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The Role of Speech-Language Pathologists in Swallowing Treatment of Individuals with HIV/AIDS

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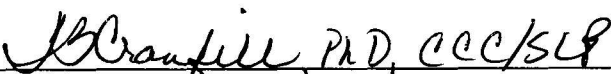
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The Role of Speech-Language Pathologists in Swallowing Treatment of Individuals with
HIV/AIDS

By

Sarah Warner

Thesis Approved:


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Date 4-08-2015

The Role of Speech-Language Pathologists in Swallowing Treatment of Individuals with
HIV/AIDS

By

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Bachelor of Arts
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Submitted to the Faculty of the Graduate School of
Eastern Kentucky University
in partial fulfillment of the requirements
for the degree of
MASTER OF ARTS IN EDUCATION
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DEDICATION

This thesis is dedicated to my parents, Craig and Lisa Warner, for their unwavering support throughout my undergraduate and graduate career.

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ABSTRACT

The role of speech-language pathologists (SLPs) in the assessment and treatment of dysphagia in individuals living with HIV/AIDS is relatively absent from the literature. Dysphagia is described as difficulty swallowing that can be caused by oral indicators, structural dysfunction, and neurological disease (Bladon & Ross, 2007; Bobba et al., 2007; Nkuize et al., 2010). Dysphagia is a prevalent symptom secondary to the HIV/AIDS virus, yet dysphagia in the HIV/AIDS population often goes untreated (Bladon & Ross, 2007). One way to improve assessment and treatment of dysphagia is to ensure medical professionals are knowledgeable of the communication and swallowing disorders that can occur in this population. There is an increasing demand for the professional services of SLPs in the clinical assessment and treatment of individuals with dysphagia secondary to HIV/AIDS.

A survey design for the current study examined trends, attitudes, and opinions of individuals living with HIV/AIDS by studying a sample of that population (Creswell, 2009). The design allowed a web-based survey to be available to individuals living with HIV/AIDS while maintaining anonymity of the participants.

Twenty-one individuals living with HIV/AIDS responded to this survey. All participants reported experiencing at least one symptom related to dysphagia. Eight participants indicated receiving services from an SLP for dysphagia symptoms. Overall, results from the current study suggest SLPs are not involved in the care of individuals with dysphagia symptoms secondary to HIV/AIDS.

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Chapter 1

Introduction

In the United States, over one million people are living with the human immunodeficiency virus (HIV), and 20% of those living with HIV are unaware of their infection ("HIV/AIDS 101," 2012). The use of highly active antiretroviral treatment (HAART) has enabled individuals with HIV and acquired immunodeficiency syndrome (AIDS) to live longer with the infection. Consequences of increased survival rate are evident in the additional symptoms experienced by people living with HIV/AIDS (Anthony & Bell, 2008; Bladon & Ross, 2007; Halvorsen, Moelleken & Kearney, 2003; Karus, Raveis, Alexander, Hanna, Selwyn, Marconi, & Higginson, 2005; Nath, Schiess, Venkatesan, Rumbaugh, Sacktor, & McArthur, 2008; Nkuize, Wit, Muls, Arvanitakis, & Buset, 2010).

Potential symptoms affecting the quality of life of individuals living with HIV/AIDS could include opportunistic infections, hepatitis, tuberculosis, oral health issues, cancer, cardiovascular health problems, diabetes, kidney disease, and dementia ("HIV/AIDS 101," 2012). A secondary symptom of oral health issues, cancer, and dementia is swallowing dysfunction, clinically titled "dysphagia" (Anteyi, Thacher, Yohanna, & Idoko, 2003; Halvorsen et al., 2003; Kallail, Downs, & Scherz, 2008; McCabe, Sheard, & Code, 2008; McNeilly, 2005; Nkuize et al., 2010; Vasquez, 2000; Swanoepoel & Louw, 2010).

Dysphagia is one symptom that can have a negative impact on the quality of life of HIV/AIDS patients. Oral lesions, structural dysfunction of the swallowing mechanism,

neurological disease, and neurological infection can cause dysphagia (Anteyi, Thacher, Yohanna, & Idoko, 2003; Halvorsen et al., 2003; Kallail, Downs, & Scherz, 2008; McCabe, Sheard, & Code, 2008; McNeilly, 2005; Nkuize et al., 2010; Vasquez, 2000; Swanoepoel & Louw, 2010). People living with HIV/AIDS who report swallowing difficulty often do not receive sufficient treatment or intervention for the symptom (Bobba, El-Dika, & Arsura, 2007; Karus et al. 2005; McNeilly, 2005). Due to the increase of additional pathologies in this population, the assessment and treatment of these individuals by a speech-language pathologist is vital (Bladon & Ross, 2007; Halvorsen et al., 2003).

Chapter 2

Literature Review

HIV

HIV is a virus that can only infect humans and weakens the immune system by destroying cells that function to fight disease and infection (McNeilly, 2005). During the first stage of HIV, labeled acute infection, large amounts of the virus are produced in the body. In the second stage, clinical latency, HIV reproduces at very low levels but is still active. Acquired immunodeficiency syndrome (AIDS) is the last and most severe stage of HIV ("HIV/AIDS 101," 2012). HIV infection can result in damage to the central nervous system (CNS) and the peripheral nervous system (PNS) (Anthony & Bell, 2008; Mathew & Bhat, 2007). Due to the damage of the CNS and/or PNS, and vulnerability to other opportunistic and infectious diseases, people living with HIV/AIDS often present with additional symptoms separate from the HIV/AIDS infection. Of these symptoms, pathologies related to communication and swallowing disorder can occur. Related pathologies include, but are not limited to dysphagia, odynophagia, xerostomia, neurocognitive disorder, neurological disease and infection, oral lesions, voice disorders, hearing loss, and language disorders (Bladon & Ross, 2007; Halvorsen et al., 2003; Matthew & Bhat, 2007; McCabe et al., 2008; McNeilly, 2005; Nath et al., 2008).

Use of HAART to Treat HIV. Currently, there is no single drug or treatment that can cure HIV/AIDS. Many individuals living with HIV/AIDS take antiretroviral treatments. When three or more antiretroviral treatments are taken in combination, it is referred to as highly active retroviral treatment (HAART) ("HIV/AIDS 101", 2012). The years before

HAART was introduced are referred to as the pre-HAART era. Conversely, the years after HAART are labeled the HAART or post-HAART era. While additional pathologies were more commonly observed in AIDS patients in the pre-HAART era, comorbidities are becoming more common in people living with HIV in the HAART era (Anthony & Bell, 2008).

In the era of HAART, the survival rate of people with HIV has increased. This treatment has also slowed the development of HIV into AIDS, increasing the amount of time from stage 1 to the final stage of AIDS (Bladon & Ross, 2007; Karus et al., 2005). Due to the complex nature of the disease, there are many variables that can cause additional symptoms in patients with HIV. Some variables are, but not limited to, the HIV infection itself, prescribed medications, damage to the CNS and/or PNS, and suppression of the immune system (Anthony & Bell, 2008; Bladon & Ross, 2007; Nkuize et al., 2010; Robinson-Papp et al., 2008). Although the progression of the disease is taking longer with the advent of HAART, individuals continue to experience comorbidities secondary to HIV/AIDS that impact functioning in day-to-day life.

Dysphagia and HIV/AIDS

Using a one-to-one-semi-structured interview schedule regarding swallowing symptoms, Bladon and Ross (2007) interviewed 120 adults with HIV. Part of the interview schedule included a chart of 27 swallowing symptoms. Bladon and Ross reported that 79.2% of participants in the study were experiencing at least one symptom within the interview schedule. The most commonly reported symptoms were dry mouth, pain on swallowing, and difficulty swallowing. Conclusions of the study

revealed that dysphagia, odynophagia, and xerostomia (dry mouth) are frequent comorbidities experienced by individuals living with HIV/AIDS. What the researchers did not report were the degree and types of treatment provided to the individuals with swallowing complaints.

Dysphagia is a prevalent symptom secondary to the HIV/AIDS virus. Dysphagia is described as difficulty swallowing and can be caused by oral indicators, structural dysfunction, and neurological disease (Bladon & Ross, 2007; Bobba et al., 2007; Nkuize et al., 2010). Odynophagia is an additional symptom reported by people living with HIV/AIDS. It is painful swallowing that can become severe enough to create a fear of eating. Patients experiencing odynophagia also report a lack of salivary secretions causing xerostomia. Xerostomia can lead to reduced sensation of the oral cavity, reduced bolus transport in the oral and pharyngeal cavities, decreased ability to chew, and reduced sensation of the oral cavity (Bladon & Ross, 2007; McNeilly, 2005; Swigert, 2007).

Oral indicators often found in individuals living with HIV/AIDS include oral candidiasis, a yeast like infection of the mouth and esophagus, and esophagitis, a fungal infection (Nkuize et al., 2010; Swanoepoel & Louw, 2010). These conditions can result in painful swallows in multiple phases and during bolus manipulation in the oral phase of the swallow. Neurological disease and infection are also commonly associated with a diagnosis of HIV/AIDS, and can impede the ability to swallow. Neurological manifestations found in individuals living with HIV/AIDS include HIV/AIDS associated dementia, HIV encephalopathy, and progressive multifocal leukoencephalopathy (PML)

(Anthony & Bell, 2008; Halvorsen et al., 2003; Kallail et al., 2008; Nath et al., 2008; Robinson, Byrd, Mindt, Oden, Simpson, & Morgello, 2008; Swanoepoel & Louw, 2010). Impaired cognitive functioning resulting from neurological manifestations can result in decreased memory, muscle strength, and motor planning or execution. These factors can cause abnormal or inefficient swallowing in individuals living with HIV/AIDS.

Dysphagia and Effects on Quality of Life (QOL). The World Health Organization defines quality of life (QOL) as a person's overall well being in relation to physical health, psychological health, social relationships, and the environment (World Health Organization [WHO], 2014). QOL is a unique and multidimensional measure because it is reliant on the perception of each individual. Health-related quality of life (HRQOL) is an additional measure of aspects that affect either mental or physical health. HRQOL is measured based upon an individual's perceptions of physical and mental health including health risks and conditions, functional status, social support, and socioeconomic status (Center for Chronic Disease Prevention and Health Promotion, 2011). The International Classification of Functioning, Disability and Health framework (ICF) outlines the dynamic interaction between dysphagia and contextual factors. These factors include body functions and structures, activities, participation, personal factors, and environmental factors (Bladon & Ross, 2007). Contextual factors in the ICF serve as an indication to how dysphagia can cause adverse effect on the measure of QOL an HRQOL. Examples of the negative impact caused by the factors of the ICF include a decrease in nutritional intake, weight loss, risk for various infections, neurological

disease, inability to partake in meals, modified/alternative feeding, and oral manifestations (Davis, 2008).

Using a symptom scale, Karus et al. (2005) interviewed 376 patients with HIV/AIDS at clinics in Alabama, Baltimore, and New York City. They found that at least 188 (50%) of the participants reported 12 negative health symptoms, one being difficulty swallowing. In addition, it was reported that 40-74% of the participants interviewed reported having eight negative health symptoms, one being dry mouth. The participants described these symptoms as highly frequent, severe, and distressing (Karus et al., 2005). According to the ICF, HIV/AIDS related swallowing difficulty is a health condition that can lead to body function and structures including oral, pharyngeal, and esophageal structures, opportunistic infections, and related medical pathologies. The impact of this health condition, when left untreated, can have a negative effect on the quality of life of persons with living HIV/AIDS (Bladon & Ross, 2007).

When dysfunction in swallowing occurs individuals are at risk for aspiration or penetration that result in compromise of their respiratory status. Halvorsen et al. (2003) defined aspiration as “leakage below the vocal cords”, and penetration as “leakage into the trachea above the level of the vocal cords” (pg. 245). Penetration and aspiration of a bolus increases the risk of acquiring an infection in the lungs such as pneumonia. Halvorsen and colleagues reported that 8 of 17 patients with HIV/AIDS were found to aspirate when presented food boluses by mouth. Of the 8 patients who were aspirating, videofluoroscopy revealed signs of aspiration pneumonia. All patients who exhibited signs of aspiration were later placed on a modified diet either receiving IV feed or tube

feeding. Aspiration pneumonia in individuals living with HIV/AIDS may be detrimental to HRQOL because of the patient's decreased ability to fight disease or infection as well as increased likelihood for hospitalization.

In the era of HAART, HIV associated weight loss and wasting is still common in individuals living with the disease (Jacobsen, Bica, Knox, Wanke, Tchetgen, Spiegelman, Silva, 2003). Jacobsen and colleagues periodically interviewed 415 participants with HIV/AIDS via telephone to study associations between acute weight loss and related symptoms. Results indicated that participants' risk for acute weight loss increased when trouble swallowing and oral symptoms were reported. The authors concluded monitoring symptoms that predict weight loss is essential to reduce adverse effects on quality of life. When doctors and health professionals are aware of risk factors, like trouble swallowing and oral symptoms, management or treatment can be provided to decrease the chances of weight loss. The ICF outlines HIV/AIDS related weight loss as an activity that can lead to a decrease in participation such as not wanting to eat with others or not wanting to eat in public (Bladon & Ross, 2007). QOL is impacted when activities and participation of daily living are decreased due to a health condition.

Dysphagia and Structural Manifestations. Dysphagia can be caused by the dysfunction of the physical structures involved in the four phases of swallowing. Dysfunction of the swallowing mechanism can occur at any individual phase of swallowing, or in combination. For example, oral infections can affect the ability to swallow during the initial (oral preparatory) stages of mastication. It has been estimated that 80-90% of individuals living with HIV/AIDS will present with oral candidiasis, an

often painful infection, at some point during their illness. Untreated oral candidiasis in individuals living with HIV/AIDS can lead to the reduction of food and liquid intake because the individuals avoid the discomfort of eating or swallowing (Vasquez, 2000). The variety of dysphagia conditions is as varied as the individuals living with HIV/AIDS. Some individuals with HIV/AIDS may experience painful swallowing secondary to oral infections, while others experience dysfunction of the swallowing mechanism itself (Anteyi et al., 2003; Halvorsen et al., 2003; Nkuize et al., 2010; Vasquez, 2000; Swanoepoel & Louw, 2010).

In a study by Halvorsen et al. (2003), 17 patients with HIV/AIDS who reported dysphagia or odynophagia were evaluated through the use of videofluoroscopy. All participants exhibited abnormalities in the oral, pharyngeal, and esophageal phases of swallowing. These abnormalities included difficulty manipulating and transporting a bolus to the back of the mouth, poor forward and backward tongue motion, delayed pharyngeal swallow, decreased laryngeal elevation, pooling in the valleculae and pyriform sinus, esophageal dysmotility, penetration, and aspiration (Halvorsen et al., 2003). The authors additionally reported that oral infections such as esophagitis were noted in four of the 17 participants examined. A significant finding of this study documented that swallowing dysfunction can occur separate from infectious involvement. This finding revealed that dysfunction of the swallowing mechanism itself caused dysphagia and odynophagia in the majority of the participants (Halvorsen et al., 2003).

Individuals living with HIV/AIDS are also susceptible to various infections that can manifest in the oral cavity and throat. Nkuize and colleagues (2010) conducted a review of 706 patients with HIV who underwent upper gastrointestinal endoscopy. The participants were divided into three groups labeled pre-HAART (1991-1994), early HAART (1999-2002), and recent HAART (2005-2008). They observed the fungal infection, candida oesophagitis, in 16 – 23% of the participants. Reflux symptoms reportedly increased in the early HAART and recent HAART groups. The authors suggested that many patients with HIV/AIDS would likely present with upper gastrointestinal symptoms during the course of their disease. Furthermore, the reflux symptoms and oral lesions could lead to dysphagia or odynophagia.

Similarly, Anteyi et al. (2003) examined 500 patients living with HIV to describe the prevalence of oral lesions through the use of structured interview and oral/perioral examinations. The authors reported 53% (266 participants) presented with oral lesions. While the oral candidiasis lesions were the highest frequency, other prevalent lesions included oral ulcerations, hairy leukoplakia, and oral Kaposi's sarcoma. The high prevalence of oral lesions in these individuals living with HIV/AIDS is important. Oral lesions are commonly associated the inability to eat or swallow which would further compromise the health status of individuals with HIV/AIDS (Anteyi et al., 2003).

Dysphagia and Neurological Disease. It is estimated that HIV/AIDS associated dementia affects 10 – 20 percent of people living with HIV/AIDS (Anthony & Bell, 2008). HIV/AIDS associated dementia is a neurocognitive disorder that is caused by the HIV infection (Kallail et al., 2008; McCabe et al., 2008). The HIV infection enters the blood

stream and is then circulated throughout the central nervous system. HIV/AIDS associated dementia can cause impairment of neurocognitive functions that most often result in executive, motor and memory deficits (Kallail et al., 2008).

In addition to HIV/AIDS associated dementia, a number of neurological diseases and infections can occur in individuals with HIV/AIDS. Opportunistic infections found in the brain of individuals living with HIV/AIDS include cytomegalovirus, herpes simplex virus, and the Epstein Barr virus (McNeilly, 2005). CNS toxoplasmosis, CNS lymphomas, and HIV encephalopathy are included in neurologic diseases commonly found in individuals living with HIV/AIDS. After computed tomography (CT) and magnetic resonance imaging (MRI), Halvorsen et al. (2003) found that 4 of 9 patients presented with neurologic infections and diseases. Four patients exhibited abnormal swallowing secondary to the neurological condition. When individuals living with HIV/AIDS experience secondary neurologic conditions, deficits related to executive functioning, motor programming, and memory can be experienced.

Memory deficits are some of the initial symptoms that are observed in patients with HIV/AIDS associated dementia (Nath et al., 2008). The damage caused by the circulation of HIV infected cerebrospinal fluid (CSF) is what often leads to memory deficits (Anthony & Bell, 2008). Using MRI, Nath et al. observed that HIV infected CSF caused atrophy within different regions of the brain. In particular, lesions appearing in the cerebral cortex contribute to memory deficits in individuals with HIV/AIDS associated dementia. When an individual experiences memory deficits, ability to swallow can be greatly affected secondary to decreased oral sensation, awareness of

environment, and awareness of actions. As HIV/AIDS associated dementia progresses, so do the communicative disorders that coexist with the disease. Memory deficits compounded by communication disorders (e.g., perseverating on a topic or decline in sentence structure) add complexity to the already failing health condition of the individual with HIV/AIDS. For example, individuals may require prompts to complete a meal, not be able to recall whether they have eaten that day, or fail to recognize the steps to preparing a meal. Communication deficits may impede their ability to communicate their wants and needs such as thirst, hunger, or discomfort when eating as well as physiological dysphagia symptoms.

HIV/AIDS associated dementia can also cause impairment in the motor function abilities of people living with the infection. Neuroimaging of patients with HIV/AIDS associated dementia reveals a reduction in white matter and grey matter in the basal ganglia (Anthony & Bell, 2008). The primary function of the basal ganglia is to regulate motor movement. The observed neuronal loss in this region, caused by the HIV/AIDS associated dementia, is what leads to deficits in motor function. Swallowing is predominately not under volitional motor control. Dysphagia can be present when there is a loss or delay in the message to the muscles or bodily structures involved in the phases of swallowing.

In a study by Robinson-Papp et al. (2008), the motor function of individuals with neurocognitive diseases was assessed. The participants included individuals with HIV/AIDS associated dementia. Overall, the researchers found that approximately 50 percent of participants presented with mild motor impairment, and 25 percent of

participants presented with severe motor impairment. It was reported that the motor impairment of participants with HIV/AIDS associated dementia was worse and most severely abnormal compared to other neurocognitive diagnoses (Robinson-Papp et al., 2008). Swallowing and feeding require unique fine motor movements that can be impacted secondary to neurological disease. These results identified the increased risk for individuals with HIV/AIDS to have dysphagia secondary to neurocognitive disease.

Treatment

Although there is an apparent need for the treatment of swallowing disorders among the HIV/AIDS population, many individuals with the disease may not receive sufficient treatment or therapy for their symptoms. Karus et al. (2005) found that of the participants who reported swallowing difficulty, only half received treatment. In addition, Bladon and Ross (2007) reported that only 33.7% of their participants who reported swallowing difficulties received treatment. While some individuals with HIV/AIDS do not receive treatment for their swallowing difficulties, those who do may not receive appropriate treatment. Medical treatment is used to attempt to treat swallowing difficulties, but often individuals do not have access to alternative resources such as a speech-language pathologist (Bladon & Ross, 2007). Evaluating, diagnosing, and managing dysphagia can be achieved through a team approach. Speech-language pathologists have expertise in diagnosing and treating dysphagia. When team members are educated with regard to the roles of other professionals, collaborative problem solving and referral can take place (Swigert, 2007). For example, if a patient with

HIV/AIDS is experiencing dysphagia, a team member could refer the patient for further evaluation by a speech-language pathologist.

Involvement of Speech-Language Pathologists in HIV/AIDS Related Dysphagia

A speech-language pathologist can provide professional expertise in the assessment and treatment of swallowing disorders (Ad Hoc Committee on the Scope of Practice in Speech-Language Pathology, 2007). Treatment of dysphagia can improve medical outcomes and overall quality of life for individuals living with HIV/AIDS (Ashford, Logemann, & McCullough, 2004). Through objective measures, a speech-language pathologist can use instrumental methods to assess an individual's swallowing. Examples of instrumental methods may include a modified barium swallow (MBS) and fiberoptic endoscopic evaluation of swallowing (FEES). Furthermore, speech-language pathologists can use subjective measures to assess swallowing such as a bedside clinical examination or physical examination of the oral and swallowing structures (Ashford et al., 2004; Swanoepoel & Louw, 2010; Walker, 2011). A speech-language pathologist can also provide treatment for swallowing disorders through stimulation therapies, dietary management, compensatory strategies, biofeedback therapy, and strength and exercise therapies (Swigert, 2007). By administering an assessment and treatment plan, speech-language pathologists can decrease hospital length of stay, need for nonoral feeding, nutritional problems, and costs related to pneumonia associated with aspiration (Ashford et al., 2004).

Individuals living with HIV/AIDS can experience a wide range of additional symptoms separate from the infection itself. There are many variables involved when

trying to determine what is causing swallowing difficulties in HIV/AIDS patients. To help better evaluate the symptoms commonly experienced by HIV/AIDS patients, more detailed assessment needs to occur (Karus et al., 2005). If symptoms associated with swallowing difficulty are better assessed, treatment and management of these issues could be tailored to the individual patient (Bobba et al., 2007). One way to improve assessment and treatment is to ensure medical professionals and other individuals involved in the care of HIV/AIDS patients are knowledgeable of the communication and swallowing disorders than can occur in people living with HIV/AIDS (Halvorsen et al., 2003; McNeilly, 2005). There is an increasing demand for the professional services of speech-language pathologists in the clinical assessment and treatment of individuals with dysphagia secondary to a diagnosis of HIV/AIDS (Bladon & Ross, 2007). Yet, the role of speech-language pathologists in the assessment and treatment of people with HIV/AIDS is relatively absent from the literature.

Purpose

The purpose of the current study was to explore the involvement of speech-language pathologists in the assessment and/or treatment of people living with HIV/AIDS. It is reported that people living with HIV/AIDS can suffer from a number of swallowing difficulties or disorders, and that sometimes these problems go untreated (Bladon & Ross, 2007). Services from speech-language pathologists were examined with regard to evaluation and treatment for individuals with HIV/AIDS.

Research Questions

The following study questions were explored:

1. What dysphagia symptoms are being experienced by individuals living with HIV/AIDS?
2. Are individuals living with HIV/AIDS being assessed or treated by a speech-language pathologist for these dysphagia symptoms?
3. If so, what is the scope and degree of the evaluation and treatment performed by a speech-language pathologist?

Chapter 3

Methods

Design

A survey design examined trends, attitudes, and opinions of individuals living with HIV/AIDS by studying a sample of that population in the current study. The design allowed a web-based survey to be available to individuals living with HIV/AIDS while maintaining anonymity of the participants.

Participants/Recruitment

Participants included individuals who were diagnosed with HIV or AIDS. The Eastern Kentucky University Institutional Review Board approved this study before it was distributed to participants. Consent to participate in the study was implied since participation was voluntary and could be discontinued at any time. One participant refused participation since no monetary compensation for participation was provided.

The principal investigator (PI) contacted various AIDS service groups in Illinois, Indiana, Kentucky, Ohio, and Washington to distribute the web-based survey in a national effort toward data collection. Service groups were contacted because they were more likely to provide support for individuals living with HIV/AIDS who were willing to participate in the study. The majority of AIDS service groups contacted were national organizations with numerous state chapters. However, most AIDS service groups contacted did not respond to the PI. Because of protected identifiers, it is unknown from what geographical region respondents were located. The service groups included, but were not limited to, support groups, public health organizations, religious

groups, and health centers. The web link for the survey was distributed by leaders of AIDS service groups or obtained through access to public flyers in order to maintain anonymity of the participants. Recruitment of participants lasted over a period of six months.

Inclusion Criteria

To be included in the study, participants met the following criteria: (1) 18 years or older, (2) diagnosed with a stage of HIV or AIDS (self-reported), and (3) native English language speakers. Participants were excluded if they were under the age of 18 or did not have a reported diagnosis of HIV or AIDS.

Sampling/Sample Size

Three sampling paradigms were implemented to obtain a maximum amount of responses to the study as possible. The first sampling paradigm used was convenience sampling. Convenience sampling occurs when participants are selected because they are available (Creswell, 2009). It was a convenience to send the survey to AIDS service groups who provide services to individuals living with HIV/AIDS. The second type of sampling paradigm was purposive sampling, occurring when participants are handpicked because they had special characteristics necessary for the purpose of the study (Creswell, 2009). The third type of sampling paradigm used was snowball sampling, which occurs when participants recommended study participation to other participants in a chain referral method (Creswell, 2009). It was considered likely that participants referred other participants to this study. The sample size contained 21 responses from

individuals living with HIV/AIDS who experienced swallowing disorders and/or had been assessed or treated by a speech-language pathologist.

Data Collection/Instrumentation

Data were collected by distributing a web link of the survey to AIDS service group leaders or through access to public flyers (Appendix A). The survey contained 14 categorical variables and three open-ended questions (Appendix B). Including open-ended questions allowed participants to expand answers, so they were not restricted to a specific response. Open-ended questions also allowed participants to expand yes or no responses if not a sufficient response.

Data Analyses

Descriptive analyses included the percentage of participants that experienced swallowing difficulty and/or disorder while living with HIV/AIDS, and whether participants had been assessed or treated by a speech-language pathologist for swallowing difficulties. The order of frequency in which swallowing symptoms occurred was calculated from most to least frequent (Table 4.3). Socioeconomic status (SES) formulated by the United States Census Bureau was used to describe SES of the participants (DeNavas-Walt, Proctor, & Smith, 2013). SES was statistically analyzed in a quintile frequency of distribution where values of participant's personal income were divided into five groups of equal frequencies (Appendix C). Analyses of the data described the average length of time participants had been living with the infection, type of treatment received for the infection, type of swallowing symptoms experienced, and the type of swallowing difficulty and/or disorder that was diagnosed.

Open-ended questions were analyzed using a thematic analysis or coding process. Coding was used to organize expanded responses into chunks or segments of texts. This process abbreviated topics into codes, helping to group similar topics or codes together (Appendix D; Creswell, 2009). Prior diagnosis of a swallowing disorder was coded to compare responses. Reasons for being assessed and/or treated by a speech-language pathologist were chunked into a single category. Another coded response included information regarding referral source. Abbreviating this particular topic revealed the type of professionals that referred respondents to a speech-language pathologist. Lastly, the number of times a respondent received professional services from a SLP was analyzed.

Chapter 4

Results

People living with HIV/AIDS can experience a number of swallowing difficulties or disorders, and sometimes these problems go untreated (Bladon & Ross, 2007). The purpose of this study was to identify the involvement of speech-language pathologists (SLP) in the assessment or treatment of people living with HIV/AIDS. Results from a 17-question survey were analyzed using descriptive and inferential statistics.

Demographic Characteristics

Demographic data are presented in Table 4.1¹. There were 21 participants with a mean age of 31.9 years (range 22-43). The sample included 12 (57.14%) male and 9 (42.86%) female participants. A similar distribution of White or Caucasian ($n=9$) and Black or African American participants ($n=8$) was noted. The sample also included three Hispanic or Latino participants, and one participant who indicated his ethnicity as “Black and Hispanic and Latino”. The majority of participants had earned a college degree and reported a mean income within the lowest (1st) quintile. Ten (46.62%) participants had Medicaid, Medicare, or other government issued insurance. The remaining participants reported having insurance through work (28.57%), private insurance (14.29%), or no insurance (9.52%).

Clinical Characteristics. The group mean of time living with HIV/AIDS was 3.83 years (range 2 months – 10 years). Participants who reported receiving assessment or treatment from an SLP ($n=8$) had been diagnosed longer ($m=5.09$ years) than

¹ All tables containing participant characteristic data can be found in Appendix E

participants who had not received assessment or treatment ($m=2.30$ years). A t-test was used to compare groups using an alpha level of .05 for all statistical tests. The difference was found to be statistically significant ($p=0.04$).

A Fisher's test was calculated to examine the relationship between participants' diagnoses (HIV, AIDS) and their intervention group (received SLP services, had not received SLP services). The association between intervention groups and diagnosis was not statistically significant ($p=0.63$). Distribution of diagnoses in the sample was unequal, with 71% of participants having a diagnosis of HIV and 29% with a diagnosis of AIDS (Table 4.2).

The most prevalent treatment medication received was Nucleoside/Nucleotide Reverse Transcriptase inhibitors (NRTIs), followed by Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs).

Dysphagia Symptoms

The first research question examined what dysphagia symptoms were experienced by individuals living with HIV/AIDS. Data revealed that all 21 participants experienced at least one symptom associated with dysphagia, with one participant who reported a total of 13 symptoms. Table 4.3 provides the symptom prevalence reported by participants. Symptoms reported with the highest frequency included heartburn (47.6%), difficulty swallowing (42.9%), difficulty swallowing pills (38.1%), dry mouth (33.3%), food catching in the throat (33.3%), and coughing while eating or drinking (28.6%). These suggest that symptoms are predominantly pharyngeal and esophageal in nature. One participant reported a symptom that was unlisted and described it as,

“feeling food is going down the wrong way and coughing something up.” This would imply dysfunction within the pharyngeal and esophageal swallowing phases. Though participants described multiple signs of oropharyngeal and esophageal dysphagia, the majority had not received assessment or treatment for dysphagia symptoms.

A t-test was used to compare the number of symptoms experienced by participants who had received SLP services and those who had not. Participants who reported receiving SLP services ($n=8$) reported more dysphagia symptoms ($m=6$) than participants who had not received SLP services ($n=13$; $m=2.85$ dysphagia symptoms). No statistically significant difference was found ($p=0.05$).

Speech-Language Pathology Experiences

The second question explored whether individuals living with HIV/AIDS were being assessed or treated by a SLP for reported dysphagia symptoms. Only 38% (8/21) of the participants indicated they had been assessed or treated by a SLP. One participant indicated being assessed or treated for dysphagia symptoms, but was unsure whether an SLP was involved with the services provided. Data for participants' diagnosis, average length of diagnosis, mean dysphagia symptoms reported, and referral source are presented in Table 4.4.

Referred Symptoms. Dysphagia symptoms reported by participants who received services from an SLP were compared to the dysphagia symptoms reported by participants who did not receive SLP services. Table 4.5 outlines the dysphagia symptoms reported in each intervention group. A Fisher's test was calculated to examine the relationship between reported symptoms and intervention groups

(received SLP services or had not receive SLP services). The only statistically significant association was between intervention groups and the reported symptom of heartburn ($p=0.02$). More participants who received SLP services ($n=8$) reported experiencing heartburn ($n=7$) than participants who had not received SLP services ($n=13$; $n=4$ reported experiencing heartburn).

Level of Speech-language Pathology Care

The third research question examined the scope and degree of services provided by a SLP. Eight participants reported speech-language pathology services included in their care. Six of the eight participants reported the degree of services received. Overall, the mean number of sessions was 2.33 (range 1-5).

Treatment Characteristics

Seven participants indicated they had been assessed and/or treated by a SLP. Five participants reported being formally diagnosed with a swallowing problem or disorder. Of those participants, four described the dysphagia as involving a diet change, swallowing problem, pain on swallowing, and body weakness. The majority received services from an SLP in a hospital setting. Table 4.6 provides data on where SLP services were provided.

Reasons for referral for SLP assessment or treatment included coughing while eating or drinking, difficulty swallowing, pain associated with swallowing, weight loss, and problems associated with eating. These align with the reported symptoms. In this study, the most commonly reported symptoms were heartburn, coughing while eating

drinking, coughing or choking during swallowing, specific foods are difficult to swallow, difficulty swallowing, food catches in the throat, and infections of the oral cavity.

Chapter 5

Discussion

The current study examined the involvement of speech-language pathologists (SLP) in the assessment or treatment of individuals living with HIV/AIDS. A survey was administered to participants living with HIV/AIDS in five states. This chapter includes a discussion of results for each research question. Limitations and conclusions are presented following the discussion of questions.

Review and Discussion of Results

To reach individuals living with HIV/AIDS, a survey was distributed to support groups, public health organizations, religious groups, and health centers. Twenty-one people completed the survey, which implied 21 participants chose to or met the requirements to complete the survey. Individuals may not have completed the survey for multiple reasons including withdrawing consent, insufficient time to complete the survey, lack of access to a computer, or confidentiality reasons. Anecdotally, some respondent queries declined participation because there was no monetary payment for participation. Additionally, not including acute care facilities may have limited access to potential participants.

Low response rate may indicate insufficient methods of survey distribution or data collection. Additionally, attempting to contact a protected population of participants may have contributed to the low response rate. The survey was confidential and did not request protected health information. Yet, perceptions of possible association to the distribution of the survey may have left some individuals questioning

confidentiality related to participation. For example, if a participant took a tab from the recruitment flyer, a passerby could assume the individual had HIV/AIDS and was participating in the study.

Dysphagia Symptoms Experienced by Individuals Living with HIV/AIDS

In the present study, all participants had or were currently experiencing at least one symptom related to dysphagia. Table 4.3 outlines the frequency of reported dysphagia symptoms by all participants. Similar to the results of previous studies (Bladon & Ross, 2007; Bobba et al., 2007; Halvorsen et al., 2003; Nkuize et al., 2010; Walker, 2011), heartburn, difficulty swallowing, difficulty swallowing pills, dry mouth, food catching in the throat, and coughing while eating or drinking were commonly experienced by participants. The majority of reported symptoms in this study were indications of possible oropharyngeal or esophageal phase dysphagia. These results are comparable to other studies with individuals with HIV/AIDS. Halvorsen et al. (2003) and Walker (2011) found through instrumental testing that all participants with HIV/AIDS demonstrated some dysfunction in at least one phase of swallowing. This study adds to the literature that indicates individuals living with HIV/AIDS are at risk for dysphagia and resulting complications. Nutrition is important to resolution of any disease course (Jacobson et al., 2003). Late stage HIV/AIDS is characterized by acute weight loss and fatigue (Anteyi et al., 2003). Maintaining optimal oral intake and reducing or preventing dysphagia symptoms may delay these acute disease effects.

Signs or Symptoms of Dysphagia. While all participants experienced at least one symptom of dysphagia, individuals who received SLP services reported more symptoms

($m=6$) compared to individuals who did not receive SLP services ($m=2.85$). The difference between groups was not statistically significant ($p \geq .05$). Data imply that reporting of more symptoms did not relate to receiving SLP services. This is important because it indicates type or severity of symptoms are not a determining factor regarding participants that received management of their symptoms. This is counter-intuitive in that more disease symptoms typically result in increased services or referrals. Results in the current study do not support this assumption.

Incidence of Dysphagia Symptoms. The frequency of each dysphagia symptom reported by individuals who received SLP services was compared to the group of participants who reported the same symptom, but did not receive SLP services. Data revealed that 18 of the 21 reported dysphagia symptoms were experienced by both groups of participants (received – did not receive SLP services). Excluding heartburn, it was found that the amount of participants who reported the same dysphagia symptom(s) between groups was not statistically significant. This suggests that besides heartburn, there was not one specific dysphagia symptom that was more likely to lead to assessment or treatment by an SLP. Practitioners may need to take note when heartburn (reflux) is reported since it may be predictive of a progression toward more involved dysfunction in swallowing.

It is unclear how the HIV/AIDS disease course for the respondents receiving SLP services influenced complaints. In a medical setting, patients often describe experiencing heartburn, which is a common clinical indication for reflux (these terms are often used interchangeably). In the HIV/AIDS population as others, heartburn could

appear secondary to irritation from medication or as an independently occurring symptom. However, with heartburn as the most frequently reported dysphagia symptom, consideration for reflux as a “red flag” to more complex sequelae is an important consideration. Recognition of reflux as potentially leading to more complex dysphagia symptoms may enable earlier diagnoses and proactive management for individuals with HIV/AIDS.

Stage of Infection

Diagnosis Category. Overall, more individuals with a diagnosis of HIV ($n=15$) responded to the survey. There was no statistically significant difference ($p \geq .05$) between diagnoses (HIV – AIDS) and intervention groups (received – did not receive SLP services). This suggests participants with a diagnosis of HIV were not more likely to receive services from an SLP than individuals with HIV/AIDS. For this study sample, stage of diagnosis was not a predictor of who received SLP services. This suggests that complexity of symptoms or disease progress did not result in increased service provision for this sample. Any individual living with HIV/AIDS, regardless the stage of diagnosis, could be experiencing symptoms of dysphagia that are going untreated. SLPs involved in initial referrals of individuals with HIV/AIDS need to encourage follow up to facilitate a continuum of care.

Length of Diagnosis. The amount of years living with a diagnosis of HIV/AIDS was a statistically significant difference ($p \leq .05$) observed between service groups (received – did not receive SLP services). Participants who received services from an SLP had been living longer with a diagnosis of HIV/AIDS ($m=5.09$ years) compared to participants who

did not receive services ($m=2.30$ years). When a person is living with a diagnosis such as HIV/AIDS for an increased period of time, they may have received more healthcare, information about co-morbidities of the infection, help relating to living with HIV/AIDS, or experienced dysphagia symptoms for a longer period of time. These factors could lead to increased awareness and intervention of dysphagia symptoms.

Scope and Degree of SLP Evaluation and Treatment

While participants in this study experienced similar symptoms of dysphagia, only 38% reported receiving services from an SLP. These results support previous research. Earlier studies have established that only a fraction of individuals with HIV/AIDS who reported swallowing difficulty had later received assessment or treatment related to dysphagia (Bladon & Ross, 2007; Karus et al., 2005). SLP services provided during early stages of the disease might enable preventive dysphagia measures to be established.

Description of Dysphagia Symptoms. The 8 participants who received services from a SLP described swallowing problems as coughing while eating or drinking, difficulty swallowing, pain associated with swallowing, weight loss, and problems associated with eating. These symptoms of dysphagia and their evaluation or treatment appear common to this population (Anteyi et al., 2003; Bladon & Ross, 2007; Jacobson et al., 2003; Vazquez, 2000). These behaviors would likely be disruptive to daily participation and engagement during meals. These dysphagia symptoms might result in oral intake avoidance as well as avoidance of social interactions during meals. This could negatively impact quality of life as it relates to common mealtime interactions, important to daily interactions within multiple settings.

Dysphagia Diagnosis. Only half of the participants who reported receiving services were diagnosed with a swallowing problem. These diagnoses were defined as a swallowing problem, pain on swallowing, and body weakness. One participant who received a diagnosis was also recommended a diet change. Formally diagnosing dysphagia is important in order to identify that separate care of swallowing problems needs to be addressed in addition to the infection itself. A diagnosis of dysphagia would need referral to SLP services to provide appropriate specialized care with regards to swallowing difficulty. It may also allow for monitoring of swallowing function over time to determine if symptoms have increased or worsened (Bladon & Ross, 2007).

Referral Source. Five of the eight participants who received services from an SLP indicated what type of professional referred them for assessment or treatment. Four participants specified that a medical doctor, including a gastroenterologist, made the referral to an SLP. One participant stated a physician and SLP worked together to refer for assessment or treatment of dysphagia symptoms. The importance that healthcare professionals work as a multidisciplinary team to provide appropriate care for individuals with HIV/AIDS is known (Karus et al., 2005; McNeilly, 2005). The fact that only half of the referrals were from a medical physician indicates the burden SLP professionals continue to face with regard to informing other health professionals about their expertise in diagnosing and treating dysphagia.

Degree and Frequency of Intervention. The mean number of sessions was 2.33 (range 1-5) for participants who reported receiving services from an SLP. The infrequency with which participants received services suggests that only an assessment

of dysphagia was performed. An SLP is often involved in clinical assessment of dysphagia to provide diet recommendations for safe oral consumption or treatment strategies (Ad Hoc Committee on the Scope of Practice in Speech-Language Pathology, 2007; Bladon & Ross, 2007; Swigert, 2007; Walker, 2011). The present study, and previous studies (Halvorsen et al., 2003; Jacobson et al., 2003), imply that involving an SLP in care can help avoid negative impacts on quality of life such as unintentional weight loss or pneumonia secondary to dysphagia.

Strengths and Limitations

The participation of SLPs in the assessment or treatment of individuals with dysphagia secondary to HIV/AIDS is relatively absent in the current literature. This study expands the research examining symptoms of dysphagia experienced by individuals with HIV/AIDS. It also investigated the scope and degree of SLP services provided to individuals living with HIV/AIDS.

The present study supports the need for identification and intervention of dysphagia symptoms that coincide with a diagnosis of HIV/AIDS. Those who are living with HIV/AIDS will be managing symptoms secondary to the infection for the remainder of their lives since no cure has been found to date. Dysphagia is one symptom that can negatively impact QOL when untreated (Bladon & Ross, 2007). Involving SLPs in the care for individuals who experience dysphagia may help to maintain appropriate and safe swallowing for nutritional intake. Promoting safe and functional swallowing may offer support to sustaining health in people living with HIV/AIDS

As with many studies of individuals in vulnerable populations, low participant response rate limits generalization of the results and likely influenced the level of significant findings. While multiple AIDS service groups were contacted regarding the study, it is unknown how many actually distributed or displayed the recruitment poster. Additional methods should be considered when attempting to contact a protected population of participants. Contacting AIDS service groups over other organizations, such as hospitals, provided quicker access to individuals living with HIV/AIDS. Perhaps, comprehensive review of the medical records charts of people with HIV/AIDS or acute hospital admissions could provide as much insight into their healthcare history.

A survey method of data collection can also limit the depth of responses from participants. Responding to close-ended questions through a web-based survey may result in limited responses that can be completed quickly and simply from prescribed choices. Mixed methods inclusive of qualitative and quantitative methods may allow for more clarification and expansion through the addition of more open-ended questions and qualitative analyses.

Conclusions

Data from the current study suggest individuals living with HIV/AIDS who receive SLP services are experiencing the same or similar reported swallowing symptoms as individuals who have not received SLP services. While some participants received SLP services, the degree and frequency with which they were provided was limited. It is important for SLPs to consider the chronicity of symptoms for the HIV/AIDS population. Implementing a health care model similar to the management provided for patients

diagnosed with cancer may be beneficial for this population. For example, individuals being treated for cancer typically receive services that monitor disease progression over time with responsive management to new symptoms whether considered related to the original cancer diagnosis or not. That type of protocol and responsiveness does not appear to be the standard of care for individuals living with HIV/AIDS. Reflux has been suggested in this study as a precursor for more complex dysphagia symptoms. Perhaps, too often, reflux is treated as a separate symptom, unrelated to the HIV/AIDS.

Consideration for screening and monitoring of symptom progression for all individuals living with HIV/AIDS may increase care with regard to dysphagia. Within this model, SLPs must provide education, assessment, treatment, and recommendations for those who are currently, or in the future, experiencing swallowing difficulty. This would allow SLPs to monitor swallowing function through follow up consults throughout the course of the infection in order to provide necessary, proactive treatment to maintain safe oral nutritional intake.

The importance of assessment or treatment of dysphagia by an SLP has been supported for the HIV/AIDS population (Bladon & Ross, 2007; Halvorsen et al., 2003; Jacobson et al., 2003). However, there is still a discrepancy in identifying distinguishing factors between participants who received SLP services and participants who did not receive SLP services. Consideration is needed as to whether healthcare professionals understand potential negative consequences on quality of life that dysphagia secondary to HIV/AIDS can have. SLPs must provide education to fellow practitioners and other health care professionals with regard to dysphagia in the HIV/AIDS population. In

addition, SLPs must advocate for their expertise to be included in the management of dysphagia for individuals living with HIV/AIDS.

Implications

The current study suggests SLPs are not consistently involved in the care of individuals with HIV/AIDS who report dysphagia symptoms. Furthermore, the degree and frequency with which SLP services are being provided to some individuals implies that only assessment is provided. If medical professionals and other individuals involved in the care of patients with HIV/AIDS are more knowledgeable of the communication and/or swallowing disorders related to the infection, they may be more likely to include a SLP in the assessment and treatment of these individuals. Including SLPs as team members would lead to more effective assessment and treatment of swallowing disorders present in individuals with HIV/AIDS (Bladon & Ross, 2007; Halvorsen et al., 2003; Jacobson et al., 2003; McNeilly, 2005). SLPs must continually advocate for their expertise in providing comprehensive care to individuals living with HIV/AIDS.

Moreover, only one participant in the current study reported an incidence of an SLP and doctor working together in dysphagia management. Collaborative dysphagia management appears lacking. This suggests an increased need for healthcare professionals to work as an interdisciplinary team. Involving SLPs in the care of individuals with HIV/AIDS who report symptoms of dysphagia may help reduce or eliminate negative effects on quality of life secondary to dysphagia.

Future Research

Future research regarding the role of SLPs in the assessment or treatment of dysphagia in individuals with HIV/AIDS is needed. In addition, examining the impact educational level, income, or insurance type have on receipt of SLP services may offer further insight into which individuals are obtaining intervention for dysphagia symptoms.

Identifying specific methods and service delivery models of assessment and treatment would provide clarity to the role of the SLP in HIV/AIDS management. The current study suggests individuals living with HIV/AIDS are experiencing symptoms of dysphagia, but few are receiving appropriate SLP assessment or treatment. More is needed to inform the profession with regard to best practice with this vulnerable population.

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APPENDIX A:
Recruitment Flyer



**IRB Protocol
Number:
14-200**

Eastern Kentucky University

Participants Wanted for a Research Study

Swallowing Disorders in HIV/AIDS Patients

The purpose of the study is to research the role of speech-language pathologists (speech therapists) in the assessment and treatment of swallowing difficulty and/or disorders experienced by individuals living with HIV and AIDS. Voluntary participation will include completing a web-based survey.

<https://www.surveymonkey.com/s/CTP6BDG>

Participants must: (1) be 18 years or older, (2) be diagnosed with a stage of HIV or AIDS, and (3) speak English as their native language.

To learn more about this research, contact the principal investigator: sarah_warner9@eku.edu
or Dr. Cranfill @ (859) 622-2115

This research is conducted under the direction of Dr. Tamara Cranfill,
Communication Disorders Program

APPENDIX B:

Swallowing Symptom & SLP Intervention Survey

1. **Please specify your age**
2. **Please specify your gender**
 - a. Male
 - b. Female
 - c. Other (Please specify below)

3. **Please specify your ethnicity**
 - a. White or Caucasian
 - b. Hispanic or Latino
 - c. Black or African American
 - d. Native American or American Indian
 - e. Asian/Pacific Islander
 - f. Other (Please specify below)

4. **What is the highest degree or level of school you have completed? *If currently enrolled, highest degree received.***
 - a. No schooling completed
 - b. Nursery school to 8th grade
 - c. Some high school, no diploma
 - d. High school graduate, diploma or the equivalent (GED)
 - e. Some college credit, no degree
 - f. Trade/technical/vocational training
 - g. Associate degree
 - h. Bachelor's degree
 - i. Master's degree
 - j. Professional degree
 - k. Doctorate degree
5. **What is your total household income?**
 - a. \$0 to \$25,999
 - b. \$26,000 to \$47,999
 - c. \$48,000 to \$73,999
 - d. \$74,000 to \$110,999
 - e. \$111,000 to 183,999
 - f. \$184,000 or more
6. **What type of insurance do you have?**
 - a. Medicaid, Medicare, or other government insurance
 - b. Health insurance at work
 - c. Private (e.g. Cigna)
 - d. None
 - e. Other (Please specify below)

7. **What is your diagnosis?**
 - a. Human Immunodeficiency Virus (HIV) Positive

- b. Acute Infection
 - c. Clinical Latency
 - d. Acquired Immunodeficiency Syndrome (AIDS)
 - e. Other (Please specify below)
-

8. How long have you been living with HIV/AIDS?

9. What type of treatment have you received or are currently receiving?

- a. Multi-Class Combination Drugs (*Atripla, Complera, Stribild, Trii*)
 - b. Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs) (*Combivir, Emtriva, Efavirenz, Epivir, Epzicom, Retrovir, Trizivir, Truvada, Videx, Viread, Zerit, Ziagen, Amdoxovir, Tenofovir alafenamide fumarate*)
 - c. Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs) (*Edurant, Intelence, Rescriptor, Sustiva, Viramune, Lersivirine*)
 - d. Protease Inhibitors (PIs) (*Aptivus, Crixivan, Invirase, Kaletra, Lexiva, Norvir, Prezista, Reyataz, Viracept*)
 - e. Entry/Fusion Inhibitors (*Fuzeon, Selzentry, Cenicriviroc, Ibalizumab, PRO 140*)
 - f. Integrase Inhibitors (*Isentress, Tivicay, Elvitegravir*)
 - g. Pharmacokinetic Enhancers (*Norvir, Cobicistat, SPI-452*)
 - h. Immune-Based Therapies (*Aralen, DermaVir, Interleukin-7, Lexgenleucel-T, Plaquenil, Proleukin, SB-728-T, Vacc-4x*)
 - i. Holistic/Alternative Therapies (e.g., acupuncture, herbal supplements, etc.)
 - j. Other (Please specify below)
-

10. Have you ever experienced the following symptoms resulting in swallowing and/or eating difficulty? (Select all that apply)

- a. Heartburn
- b. Dry mouth
- c. Changes to the ability to taste
- d. Difficulties with eating
- e. Pain on swallowing
- f. Specific foods that are difficult to swallow
- g. Difficulty swallowing
- h. Burning/tingling sensation in the mouth
- i. Hot food is easier to swallow than cold
- j. Food remaining in the mouth after swallowing
- k. Solids are more difficult than liquids
- l. Cold food is easier to swallow than hot
- m. Difficulty chewing
- n. Excessive saliva or mucus in the mouth
- o. Coughing while eating or drinking
- p. Difficulty swallowing pills
- q. Food catches in the throat
- r. Coughing or choking after swallowing

- s. Takes a long time to swallow
- t. Choking while eating or drinking
- u. Food comes back up after swallowing
- v. Coughing or choking during swallowing
- w. Drooling
- x. Coughing or choking before swallowing
- y. Liquids are more difficult to swallow
- z. Nasal regurgitation
- aa. Food falling out of the mouth
- bb. Infections of the oral cavity
- cc. Other (Please specify below)

11. Have you ever been diagnosed with a swallowing problem and/or disorder?

- a. Yes
- b. No
- c. Other (Please specify below)

12. If you responded yes to #11, please explain the swallowing problem and/or disorder with which you were diagnosed:

13. Have you ever been assessed or treated by a speech-language pathologist?

- a. Yes
- b. No
- c. Other (Please specify below)

14. If you responded yes to #13, what was the reason for being assessed and/or treated by the speech-language pathologist?

15. If you responded yes to #13, for what length of time/how many sessions were you seen by the speech-language pathologist?

16. If you responded yes to #13, who referred you to be seen by the speech-language pathologist?

17. If you responded yes to #13, in what setting were you seen by the speech-language pathologist?

- a. Hospital
 - b. Medical Clinic
 - c. Speech-Language Hearing Clinic
 - d. Other (Please specify below)
-

Appendix C:

Personal Income Quintile Frequency

Quintile	Income Range	(n)
Lowest Quintile	0 - 25, 999	7
Second Quintile	26, 000 - 47, 999	6
Middle Quintile	48, 000 - 73, 999	4
Fourth Quintile	74, 000 - 110, 999	4
Highest Quintile	111, 000 - 183, 999	0
Top 5 Percent	184, 000 or more	0

Appendix D:
Thematic Analysis

Themes	(n)	Examples of quotes reflecting theme
Diagnosed with a swallowing problem/disorder	5	Diet change; Swallowing problem; Pain on swallowing; Body weakness
Assessed/Treated by a speech therapist	7	Not reported
Reasons for being assessed/treated by a speech therapist	7	Coughing while eating/drinking; Difficulty swallowing; Pain associated with swallowing; Weight loss; Problems associated with eating
Amount of assessment/treatment	8	2.33 (<i>range</i> 1-5)
Referral source	6	Doctor; Gastroenterologist; Unknown
Location of assessment/treatment	8	Hospital; Medical Clinic

Appendix E:

Participant Characteristic Tables

Table 4.1
 Demographic Characteristics for Participants ($N = 21$)

Demographic Characteristic	Percent	(<i>n</i>)
Age, mean years	$M=31.9$	
<i>Gender</i>		
Male	57.14	12
Female	42.86	9
<i>Ethnicity</i>		
White or Caucasian	42.86	9
Hispanic or Latino	14.29	3
Black or African American	38.1	8
Other	4.76	1
<i>Educational Level</i>		
High school graduate, diploma or GED	14.29	3
Some college credit, no degree	14.29	3
Trade/technical/vocational training	14.29	3
Associate degree	14.29	3
Bachelor's degree	33.33	7
Master's degree	9.52	2
<i>Personal Income</i>		
\$0 to \$25,999	33.33	7
\$26,000 to \$47,999	28.57	6
\$48,000 to \$73,999	19.05	4
\$74,000 to \$110,999	19.05	4

Table 4.2

Clinical Category, Medication, and Length of Diagnosis for Participants (N=21)

Clinical Characteristic		Percent	(n)
Length of Diagnosis, mean years	<i>M</i> =3.83		
<i>Diagnosis</i>			
HIV		71.43	15
AIDS		28.57	6
<i>Treatment Medication</i>			
Multi-Class Combination Drugs		23.81	5
NRTIs		90.48	19
NNRTIs		76.19	16
Protease Inhibitors (PIs)		42.86	9
Entry/Fusion Inhibitors		38.1	8
Integrase Inhibitors		4.76	1
Pharmacokinetic Enhancers		14.29	3
Immune-Based Therapies		33.33	7
Holistic/Alternative Therapies		19.05	4

Table 4.3
Percentage of Participants in Each Symptom Category

Variable	Percent	(n)
<i>Symptom</i>		
Heartburn	47.6	10
Difficulty swallowing	42.9	9
Difficulty swallowing pills	38.1	8
Dry mouth	33.3	7
Food catches in the throat	33.3	7
Coughing while eating or drinking	28.6	6
Difficulties with eating	23.8	5
Burning/tingling sensation in the mouth	23.8	5
Pain on swallowing	19.0	4
Coughing or choking during swallowing	19.0	4
Specific foods that are difficult to swallow	14.3	3
Infections of the oral cavity	14.3	3
Hot food is easier to swallow than cold	9.5	2
Difficulty chewing	9.5	2
Changes to the ability to taste	9.5	2
Food remaining in the mouth after swallowing	4.8	1
Solids are more difficult than liquids	4.8	1
Cold food is easier to swallow than hot	4.8	1
Coughing or choking after swallowing	4.8	1
Takes a long time to swallow	4.8	1
Choking while eating or drinking	4.8	1
Other (please specify)	4.8	1
Excessive saliva or mucus in the mouth	0	0
Food comes back up after swallowing	0	0
Drooling	0	0
Coughing or choking before swallowing	0	0
Liquids are more difficult to swallow	0	0
Nasal regurgitation (food coming out the nose)	0	0
Food falling out of the mouth	0	0

Table 4.4
Participants Who Reported Speech-Language Pathology Services (n=8)

Participant	Diagnosis	Length of Diagnosis (years)	# of Dysphagia Symptoms	Referral Source
P1	AIDS♦	7	5	not reported
P2	AIDS♦	6	8	not reported
P3	AIDS♦	10	13	Doctor
P4	HIV*	5.25	6	not reported
P5	HIV*	2.5	2	Gastroenterologist
P6	HIV*	3	3	Doctor
P7	HIV*	4	5	Doctor
P8	HIV*	3	5	Doctor (working w/ SLP)
Mean		5.09	9.25	

Note: ♦ = Acquired Immunodeficiency Syndrome (AIDS), * = Human Immunodeficiency Virus (HIV)

Table 4.5
Dysphagia Symptoms Reported by Intervention Groups

Dysphagia Symptom	Reported Intervention by SLP	No Reported Intervention by SLP	p Value
Heartburn	7	4	0.02*
Difficulty swallowing	6	4	0.08
Difficulty swallowing pills	3	4	1
Dry mouth	2	2	0.62
Food catches in the throat	3	4	1
Coughing while eating or drinking	4	3	0.35
Difficulties with eating	3	2	0.33
Burning/tingling sensation in the mouth	2	3	1
Pain on swallowing	3	1	0.25
Coughing or choking during swallowing	3	1	0.25
Specific foods that are difficult to swallow	2	1	0.53
Infections of the oral cavity	2	1	0.53
Hot food is easier to swallow than cold	1	1	1
Difficulty chewing	1	1	1
Changes to the ability to taste	2	0	0.13
Food remaining in the mouth after swallowing	1	0	0.38
Solids are more difficult than liquids	0	1	1
Cold food is easier to swallow than hot	0	1	1
Coughing or choking after swallowing	0	1	1
Takes a long time to swallow	1	0	0.38
Other (please specify)	0	1	1

Note: * = statistical significance

Table 4.6

Treatment Location Percentage Reported by Participants (N=21)

Treatment Location	Percent	(n)
Hospital	87.5	7
Medical Clinic	12.5	1
Speech-Language Hearing Clinic	0	0
Home-health	0	0