancer treatment. This referral recommendation is especially important for individuals served by an integrated team that does not include SLPs.

Further, SLPs should intensify our efforts to educate other professionals about dysphagia. Small scale efforts might include SLPs contacting allied health and other medical workers and informing these colleagues about the dysphagia services we provide. In-service trainings, attending and presenting at conferences for other professionals, or publishing in journals outside of our own discipline are just a few ideas that might help us reach other medical workers. On a national level, organizations such as ASHA could devote some of their considerable resources to spreading awareness about dysphagia. Improving the knowledge of the general public about dysphagia and the associated healthcare professionals will improve the likelihood that people with dysphagia are referred to services at appropriate times.

Conclusion

When providing dysphagia treatment, SLPs must provide EBP centered around an individual’s perspective. Countless chronic and acute challenges are commonly faced by individuals with HNC and dysphagia. To improve evidence-based services, SLPs should consider the compounding psychological and physiological difficulties contributing to an individual’s abilities to effectively participate in speech therapy. By learning the perspectives of individuals with HNC and dysphagia, clinicians can adapt provided treatments to better address the needs of this population. In this study, six participants shared their ideas about facilitators of effective treatment experiences and barriers to positive treatment experiences. The themes described investigated the participants’ experiences with accessing referrals, managing physical challenges, accessing services financially, and navigating psychological reactions. Further studies are warranted to gain information on this population due to the complexity and variability amongst individuals with HNC.

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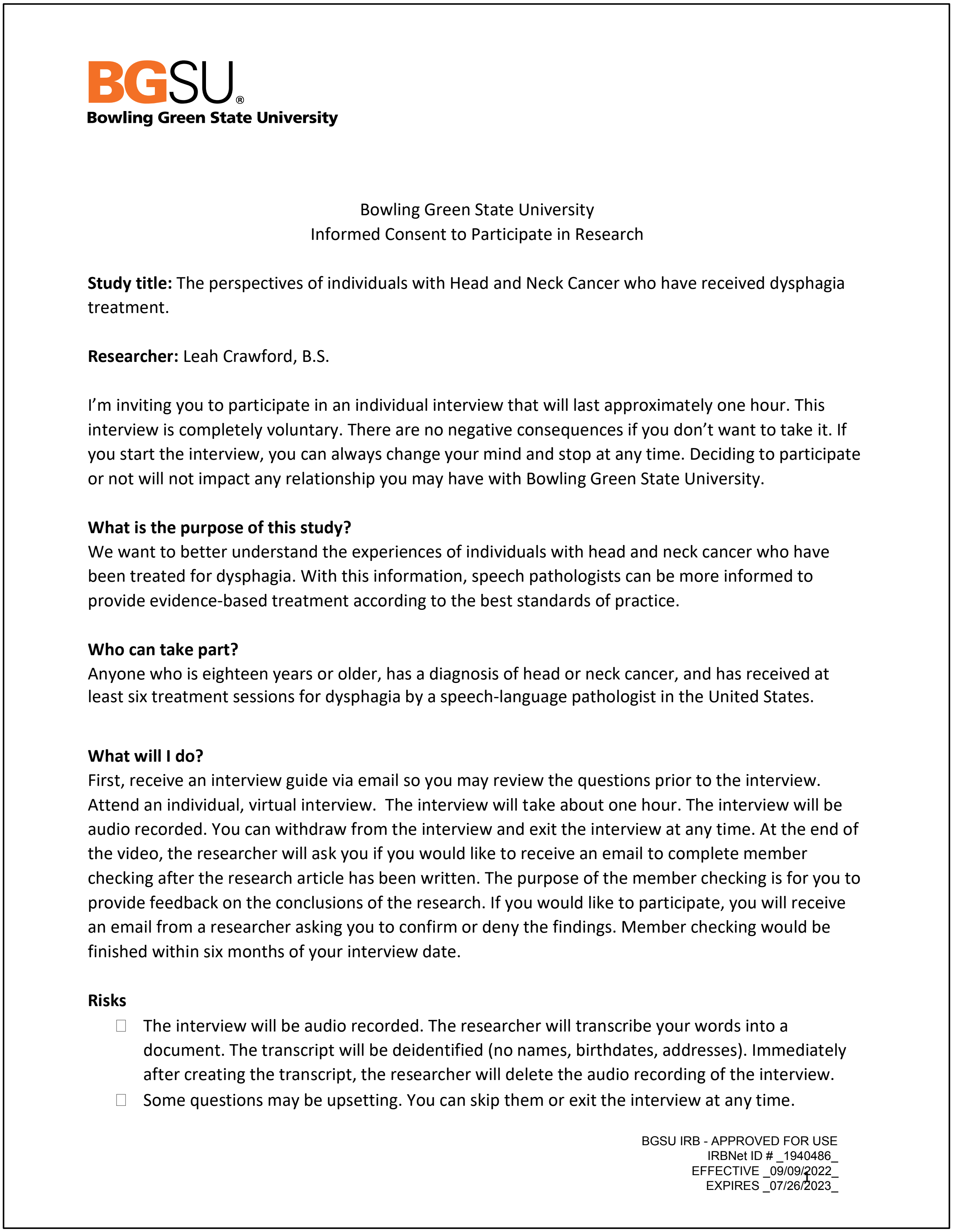
APPENDIX A. INFORMED CONSENT



BGSU®
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Bowling Green State University
Informed Consent to Participate in Research

Study title: The perspectives of individuals with Head and Neck Cancer who have received dysphagia treatment.

Researcher: Leah Crawford, B.S.

I'm inviting you to participate in an individual interview that will last approximately one hour. This interview is completely voluntary. There are no negative consequences if you don't want to take it. If you start the interview, you can always change your mind and stop at any time. Deciding to participate or not will not impact any relationship you may have with Bowling Green State University.

What is the purpose of this study?

We want to better understand the experiences of individuals with head and neck cancer who have been treated for dysphagia. With this information, speech pathologists can be more informed to provide evidence-based treatment according to the best standards of practice.

Who can take part?

Anyone who is eighteen years or older, has a diagnosis of head or neck cancer, and has received at least six treatment sessions for dysphagia by a speech-language pathologist in the United States.

What will I do?

First, receive an interview guide via email so you may review the questions prior to the interview. Attend an individual, virtual interview. The interview will take about one hour. The interview will be audio recorded. You can withdraw from the interview and exit the interview at any time. At the end of the video, the researcher will ask you if you would like to receive an email to complete member checking after the research article has been written. The purpose of the member checking is for you to provide feedback on the conclusions of the research. If you would like to participate, you will receive an email from a researcher asking you to confirm or deny the findings. Member checking would be finished within six months of your interview date.

Risks

- The interview will be audio recorded. The researcher will transcribe your words into a document. The transcript will be deidentified (no names, birthdates, addresses). Immediately after creating the transcript, the researcher will delete the audio recording of the interview.
- Some questions may be upsetting. You can skip them or exit the interview at any time.

BGSU IRB - APPROVED FOR USE
IRBNet ID # _1940486_
EFFECTIVE _09/09/2022_
EXPIRES _07/26/2023_

APPENDIX B. INTERVIEW GUIDE

1. How much therapy did you receive?
2. Do you currently receive speech therapy services?
3. Tell me the story of your experience with dysphagia treatment.
4. What about the therapy was helpful to you?
5. Can you provide an example of a therapy experience that went well?
6. What about the therapy was negative?
7. Can you provide an example of a therapy experience that went poorly?
8. What could your speech therapist have done to improve their services?
9. Did you feel that you received enough speech therapy sessions or too many speech therapy sessions?
10. How was your experience gaining access to speech services?
11. What specific barriers did you experience trying to access speech services?
12. Were the speech therapy services worth your time and money?
13. How did the speech pathologist do in answering your questions?
14. How did the therapist do at meeting your goals?
15. Did you feel supported by your speech therapist when receiving services?
16. How did you feel about managing your symptoms after you were discharged from swallowing therapy?
17. Is there anything else that you would like to share?
18. Do you have any questions for me?