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# The Psychosocial Effects of Dysphagia

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THE PSYCHOSOCIAL EFFECTS OF DYSPHAGIA

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Bachelor of Science in Speech Pathology and Audiology

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Submitted in partial fulfillment of requirements for the degree

MASTER OF ARTS IN SPEECH PATHOLOGY AND AUDIOLOGY

at the

CLEVELAND STATE UNIVERSITY

August 2015

We hereby approve this thesis for

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## **DEDICATION**

*Dedicated to my mom and dad who have always provided me with endless love and support.*

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This work would not have been possible without the support of several sources. First, I would like to thank the members of my committee for their time and feedback throughout the stages of this study process. I would especially like to thank the chair of my committee, Dr. Violet Cox, for being a wonderful and hard-working mentor.

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# **THE PSYCHOSOCIAL EFFECTS OF DYSPHAGIA**

ALLISON D. LOTTER

## **ABSTRACT**

The purpose of this study is to determine the psychosocial effects of dysphagia in adults with a non-terminal, non-progressive neurological condition. Additionally, this study aims to provide potential differences in the psychosocial effects of dysphagia given gender and age range. This information is crucial for speech-language pathologists (SLPs) to better understand the psychosocial consequences of dysphagia and provide a more comprehensive and appropriate approach to therapy. This study is a pseudo-qualitative design that includes adults, age 20-90 years old, diagnosed with dysphagia secondary to a non-progressive, non-terminal medical condition. Descriptive statistics revealed that there are psychosocial effects of dysphagia, which differ in gender and age range. The results serve to provide some insight into the devastating impact of dysphagia on a person's life and overall quality of life. It is of vital importance that SLPs be aware of the impact of the disorder on the individual's overall quality of life, so that more efficient methods to help the person regain normal swallowing skills may be employed.

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## **CHAPTER I**

### **INTRODUCTION**

Dysphagia is defined as difficulty moving food from the mouth to the stomach. Dysphagia can produce adverse complications, including malnutrition, dehydration, and episodes of pneumonia. This condition can occur in any age group, from newborns to elderly, as a result of congenital abnormalities, structural damage, and/or medical conditions (Logemann, 1998). The speech-language pathologist (SLP) is a crucial member of the multidisciplinary team that treats the individual with dysphagia. Since dysphagia is explicitly medical in nature, the physical health aspects of dysphagia are often the primary focus of treatment. Unfortunately, the psychosocial effects of dysphagia are less understood and often ignored throughout the treatment process.

#### **The Normal Swallow**

The normal swallow involves an orderly physiologic process of moving ingested material and saliva from the mouth to the stomach. "This process usually occurs so smoothly and effortlessly that it belies the complexity of then neuromuscular apparatus that executes and orchestrates the swallowing sequence" (Dodds, Stewart, & Logemann,

1990, p. 953). The swallowing process has four phases: (1) oral preparatory phase, (2) oral phase, (3) pharyngeal phase, and (4) esophageal phase. The oral preparatory phase requires mastication (i.e., chewing) of a bolus (i.e., a compacted formation of food) and mixing it with saliva. During the oral phase of the swallow, the bolus is moved posteriorly from the oral cavity into the pharynx. The pharyngeal phase, or the reflexive stage of the swallow, involves the transport of the bolus to the esophagus without aspiration (i.e., airway closure). Finally, the esophageal phase occurs when the bolus is moved from the esophagus to the stomach (Dodds et al., 1990).

### **Dysphagia**

"Anatomic or physiologic swallowing disorders may occur in any phase of the swallow" (Logemann, 1984, p. 43). In the oral preparatory phase, deficits may include reduced range of motion of the jaw, weak lip seal, and/or impaired salivary glands. Disorders of the oral phase may include poor lip seal, reduced range of motion of the tongue or jaw, decreased strength of the cheeks, and decreased oral sensitivity. Unique to this phase is damage to the posterior movement of the tongue to propel the bolus towards the pharynx in order to trigger the swallow (Braden, 2007). Pharyngeal phase disorders of the swallow may include delayed/ absent trigger of the swallow reflex, reflux into the nasal cavity, reduced pharyngeal peristalsis (contraction of pharyngeal walls) to move food down the esophagus, reduced laryngeal elevation; and/or damage to laryngeal adduction in order to sufficiently close the airway (Logemann, 1984). Finally, impairments at the esophageal phase of the swallow "result in the bolus begin pushed back up the tract from the esophagus into the pharynx" (Braden, 2007).

Aspiration, or the entry of food into the airway below the true vocal folds, may occur at any stage of the swallowing process. During the oral preparation phase, aspiration can occur before the swallow if the patient loses control of the bolus with his/her tongue, causing the food to fall into the pharynx before the swallow is initiated, and the airway is not closed. During the pharyngeal phase, aspiration can occur during the swallow when material slips into the larynx due to insufficient airway closure. Aspiration may occur after the swallow when residual material remains in the pharynx and falls into the airway, which may not be sufficiently closed (Logemann, 1984). Aspiration of food into the lower airway results in subsequent aspiration pneumonia, a common problem in patients with severe dysphagia (Daniels & Huckabee, 2014).

Approximately 6-10 million adults suffer from dysphagia in the United States. Dysphagia occurs when a medical condition weakens or damages the muscles and nerves involved in the swallowing process. Conditions such as stroke or traumatic brain injury may affect the coordination of the muscles used for swallowing or limit the sensation in the mouth or throat. Other conditions such as cancer of the head, neck or esophagus, Parkinson's disease, dementia, or cleft palate (in infants) may cause dysphagia (National Institute of Health, 2010).

### **Current Treatment – The Medical Model**

The approach to managing dysphagia represents a multidisciplinary model and traditionally follows a medical model for treatment. The medical model "views the physician as responsible for diagnosing the illness, deciding on an appropriate treatment, and assuring that the treatment is carried out as prescribed" (Anderson, 1995, p. 412). The dysphagia team typically includes the patient's physician, the swallowing therapist

(the SLP), nursing staff, dietitian, occupational therapist, physical therapist, pharmacist, and radiologist. The swallowing therapist's job is to "identify the symptom(s) during a diagnostic procedure and determine the underlying abnormality in anatomy or physiology that causes the symptom(s)" (Logemann, 1998). Following the evaluation, the swallowing therapist may provide a regimen of a progressive exercise program or sensory stimulation activities designed to improve the swallowing function along with a modified diet. Swallowing therapy is primarily focused on continuous adequate nutrition and hydration for the patient. It is crucial for the swallowing therapist to consult with the patient's physician, nursing team, and dietitian to determine the most appropriate program for the patient to maintain nutrition and improve the function of swallowing (Logemann, 1998).

Dietary modification is a crucial aspect of therapy for dysphagia. "Once diagnosed with dysphagia, the patient must be nourished safely while being taught therapeutic and compensatory strategies for dealing with the swallowing disorder" (O'Gara, 1990, p. 209). The two crucial factors regarding dietary modification of dysphagia are to maintain adequate nutrition and ensure safe oral feeding (Martin, 1991). Foods and liquids may be modified to provide a nutritious diet that is safe for the individual with dysphagia. Liquid modifications include: nectar-like (slightly thicker than water) and honey-like (liquids with the consistency of honey). Food modifications include: mechanical soft (moist, soft-textured foods, one-quarter inch thick pieces) and puree (pureed, cohesive foods; "pudding-like") (Zwiefelhofer, 2002). For individuals with dysphagia who cannot safely consume food or liquid orally, an alternative feeding method is implemented (O'Gara, 1990). "The ultimate goal is to train the patient to select

the proper foods and use the recommended swallowing techniques" (Martin, 1991, p. 129). "Because of its' [dysphagia] overtly medical nature, there has been considerable focus dealing with the direct physical health aspects of dysphagia management" (Threats, 2007, p. 323). Although improving the physical function of swallowing is necessary, the psychosocial consequences of dysphagia are often ignored and less understood by the dysphagia team (Ekberg, Hamdy, Woisard, Wuttge-Hannig, & Ortega, 2002).

### **World Health Organization Model**

The World Health Organization (WHO) defines health as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (World Health Organization [WHO], 2006, p. 1). "In the case of dysphagia, which can cause disease or infirmity, it might appear that this expanded definition of health is not necessary" (Threats, 2007, p. 324). However, in a general sense, dysphagia is not only a chronic disability, but it also has possible activity and participation limitations and psychosocial consequences. The approach to dysphagia diagnosis and treatment can be further described by using the WHO International Classification of Functioning, Disability and Health-2 (ICIDH-2) (Threats, 2007).

### **Body Structure and Body Function**

"Body structures are anatomical parts of the body such as organs, limbs, and their components. Impairments are problems in body function or structure as a significant deviation or loss" (World Health Organization [WHO], 2001, p. 10). The body structure codes of the ICIDH-2 covers parts of the behaviors, neurological systems, and structures that are necessary to carry out "the physical act of taking food into the mouth, appropriately handling it, and getting it into the stomach" (Threats, 2007, p. 325). The use

of severity levels can identify how the structure deviates from the norm and/or is the abnormality is unilateral or bilateral (Threats, 2007).

"Body functions are the physiological functions of body systems (including psychological functions). Impairments are problems in body function or structure as a significant deviation or loss" (WHO, 2001, p. 10). The ICIDH-2 describes body function by the particular movements of swallowing, which are sucking, biting, chewing, manipulation of food in mouth, and salivation. Additionally included is the cognitive input required during the oral and pharyngeal phases of the swallow (i.e., attention, memory, motivation, appetite, craving, problem solving, vision, smell, taste). The qualifiers describe the extent of movement, speech, and efficiency deviating from the norm (Threats, 2007). "These behaviors need to be assessed to address the swallowing difficulties of those with dysphagia because they contribute to risk factors for aspiration and choking" (Threats, 2007, p. 325).

### **Activities and Participation**

"Activity is the execution of a task by an individual. Participation is involvement in a life situation. Activity Limitations are difficulties an individual may have in executing activities. Participation Restrictions are problems an individual may experience in involvement in life situations" (WHO, 2001, p. 12). The activities and participation codes for the intake of food and liquids are as follows: eating (i.e., carrying out tasks/ action of eating food, bringing food to mouth, consuming food in acceptable manner, cutting/ breaking food, opening bottles/ cans, using utensils, having meals or dining); and drinking (i.e., holding a drink, bringing drink to mouth, consuming drink in acceptable



manner, mixing/ stirring/ pouring liquid, opening bottles/ cans, drinking through straw). The activities and participation codes related to eating and drinking behaviors are as follows: preparing meals, remunerative employment, informal associations, ceremonies, recreation and leisure; and organized religion (Threats, 2007).

Eating is a social behavior, therefore, "the evaluation of the severity of the swallow should also include the effects of dysphagia on these activities" (Threats, 2007, p. 325). Assessment and treatment of dysphagia centers around the behavior and performance in the clinical setting, behavior in persons' real lives, and performance without assistance. Activity limitations and participation restrictions can have an adverse effect on individuals with dysphagia. If the person with dysphagia spills most of the food before getting it from the plate to the mouth, or food spills from the mouth while chewing, the person has an increased chance of malnutrition. Thus, these activity limitations may inhibit the person to eat appropriately in social settings and/or with others. Also, "important ritualistic eating could be affected, such as that associated with religious ceremonies (e.g., a devout Roman Catholic person being unable to take Holy Communion)" (Threats, 2007, p. 327).

### **Environmental Factors and Personal Factors**

"Environmental Factors make up the physical, social and attitudinal environment in which people live and conduct their lives" (WHO, 2001, p. 14). This component is necessary to understand the effect of dysphagia on a persons' lifestyle. The environmental factors codes most related to swallowing are as follows: food; products and technology for personal use in daily living; light; sound; immediate family; friends; personal care providers and personal assistants; individual attitudes of immediate family members;

different attitudes of health professionals; and health services, systems and policies.

"Unlike the other qualifiers in the ICF, environmental factors can be evaluated as either facilitators or barriers" (Threats, 2007, p. 327) (e.g., availability of appropriate food consistency, support/ attitudes of family members). For example, the ICF code, "attitude of health professionals," may determine whether a patient is considered appropriate for dysphagia treatment (e.g., frail or elderly patients). Additionally, the attitude and support of individuals in the patient's environment(s) are primarily regulated by culture. One signature of any culture is what and how foods are consumed (Threats, 2007). For example, in a culture where meat is primarily consumed, a person who has difficulty with chewing food may have trouble in social settings; compared to a person with the same kind dysphagia, but of a culture that consumes mostly rice and soft vegetables (Threats, 2007).

"Personal Factors are the particular background of an individual's life and living, and are composed of features of the individual that are not part of a health condition or health states" (WHO, 2001, p. 15) (e.g., demographics, personality traits, lifestyle). Since eating and drinking are behaviors, there are a wide variety of food and liquid preferences and eating styles (e.g., slow versus fast eating, large versus small consumption of food or liquid). However, when a person has dysphagia, "these preferences and personality traits influence everything from their reaction to having dysphagia to how willing they are to follow dysphagia precautions" (Threats, 2007, p. 327).

### **Psychosocial Model**

The term 'psychosocial' can be briefly described as "pertaining to the influence of social factors on an individual's mind or behavior, and the interrelation of behavioral and

social factors" (Martikainen, Bartley & Lahelma, 2002, p. 1091). Decreasing the risk of psychosocial effects (e.g., social isolation, depression) should be one of the ultimate goals for patients with dysphagia (Threats, 2007). Although the physical consequences of dysphagia are the primary focus of diagnoses and treatment, the psychosocial consequences of dysphagia are less understood and often ignored. It is crucial for the medical team to recognize that eating and drinking are considered social and pleasurable experiences, as they are typically the focus of celebration and/or religious holidays. Persons with dysphagia can become isolated, feel excluded, and/or feel anxiety or distress at mealtime, due to the effects of their condition (Ekberg et al., 2001). "For there to be a decreased risk of social isolation, the intake of adequate nutrition has to occur within the social contexts of eating and drinking behaviors" (Threats, 2007, p. 332). Additionally, if an individual with dysphagia's views of eating and overall competence during a meal are decreased, the amount of food or liquid consumption can be limited (Threats, 2007).

### **Psychosocial Views of Eating and Drinking**

It is important for SLPs to understand how people view and describe food because if a person is deprived of food he/she enjoys or has dietary modifications, his/ her views of food will also change. According to Rappoport, Peters, Downey, McCann and Huff-Corzine (1993), people describe or recall food in terms of meals, snack, or familiar menu designations. Hence, food is not thought of in terms of specific items or categories. For example, a cheeseburger, fries and shake or turkey dinner are more conceptualized than the components that make up these units. Additionally, that people explain food choices using the following terms: pleasure (e.g., any form of sensory, emotion or aesthetic

pleasure), health (e.g., maintains health or energy, prevents disease), and/or convenience (e.g., readily available, low cost, easy preparation, little preparation time). For example, "if a person is in a hurry for lunch, the pleasure value of a steak might be outweighed by the convenience value of a hamburger" (Rappoport et al., 1993, p. 35).

Food choice and rationalization may be dependent on gender and age. According to Rappoport et al. (1993), women typically have an increased preference for low-calorie foods and are more concerned and knowledgeable about the health values of food, compared to men. Both women and older adults are more likely to have healthier eating patterns than men or younger adults. Both men and women associate food with social relationships relating to family (e.g., siblings, relatives). Although, women additionally relate food to places or behavior settings (e.g., games, picnic, Disneyland, cookout), as opposed to men. There is a significant age difference between younger and older adults regarding the social relationship association of food. Younger adults are more likely to relate food to particular persons or social relationships; whereas, older adults relate food to the idea of "children" (e.g., oatmeal, macaroni and cheese) or events (e.g., wedding, birthday) (Rappoport et al., 1993).

Difficulty eating not only threatens biological survival, but also has consequences on an individual's psychological/ emotional and social life. "Dysphagia can destroy the social opportunities and pleasures of mealtimes, affect the quality of the patient's relationship with his/her caregiver and family, and can further undermine health and confidence" (Ekberg et al., 2002, p. 140). Therefore, adults with dysphagia often display feelings of isolation, anxiety, alienation, shame, and/or despair at mealtime regarding their condition (Ekberg et al., 2002). According to Gustafsson (1995), a proposed

classification of the psychological/ emotional symbolic content of food are as follows: security food (i.e., milk), reward foods (i.e., candy, ice cream), fetish foods (i.e., meat for energy, fish for brain), holiday foods (i.e., birthday cake, Easter eggs), and maturity foods (coffee, alcohol). Adults with dysphagia are partly or entirely omitted from these symbolic values of food, and consequently, an important aspect of their life is also excluded (Gustafsson, 1995).

### **Current Research**

Ekberg et al. (2002) examined the psychosocial effects of individuals with dysphagia through a survey in hospitals and nursing homes from four European countries (United Kingdom, Spain, Germany, and France). Ekberg et al. (2002) found that individuals with dysphagia have psychological and social consequences that affect their quality of life, as dysphagia was typically "under recognized, poorly diagnosed, and poorly managed." The most common psychological and social consequences among these individuals included increased sense of isolation, loss of self-esteem, avoidance of eating with others, and anxiety or panic during mealtime. Additionally, only 32% of individuals who completed the survey admitted to receiving professional treatment for their dysphagia (Ekberg et al., 2002).

Ekberg et al. (2002) discovered significant differences among the dysphagia patients given their residing country. For example, in France, more males than females were diagnosed with dysphagia compared to the United Kingdom, Spain, and Germany, where two-thirds of individuals diagnosed with dysphagia were women. The dysphagia patients in Spain and France were older, compared to dysphagia patients in the United Kingdom and Germany. Finally, and most compelling, was Germany dysphagia patients

were most likely to receive professional treatment after their diagnosis, whereas dysphagia patients from France and the United Kingdom were least likely to receive professional treatment. Ultimately, the researchers concluded that dysphagia has a severe social and psychological consequence in a persons' with dysphagia's quality of life (Ekberg et al., 2002).

### **Gaps in the Research**

Although these psychological and social effects are prevalent in European countries, these items may differ in individuals with dysphagia in the United States. Additionally, the survey conducted by the researchers does not require the person to identify the condition in which the dysphagia is co-occurring (i.e., cerebral vascular accident, traumatic brain injury, cancer). Therefore, it is hard to distinguish whether the psychological and social consequences are due to the primary diagnosis of a progressive or acute disease, or solely the dysphagia diagnosis.

### **Statement of the Problem**

There is limited research regarding the psychosocial effects of dysphagia, which creates the need for SLPs to thoroughly understand and address these consequences in the therapy setting. Although there is thorough research regarding the physical treatment of dysphagia, there is little to no research, to the best of this current researcher's knowledge, that looks specifically at the psychosocial consequences of dysphagia in adults with a non-terminal or non-progressive medical condition. Compensatory strategies are the primary treatment method taught to individuals with dysphagia; however, these strategies do not necessarily lessen the psychosocial impact for the person with dysphagia (Miller, Noble, Jones, & Burn, 2006)

### **Purpose of the Study**

The purpose of this study is to discover the psychosocial effects of dysphagia in adults with a non-terminal or non-progressive medical condition (e.g., cerebral vascular accident, traumatic brain injury). Additionally, this study aims to provide potential differences in the psychosocial effects of dysphagia given gender and age range. This information is necessary for SLPs to better understand the psychosocial consequences of dysphagia, and furthermore, provide a more comprehensive, appropriate, and individualized approach to therapy. Therefore, the person with dysphagia will benefit from not only the physical treatment of dysphagia but also the psychosocial aspects of this condition.

### **Research Questions**

The goal of this study is to further identify and understand the psychosocial consequences of adults with dysphagia, and the differences amongst gender and age range. This study attempts to answer the following questions:

1. What are the psychosocial effects of dysphagia in adults with a non-terminal, non-progressive medical condition?
2. How do the psychosocial effects of dysphagia differ in males versus females?
3. How do the psychosocial effects of dysphagia differ in age range?

## **CHAPTER II**

### **METHODOLOGY**

The Institutional Review Board (IRB) of MetroHealth Medical Center and Cleveland State University approved the investigation, materials, and procedures of this study.

The objective of this study was to explore the participant's self-perceptions regarding their current life with dysphagia. The current researcher used a pseudo-qualitative paradigm for this study based on the grounded theory. According to Glaser and Strauss (1967), grounded theory involves focusing on a specific category of interest (e.g., dysphagia) and then collecting and "analyzing data to find concepts, properties of concepts, and relationships between concepts (p. 97)." The grounded theory further allows the investigator to "develop a theory around a 'core' category to explain the process under investigation" (Skeat & Perry, 2008, p. 97). Qualitative research is beneficial for practicing SLPs because it is useful "for understanding the complexities of disorders, and the experiences of clients" (Skeat & Perry, 2008, p. 96)



## **Participants**

Participants were recruited at MetroHealth Medical Center during an outpatient appointment. A total of 20 individuals of both genders participated in this study. There were no financial incentives provided for participation. All participants were adults, ages 20-90 years old. According to Seccombe and Ishii-Kuntz (1991), the age ranges used in this study were categorized by the following cohorts: 20-34 years old (young adults), 35-54 years old (middle-aged adults), 55-64 years old (the young old), 65-74 years old (the middle old), 75-84 years old (the old), and 85-90 years old (the old old).

Participants with chronic dysphagia secondary to a medical condition that was non-terminal and/or non-progressive (i.e., stroke, traumatic brain injury, spinal cord injury) were included in this study. Patients with a terminal illness (i.e., cancer), progressive disease (i.e., Parkinson's disease), and/or non-English speaking were excluded from this study. Additionally, patients considered cognitively incapable of completing an informed consent were excluded.

## **Procedure**

Once identified as meeting the criteria for the study by an SLP at MetroHealth Medical Center, patients were offered the opportunity to participate (see Appendix A). After the patients' appointment, the student investigator approached the patient to confirm that he/she would like to take part in the study. If the patient declined, he/she was thanked for their time and wished a good recovery. If the patient agreed, informed consent was received, and then the student investigator administered the questionnaire.

All participants who agreed to participate in this study received a Non-Return Cover Memo from MetroHealth Medical Center and signed the Cleveland State

University consent form after discussing this study with the examiner. These documents provided further information regarding this study. The participants were offered copies of the consent documents for their personal reference.

### **Materials**

A structured, semi-open ended questionnaire was the primary method of data collection. A questionnaire created by Ekberg et al. (2002) was developed based on relevant research questions related to the potential psychosocial effects of dysphagia. The questionnaire primarily focused on the participant's current lifestyle with dysphagia and consisted of 20 questions covering four main areas: background information, current eating status, daily life with dysphagia, and personal life with dysphagia. All questionnaire interviews lasted approximately 15 minutes each. See Appendix B for a sample questionnaire protocol.

### **Data Collection**

All data were collected in the form of an interview questionnaire. The student investigator manually recorded responses onto each participants' questionnaire. Participants were assigned a code based on gender and age range for identification on the data collection form.

## **CHAPTER III**

### **RESULTS**

#### **Participant Data**

Descriptive data were compiled for the gender and age range of each participant. There were 20 participants, 11 male and nine female. The age range of the participants was 35-90 years old and were categorized in the following age ranges: three participants in the 35-54 year age range, five participants in the 55-64 year age range, five people in the 65-74 year age range, five people in the 75-84 year age range, and two people in the 85-90 year age range. There were no participants in the 20-34 year age range. The gender and age range for each participant are presented in Table I. The mean age and standard deviations of participants in each age group are presented in Table II.

**Table I. Demographics of Participants (N=20)**

Participants	Gender	Age Range
1	M	35-54 years old
2	M	35-54 years old
3	M	55-64 years old
4	M	65-74 year old
5	M	65-74 years old
6	M	75-84 years old
7	M	75-84 years old
8	M	75-84 years old
9	M	75-84 years old
10	M	85-90 years old
11	M	85-90 years old
12	F	35-54 years old
13	F	55-64 years old
14	F	55-64 years old
15	F	55-64 years old
16	F	55-64 years old
17	F	65-74 years old
18	F	65-74 years old
19	F	65-74 years old
20	F	75-84 years old

Note. F = Female, M = Male

**Table II. Means and Standard Deviations of Participants' Age (N=20)**

Age range	<i>M</i>	<i>SD</i>
35-54	46.333	10.017
55-64	60	3.391
65-74	69.6	3.578
75-84	78.6	3.507
85-90	88	1.414

Participant's onset, etiology, and symptoms of dysphagia are listed in Table III. Onset of dysphagia ranged from 1 month to more than 1 year prior to the time the questionnaire was administered. Etiology of dysphagia resulted from Bell's palsy, traumatic brain injury (TBI), stroke, other (i.e., spinal cord injury), or unknown. Most participants' dysphagia symptoms were persistent cough, difficulty swallowing liquids, hoarse vocal quality, and sensation of food sticking in throat or chest.

**Table III. Participants' Dysphagia Characteristics (N=20)**

<b>Participants</b>	<b>Onset (months)</b>	<b>Etiology</b>	<b>Dysphagia Symptoms</b>
<b>1</b>	1-4	Bell's palsy	Drooling
<b>2</b>	5-7	TBI	Not able to swallow Difficulty swallowing liquids Hoarse vocal quality Persistent cough Short of breath
<b>3</b>	1-4	Stroke	Persistent cough
<b>4</b>	1-4	TBI	Hoarse vocal quality Persistent cough
<b>5</b>	1-4	Other	Persistent cough
<b>6</b>	12+	Other	Sensation of food sticking in throat or chest Regurgitation of food
<b>7</b>	1-4	Other	Not able to swallow
<b>8</b>	1-4	Unknown	Difficulty swallowing liquids Sore throat
<b>9</b>	12+	Unknown	Difficulty swallowing liquids Persistent cough
<b>10</b>	1-4	Other	Hoarse vocal quality Persistent cough
<b>11</b>	Unknown	Stroke	Unknown
<b>12</b>	5-7	TBI	Hoarse vocal quality
<b>13</b>	Unknown	GERD	Sensation of food sticking in throat or chest Heartburn/ acid reflux
<b>14</b>	12+	Unknown	Sensation of food sticking in throat or chest Hoarse vocal quality
<b>15</b>	1-4	Other	Hoarse vocal quality
<b>16</b>	5-7	Unknown	Not able to swallow Difficulty swallowing liquids Sore throat Persistent cough Short of breath
<b>17</b>	1-4	Unknown	Difficulty swallowing liquids Loss of appetite
<b>18</b>	12+	Other	Not able to swallow Difficulty swallowing liquids Sensation of food sticking in throat or chest Persistent cough
<b>19</b>	1-4	GERD	Sensation of food sticking in throat or chest
<b>20</b>	12+	Unknown	Sensation of food sticking in throat or chest Persistent cough

Note. TBI = Traumatic Brain Injury

Participant's diet level and eating techniques are listed in Table IV. Ten participants ate regular solid foods, one participant was trialing solid foods; five participants ate mechanical soft foods; and one participant was trialing pureed foods and one participant was eating pureed vegetables. Twelve participants drank thin liquid consistencies, one participant was trialing thin liquid consistencies; one participant drank nectar thick liquids; and two participants drank honey thick liquid consistencies. Five participants were none per oral (NPO) or receiving alternate feeding. Most participants used the small bites or sips technique when consuming food and/ or drink.

**Table IV. Participants' Diet Level (N=20)**

<b>Participants</b>	<b>Solids</b>	<b>Liquids</b>	<b>NPO and/or Alternate feeding</b>	<b>Techniques</b>
<b>1</b>	Regular	Thin		Small bites/ sips Alternate consistencies
<b>2</b>	Regular (trials) Pureed (trials)	Thin (trials)	Alternate feeding	Chin tuck Small bites/ sips Eat and swallow slowly Alternate consistencies
<b>3</b>	Mechanical soft Pureed vegetables	Honey thick		Small bites/ sips
<b>4</b>			NPO Alternate feeding	No response
<b>5</b>	Regular	Thin		Small bites/ sips Thoroughly chew food before swallowing
<b>6</b>	Mechanical soft	Thin		Small bites/ sips Eat and swallow slowly Thoroughly chew food before swallowing
<b>7</b>			NPO Alternate feeding	No response
<b>8</b>	Mechanical soft	Thin		Chin tuck Small bites/ sips Eat and swallow slowly
<b>9</b>	Regular	Thin		Unknown
<b>10</b>			Alternate feeding	No response
<b>11</b>	Mechanical soft	Honey thick		Small bites/ sips Eat and swallow slowly Alternate consistencies
<b>12</b>			NPO Alternate feeding	No response
<b>13</b>	Regular	Thin		Small bites/ sips Eat and swallow slowly Alternate consistencies
<b>14</b>	Regular	Thin		Small bites/ sips Eat and swallow slowly Alternative consistencies
<b>15</b>	Regular	Thin		Small bites/ sips Thoroughly chew food before swallowing
<b>16</b>	Regular	Thin		Thoroughly chew food before swallowing



17	Mechanical soft	Nectar thick	Small bites/ sips Alternate consistencies
18	Regular	Thin	Small bites/ sips Thoroughly chew food before swallowing
19	Regular	Thin	Unknown
20	Regular	Thin	Unknown

Note. NPO = None Per Oral

Participant's current status as to whether they were receiving speech language therapy at the time the survey was administered and the onset of therapy are listed in Table V. Nine participants were currently receiving therapy services, while 11 were not. Of the nine participants, eight have been receiving therapy for 1 to 4 months and one has been receiving therapy for 5 to 7 months.

**Table V. Participants' Dysphagia Treatment (N=20)**

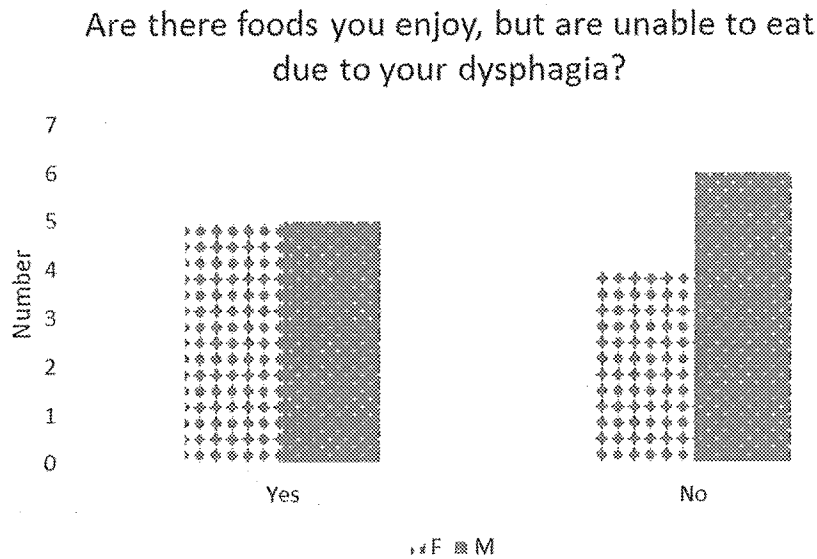
Participants	Receiving Speech Language Therapy	Onset of Therapy (months)
1	No	
2	Yes	5-7
3	Yes	1-4
4	Yes	1-4
5	No	
6	No	
7	Yes	1-4
8	Yes	1-4
9	No	
10	Yes	1-4
11	Yes	1-4
12	Yes	1-4
13	No	
14	No	
15	No	
16	No	
17	Yes	1-4
18	No	
19	No	
20	No	

## Analysis of the Psychosocial Factors of Dysphagia Based on Gender

Descriptive data were compiled to compare the psychosocial factors of dysphagia in males versus females.

The data indicated that five females and five males felt there are foods they enjoy but are unable to eat because of dysphagia. Four females and six males felt there are foods they enjoy that they are still able to eat, even with dysphagia (See Figure 1).

**Figure 1. “Are there foods you enjoy, but are unable to eat due to your dysphagia?”**

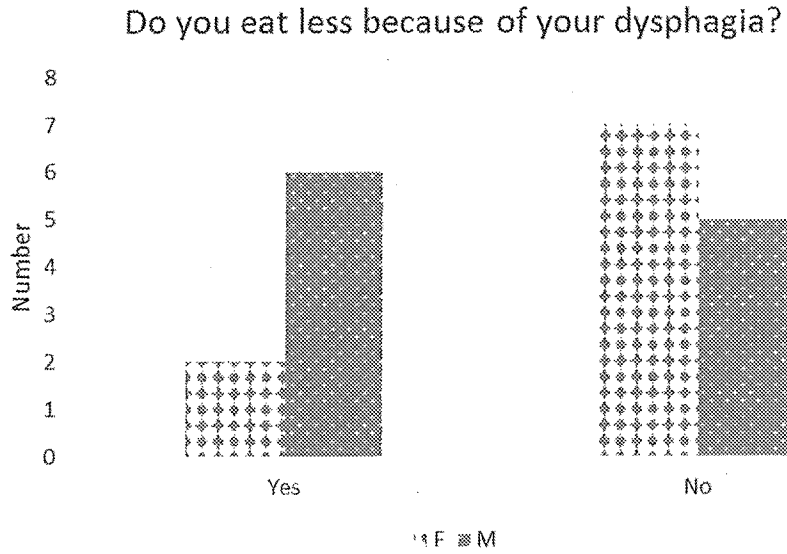


Note. F = Female, M = Male

The data indicated that two females and six males eat less due to dysphagia.

Seven females and five males do not eat less due to dysphagia (See Figure 2).

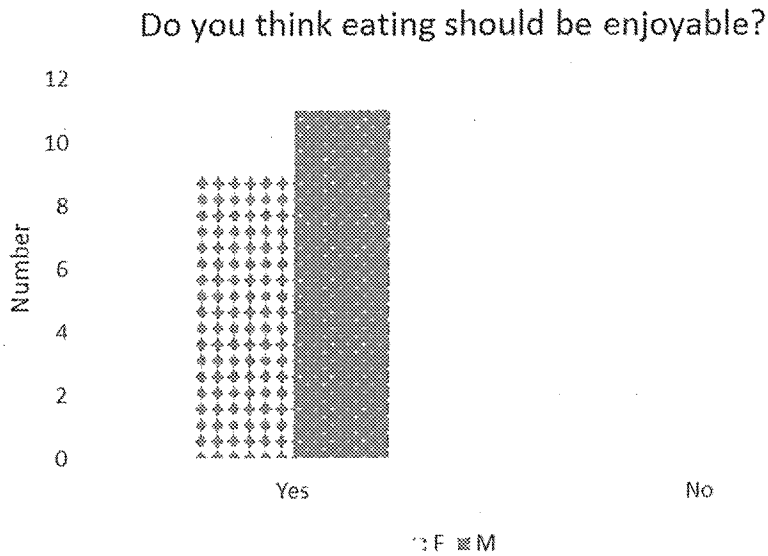
**Figure 2. “Do you eat less because of your dysphagia?”**



Note. F = Female, M = Male

The data indicated that all participants (nine females and 11 males) felt that eating should be enjoyable (See Figure 3).

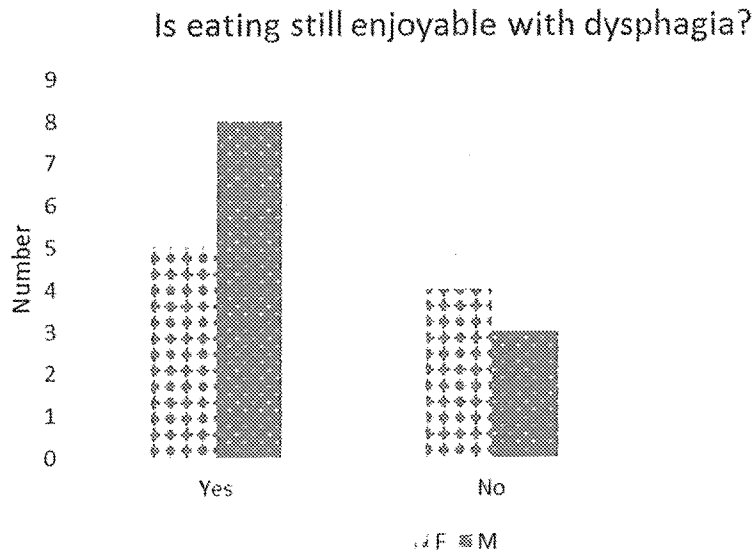
**Figure 3. “Do you think eating should be enjoyable?”**



Note. F = Female, M = Male

The data indicated that five females and eight males felt that eating is still enjoyable with dysphagia. Three males and four females felt that eating is not enjoyable with dysphagia (See Figure 4).

**Figure 4. “Is eating still enjoyable with dysphagia?”**



Note. F = Female, M = Male

The data indicated that three females and six males felt content during meal time. One female and two males avoided eating with others. Two males felt embarrassed during meal time. Three females felt anxiety and/or panic during meal time. One female and three males provided “no response” to this question (See Table VI).

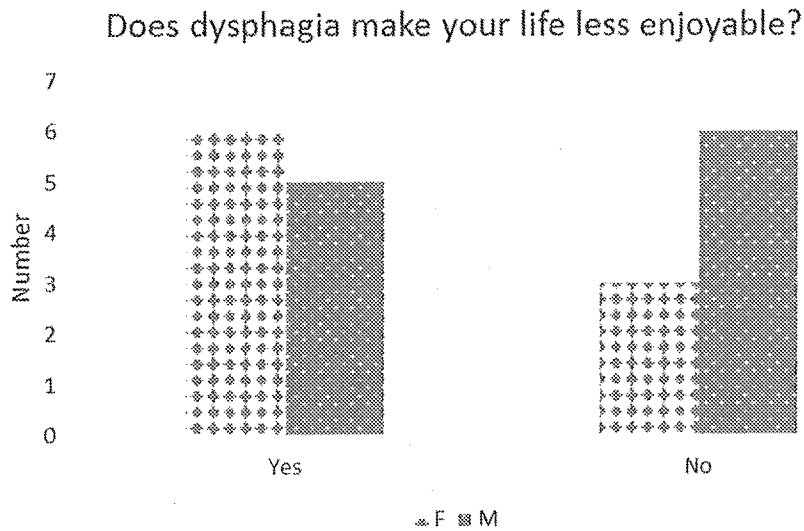
**Table VI. “Which do you feel applies to you regarding meal time?”**

	Content	Avoid eating with others	Embarrassed	Anxiety/Panic	Unsure	No Response
<b>F</b>	3	1	0	3	1	1
<b>M</b>	6	2	2	0	0	3

Note. F=Female, M=Male

The data indicated that three females and six males felt that dysphagia does not make their life less enjoyable. Six females and five males felt that dysphagia does make their life less enjoyable (See Figure 5).

**Figure 5. “Does dysphagia make your life less enjoyable?”**



Note. F = Female; M = Male

The data indicated that four females and four males felt that social interaction has been most impacted by dysphagia. One male felt his career is most impacted by dysphagia. Two males felt their hobbies are most impacted by dysphagia. One male replied “other.” Five females and four males are “unsure” or “don’t know” which areas of life are most impacted by dysphagia. Two males provided “no response” to this question (See Table VII).

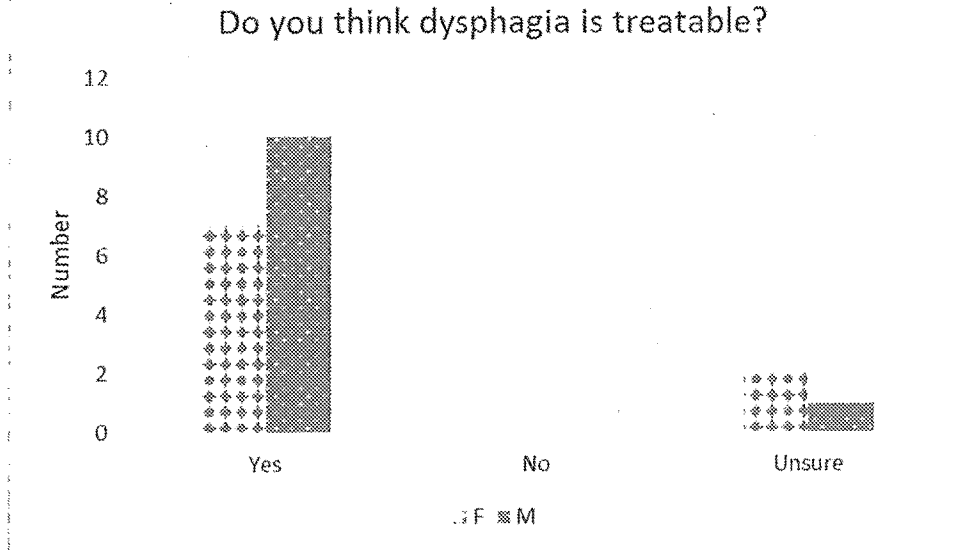
**Table VII. “What areas of your life have been most impacted by dysphagia?”**

	Social Interaction	Career	Hobbies	Finances	Other	Unsure	No Response
<b>F</b>	4	0	0	0	0	5	0
<b>M</b>	4	1	2	1	1	4	2

Note. F = Female, M = Male

The data indicated that seven females and 10 males felt that dysphagia is treatable. Two females and one male are “unsure” if dysphagia is treatable (See Figure 6).

**Figure 6. “Do you think dysphagia is treatable?”**



Note. F = Female, M = Male

The data indicated that two females and four males felt content about their dysphagia diagnosis. Three females and five males felt frustrated about their dysphagia diagnosis. Two females and male males felt depressed about their dysphagia diagnosis. Three females and one male felt embarrassed about their dysphagia diagnosis (See Table VIII).

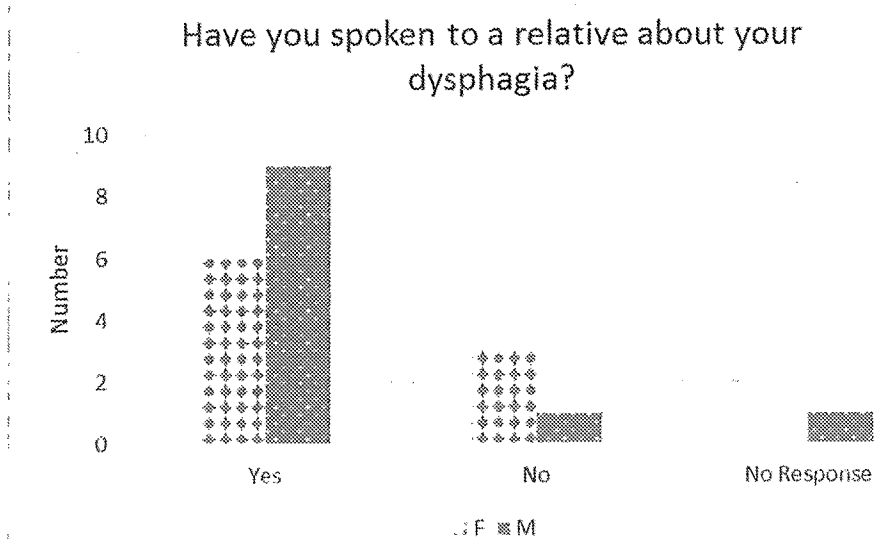
**Table VIII. “How have you emotionally reacted to your dysphagia diagnosis?”**

	Content	Frustrated	Depressed	Embarrassed
<b>F</b>	2	3	2	3
<b>M</b>	4	5	2	1

F = Female, M = Male

The data indicated that six females and nine males have spoken to a relative about their dysphagia. Three females and one male have not spoken to a relative about dysphagia. One male provided “no response” for this question (See Figure 7). Of the participants who responded that they spoke to a relative about their dysphagia, the data indicates that four females and six males have spoken to their spouse; one male spoke to his parent(s); one male spoke to a friend; one female and two males spoke to their sibling(s); three females and three males spoke to their child(ren); and one female replied “other” (See Table IX). Of the participants who responded that they have not spoken to a relative about their dysphagia, the data indicated that one female and one male feel embarrassed and two females provided “no response” for this question (See Table X).

**Figure 7. “Have you spoken to a relative about your dysphagia?”**



Note. F = Female, M = Male

**Table IX. “Who have you spoken to about your dysphagia?”**

	Spouse	Parent(s)	Friend(s)	Sibling(s)	Child(ren)	Other
<b>F</b>	4	0	0	1	3	1
<b>M</b>	6	1	1	2	3	0

Note. F = Female, M = Male

**Table X. “Why have you not spoken to anyone about your dysphagia?”**

	Embarrassed	Afraid	It can't be treated	No Response
<b>F</b>	1	0	0	2
<b>M</b>	1	0	0	0

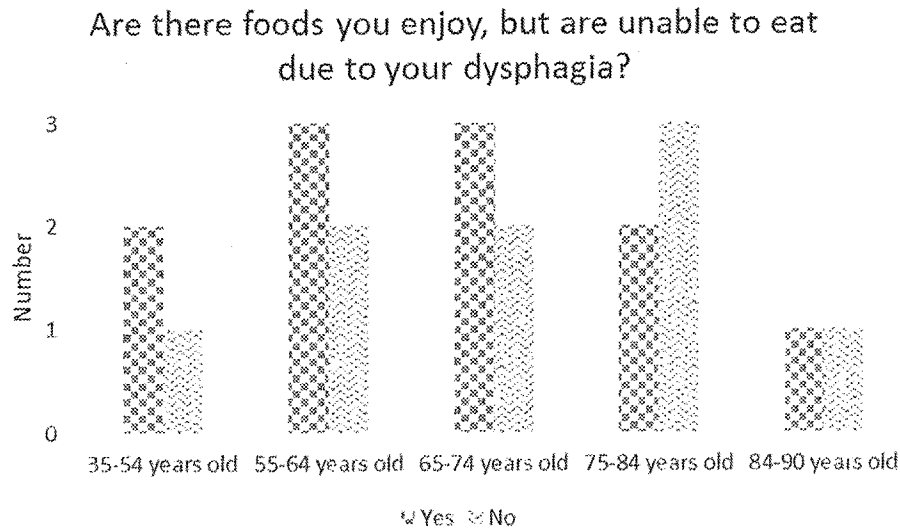
Note. F = Female, M = Male

**Analysis of the Psychosocial Factors of Dysphagia Based on Age Range**

Descriptive data were compiled to compare the psychosocial factors of dysphagia in age ranges.

The data indicated that more participants in the 35-54, 55-64, and 65-74 year age ranges felt there are foods they enjoy but are unable to eat because of dysphagia. More participants in the 75-84 year age range felt there are foods they enjoy that they are still able to eat, even with dysphagia. There is no difference in answers for participants in the 84-90 year age range (See Figure 8).

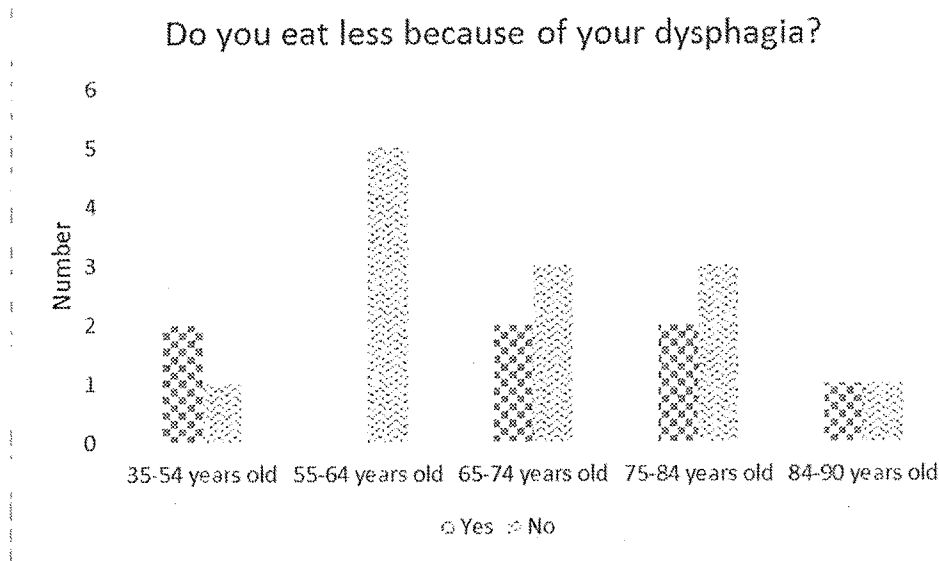
**Figure 8. “Are there foods you enjoy, but are unable to eat due to your dysphagia?”**





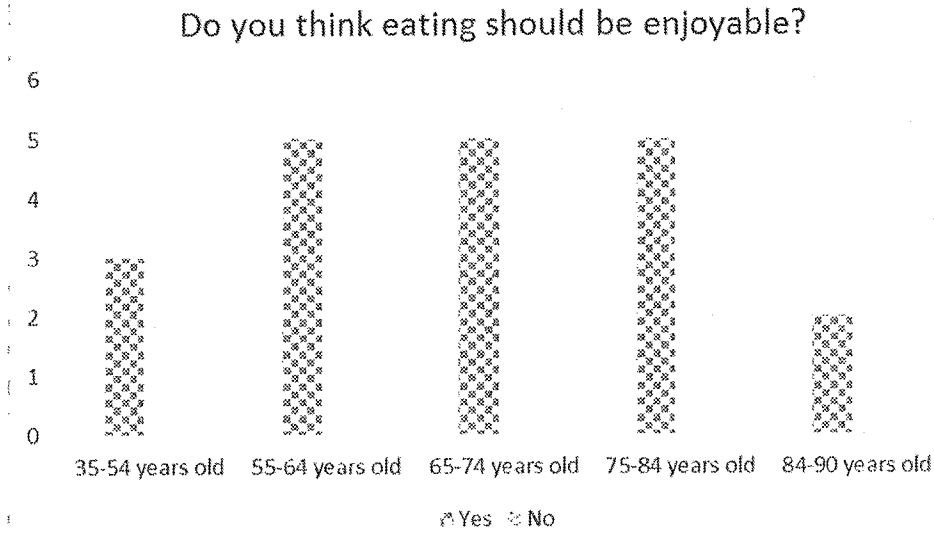
The data indicated that more participants in the 35-54 year age range eat less due to dysphagia. All participants in the 55-64 year age range do not eat less due to dysphagia. More participants in the 65-74 and 75-84 year age range do not eat less due to dysphagia. There is no difference in answers for participants in the 84-90 year age range (See Figure 9).

**Figure 9. “Do you eat less because of your dysphagia?”**



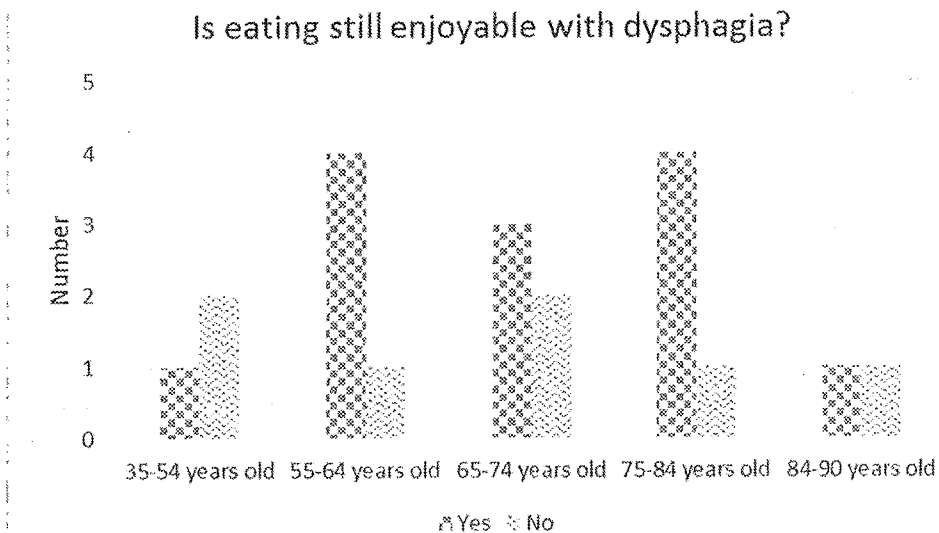
The data indicated that participants in all age ranges felt that eating should be enjoyable (See Figure 10).

**Figure 10. “Do you think eating should be enjoyable?”**



The data indicated that more participants in the 55-64, 65-74, and 75-84 year age ranges felt that eating is still enjoyable with dysphagia. More participants in the 35-54 year age range felt that eating is not enjoyable with dysphagia. There is no difference in answers for participants in the 84-90 year age range (See Figure 11).

**Figure 11. “Is eating still enjoyable with dysphagia?”**



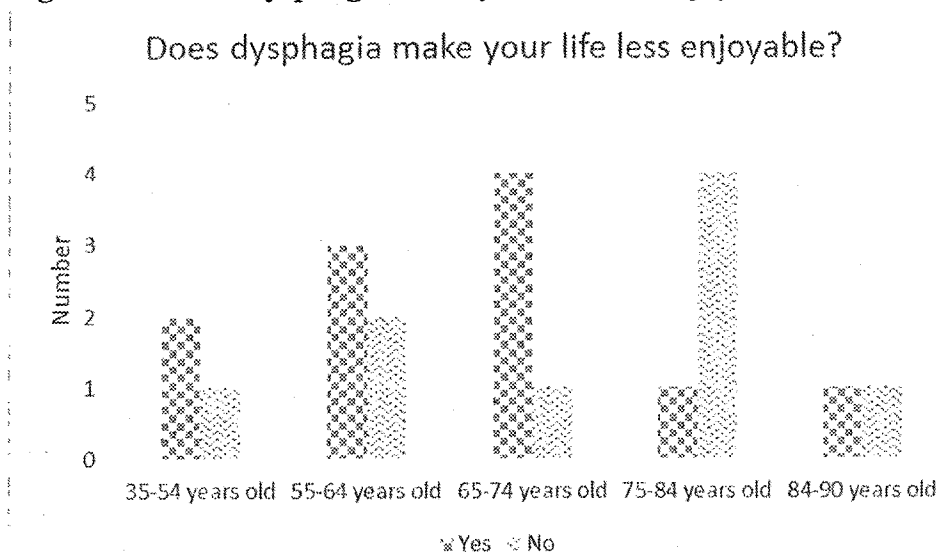
The data indicated that more participants in the 75-84 year age range felt content during meal time. Participants in the 35-54, 65-74, 75-84 year age ranges avoided eating with others. Participants in the 35-54 year age range felt embarrassed during meal time. More participants in the 55-64 year age range felt anxiety and/or panic during meal time (See Table XI).

**Table XI. "Which do you feel applies to you regarding meal time?"**

	Content	Avoid eating with others	Embarrassed	Anxiety/Panic	Unsure	No Response
<b>35-54</b>	1	1	1	0	0	1
<b>55-64</b>	2	0	0	3	0	0
<b>65-74</b>	2	1	0	1	1	1
<b>75-84</b>	3	1	1	0	0	1
<b>85-90</b>	1	0	0	0	0	1

The data indicated that participants in the 35-54, 55-64, and 65-74 year age ranges felt that dysphagia makes their life less enjoyable. Participants in the 75-84 year age range felt that dysphagia does not make their life less enjoyable. There is no difference in answers for participants in the 84-90 year age range (See Figure 12).

**Figure 12. "Does dysphagia make your life less enjoyable?"**



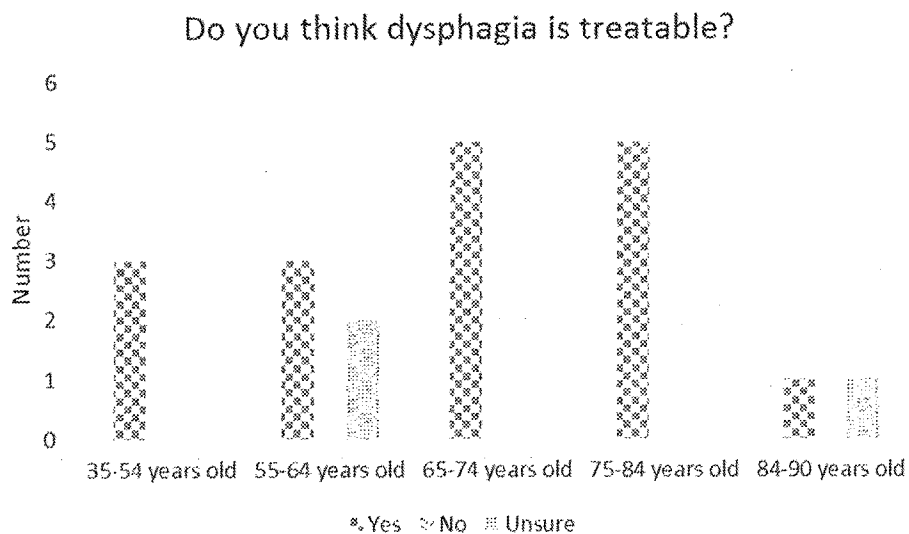
The data indicated that more participants in the 35-54 year age range felt that social interaction has been most impacted by dysphagia. One participant in the 35-54 year age range felt that career is most impacted by dysphagia. Participants in the 35-54 and 65-74 year age range felt their hobbies are most impacted by dysphagia. One participant in the 65-74 year age range replied that finances are most impacted by dysphagia. (See Table XII).

**Table XII. "What areas of your life have been most impacted by dysphagia?"**

	Social Interaction	Career	Hobbies	Finances	Other	Unsure	No Response
35-54	3	1	1	0	0	0	0
55-64	2	0	0	0	0	3	0
65-74	2	0	1	1	1	2	0
75-84	1	0	0	0	0	3	1
85-90	0	0	0	0	0	1	1

The data indicated that most participants in the 35-54, 55-64, 64-74, and 75-84 year age ranges felt that dysphagia is treatable. There is no difference in answers for participants in the 84-90 year age range (See Figure 13).

**Figure 13. "Do you think dysphagia is treatable?"**



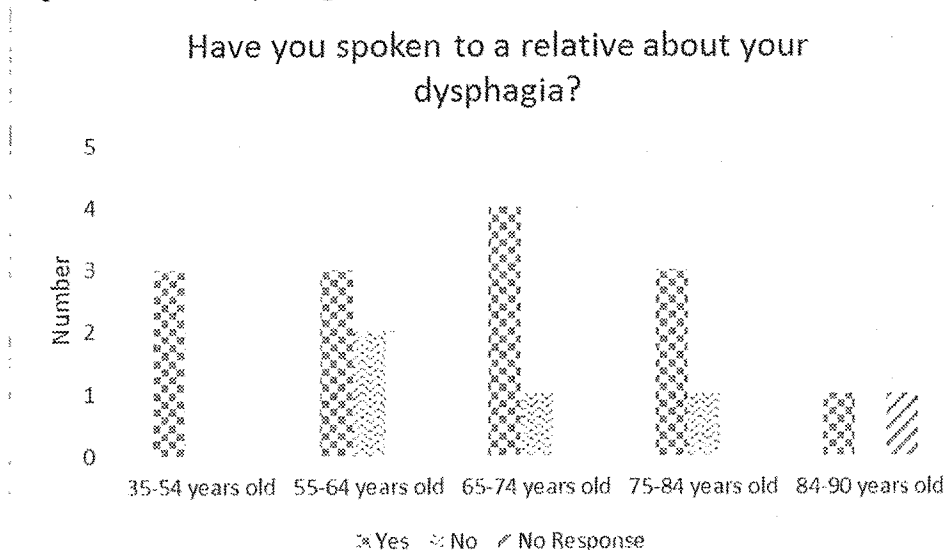
The data indicated that more participants in the 55-64 and 65-74 year age ranges felt content about their dysphagia diagnosis. More participants in the 75-84 year age range felt frustrated about their dysphagia diagnosis. More participants in the 65-74 year age range felt depressed about their dysphagia diagnosis. More participants in the 55-64 year age range felt embarrassed about their dysphagia diagnosis (See Table XIII).

**Table XIII. "How have you emotionally reacted to your dysphagia diagnosis?"**

	<b>Content</b>	<b>Frustrated</b>	<b>Depressed</b>	<b>Embarrassed</b>
<b>35-54</b>	0	2	0	1
<b>55-64</b>	2	2	1	2
<b>65-74</b>	2	1	3	0
<b>75-84</b>	1	3	0	1
<b>85-90</b>	1	1	0	0

The data indicated that most participants in the 35-54, 55-64, 65-74, and 75-84 year age range have spoken to a relative about their dysphagia. One participant in the 84-90 year age range provided “no response” for this question (See Figure 14). Of the participants who responded that they spoke to a relative about their dysphagia, the data indicated that more participants in the 35-64 and 75-84 year age ranges spoken to their spouse; 1 participant in the 35-54 year age range spoke to his/her parent(s); 1 participant in the 35-54 year age range spoke to a friend; participants in the 35-54, 55-64, and 65-74 year age range spoke to their sibling(s); more participants in the 75-84 year age range spoke to their child(ren); and 1 participant in the 55-64 year age range replied “other” (See Table XIV). Of the participants who responded that they have not spoken to a relative about their dysphagia, the data indicated that one participant in the 55-64 and 75-84 year age ranges felt embarrassed and one participant in the 55-64 and 65-74 year age ranges provided “no response” for this question (See Table XIV).

**Figure 14. “Have you spoken to a relative about your dysphagia?”**



**Table XIV. "Who have you spoken to about your dysphagia?"**

	Spouse	Parent(s)	Friend(s)	Sibling(s)	Child(ren)	Other
<b>35-54</b>	3	1	1	1	1	0
<b>55-64</b>	1	0	0	1	0	1
<b>65-74</b>	2	0	0	1	1	0
<b>75-84</b>	3	0	0	0	4	0
<b>85-90</b>	0	0	0	0	1	0

**Table XV. "Why have you not spoken to anyone about your dysphagia?"**

	Embarrassed	Afraid	It can't be treated	No Response
<b>35-54</b>	0	0	0	0
<b>55-64</b>	1	0	0	1
<b>65-74</b>	0	0	0	1
<b>75-84</b>	1	0	0	0
<b>85-90</b>	0	0	0	1

In summary, there appear to be distinct psychosocial differences amongst gender and age range of those diagnosed with dysphagia.

## **CHAPTER IV**

### **DISCUSSION**

The primary purpose of this study was to examine pseudo-qualitatively the psychosocial impact of dysphagia on individuals affected. Three broad questions were investigated: (1) What are the psychosocial effects of dysphagia in adults with a non-terminal, non-progressive medical condition? (2) How do the psychosocial effects of dysphagia differ in males versus females? (3) How do the psychosocial effects of dysphagia differ in age range?

#### **The Psychosocial Effects of Dysphagia in Adults from Their Perspective**

Regarding the first question, the results suggest that the psychosocial effects of dysphagia are frustrated, embarrassed, depressed and content. Although most participants provided more than one answer to this question, "frustrated" appears to be the emotional response expressed by the majority of participants regarding their dysphagia diagnosis. All participants agreed that eating should be an enjoyable aspect of life and surprisingly, most of them feel that eating is still enjoyable with dysphagia. The participants who did not feel that eating was still enjoyable were diagnosed with dysphagia over five months



ago and/or had a change in dietary levels (e.g, mechanical soft foods, NPO, alternate feeding).

Although most participants felt that eating was still enjoyable, even with dysphagia, the majority of participants replied that dysphagia does make their life less enjoyable. Areas of life, including social interaction, career, hobbies, and other areas of life (i.e., consuming alcohol, eating in restaurants), were all negatively impacted by dysphagia. This response bears some significance to individuals with dysphagia and quality of life issues while suffering from dysphagia.

Almost all participants reported that they had talked to a relative or friend about their dysphagia. The small number of participants who indicated that they have not discussed their dysphagia with others also reported that they were embarrassed or provided no response.

#### **The Psychosocial Effects of Dysphagia Comparison: Males versus Females**

The results suggest there are psychosocial difference between males compared to females regarding their lifestyles with dysphagia. The results indicated that more men feel content and/or frustrated with their dysphagia diagnosis compared to the majority of women, who feel frustrated and/or embarrassed (Table VIII). This finding may suggest that males are more accepting of their dysphagia diagnosis, but may have days of frustration. Whereas, females are less accepting of the diagnosis and consistently feel embarrassed and frustrated about their condition.

Both genders equally agreed that eating should be an enjoyable aspect of life (Figure 3). The majority of males felt they eat less because of their dysphagia compared to females (Figure 2). This finding may suggest that males typically to eating larger

portions of food and beverage at mealtime compared to females. With a dysphagia diagnosis, food modifications, and/or use of techniques, males may feel as if they are consuming less food and drink. However, more males reported they are still eating foods they enjoy compared to the females, who felt they are no longer eating foods they enjoy due to dysphagia (Figure 1). Although not identified by this study, some anecdotal reports have been reported by nursing staff and family members that males tend not following diet recommendations as precisely as females.

During meal time, the majority of males felt content, avoided eating with others, and/or embarrassed during meal time, whereas females typically felt anxiety or panic during meal time (Table VI). Overall, males reported they felt that eating was still enjoyable with dysphagia, whereas women felt that eating was not as enjoyable (Figure 4). As similarly stated above, this may be due to males being more accepting of their dysphagia diagnosis compared to females. Additionally, females eating fewer foods they enjoy and consistently feeling anxiety or panic during meal time may account for the reason they no longer enjoy eating.

Overall, more females felt their life was less enjoyable with dysphagia and were unsure if dysphagia was treatable, compared to males (Figures 5 and 6). As similarly stated above, this finding is consistent with how females feel about eating (i.e., not enjoyable). Both males and females reported that the area of life most impacted was social interaction. However, males reported additionally that hobbies, career, and finances, were equally affected (Table 7). This may suggest that both genders feel unable to fully participate when dining out at restaurants, during family mealtime, or at social gatherings (e.g., wedding, birthday party). This is supported by Rappoport et al. (1993),

who stated that both men and women associate food with social relationships relating to family (e.g., siblings, relatives, spouse).

Finally, more males have spoken to relatives, or a friend about their dysphagia compared to females (Figure 7). This may suggest that women may feel too embarrassed to share their diagnosis and struggles with dysphagia to others (Table 9). However, the majority of females and males tended to discuss their dysphagia with their spouse and/or children (Table 10).

### **The Psychosocial Effects of Dysphagia Comparison: Age Ranges**

The results suggest there are psychosocial differences between age ranges. Age ranges were explicitly grouped in the subsequent cohorts: 35-54 years (middle aged), 55-64 years (young old), 65-74 years (middle old), 75-84 (old), and 85-90 years (old-old). The majority of the middle aged cohort felt frustrated about their dysphagia diagnosis; while the young old cohort equally felt content, frustrated, and/or embarrassed; the middle old cohort felt depressed; the old cohort felt frustrated; and the old-old cohort equally felt content and frustrated (Table 13). These results provide an inconsistent pattern for all age cohorts but do suggest that all cohorts are impacted by dysphagia and emotions towards dysphagia are individually based.

All age ranges agreed that eating should be an enjoyable aspect of life (Figure 10). But the majority of middle aged participants felt they eat less because of their dysphagia compared to the other age cohorts (Figure 9). This may be due to the social aspect of eating being impacted, which leads to this cohort feeling as if they eat less. This finding is consistent with research by Rappoport et al. (1993), who suggested that younger adults are more likely to relate food to social relationships. More middle aged,

young old, and middle old adults felt there were foods they enjoyed but are no longer able to eat due to dysphagia; whereas most of the old cohort are continuing to eat foods they enjoy, even with dysphagia (Figure 8). One can speculate here that as people age normally, they have the expectations of making adjustments to lifestyle issues, for example, older healthy individuals tend to change food textures secondary to changes in their dentition. Consequently, it may not be unusual for older persons to accommodate to a food texture change that might be prompted by the dysphagia. During meal time, the middle aged cohort felt equally content, avoided eating with others, or embarrassed, whereas the young old cohort felt anxiety or panic during, and the remaining cohorts felt content (Table XI).

In general, all age groups reported they felt their life was less enjoyable with dysphagia (Figure 12). Of significance was the fact that the middle old cohort (65-74 years old) felt most unsure about whether dysphagia was treatable, and thus felt more depressed about their dysphagia diagnosis (Figure 13). It can only be speculated that since this is the age group that most likely is in the early years of retirement, they may be despairing or dreading the future in anticipation of the inevitable life cycle changes thus experiences a feeling of doom.

The areas of life most impacted by dysphagia for the middle aged group (35-54 years old) was social interaction, career, and hobbies, respectively. Since this cohort is at the peak of their careers and socially involved with family and friends, this finding is consistent with the negative impact of dysphagia on their lifestyle. Most of the participants in the young old, middle old, old and old-old cohorts replied they were unsure or provided no response to which area of life was most negatively impacted by

dysphagia (Table XII). Many of the participants provided that they have not thought about areas of life affected by dysphagia. It could be that the effect of dysphagia may have had such a global effect that they were unable to parcel out any one area affected more so than the other.

Finally, almost all of the participants in each age group reported they have spoken to relatives or a friend about their dysphagia. However, there were participants in the young old, middle old, old, and old-old cohorts that haven't spoken to anyone about their dysphagia (Figure 14). Majority of participants in the middle aged and middle old cohorts primarily discussed their dysphagia condition with a spouse; while young old participants equally talked a spouse or a sibling; and the old and old-old cohorts mostly spoke to their children (Table XIV). Participants in the young old and old cohorts replied embarrassed; and participants in the young old, middle old, and old-old answered no response for this question (Table XV). This finding, in general, suggests that although majority of participants do speak to relatives and/or friends about their condition, there are few who choose not to discuss their condition due to embarrassment or other individually based reasons.

Overall, many of the participants displayed feeling of frustration, anxiety, or depression regarding their dysphagia diagnosis. Additionally, social interaction is the primary aspect of life affected by dysphagia reported by the participants. Many of the findings were consistent with the findings of Ekberg et al. (2002), which states that "dysphagia can destroy the social opportunities and pleasures of mealtimes, affect the quality of the patient's relationships with family, and can further undermine health and confidence" (p. 140).

## **CHAPTER V**

### **CONCLUSION**

This study represents a modest attempt to quantify through a pseudo-qualitative investigation, the psychosocial effects of dysphagia from the individual's perspective. Results reveal that there are psychosocial effects, impact, and differences across gender and age ranges. Some of the psychosocial effects of dysphagia identified by participants in this study represent the gamut of emotional and life altering changes concurrently identified in the literature regarding other chronic illnesses. For example, participants in this study identified frustration, embarrassment, depression, anxiety or panic, and other affected areas of life such as social interaction, career, hobbies, and finances. In general, social interaction is most impacted by dysphagia. The impact of the psychosocial effects of dysphagia differs in gender, where females with dysphagia enjoy eating and life less, compared to males. Age range differences suggest that the middle aged cohort (35-54 years old) with dysphagia enjoy eating less compared to other cohorts. Additionally results suggest that the middle aged, young old (55-64 years old), and middle old (65-74

years old) cohorts enjoy life less, compared the old (75-84 years old) and old-old (85-90 years old) cohorts.

### **Implications**

While this study was small in scope, the results serve to provide some insight into the devastating effects of dysphagia upon a person's life and overall quality of life. This information is crucial for SLPs who are swallowing specialists, in terms of service delivery. It is of vital important that SLPs be aware of the impact of the disorder on the individual's overall quality of life, so that more effective methods to help the person regain normal swallowing skills may be employed. Therefore, instead of providing treatment that focuses on the etiology of dysphagia, treatment should consist of tailored goals that are both functional and individualized to the clients' needs. This may entail the SLP to provide counseling support, since the psychological, emotional, and social states of the patient are so impacted by dysphagia. Additionally, being sensitive to the psychological impact of dysphagia may serve as a means of probing more into the type of foods a patient may be able to manage without embarrassment. Such an approach to treatment naturally involves input from the patient. When patients are involved in the process of creating their treatment goals, they will be more determined to meet these goals, which ultimately results in overall improved successful outcome.

### **Limitations and Future Studies**

Although this study was highly provocative, there were significant limitations. A primary limitation of this study was the small sample size overall and within the various cohort groups. A second limitation of this study is the lack of equal numbers of

participants within designated groups. Moreover, the young adult cohort (20-34 years old) failed to provide any participants, which may have been due to limited availability of participants. Including the young adult cohort would have provided a more representative sample population living with dysphagia. A third limitation is the researcher did not consider ethnic differences associated with the psychosocial effects of dysphagia. Information regarding the psychosocial effects of dysphagia amongst ethnic groups (e.g., Caucasian, African-American, Asian, Hispanic) would provide practicing clinicians with information to tailor and individualize treatment.

The relatively small sample size of this survey does not allow for an accurate analysis of the psychosocial differences between gender and age. A larger study that includes more participants and diversity would be able to better address the psychosocial effects of dysphagia and provide additional data on ethnicity, gender and age differences. The geographic focus of this study also limited the ability to analyze a wider population sample. This study included outpatients from a local area hospital. However, future research should expand the geographic focus area to include multiple cities and settings to obtain a more representative sample. Additionally, further studies focusing on how to incorporate the psychosocial aspects of dysphagia in therapy are still needed. Furthermore, this study utilized descriptive statistics as a means to analyze the results of this questionnaire. It would be beneficial to utilize inferential statistics in future studies to determine if a statistical significance is present in the data.



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## **APPENDICES**

## **APPENDIX A: SCRIPT**

### **Script for Recruitment**

**Used by the Medical Speech Language Pathologist**

*"A graduate student from Cleveland State University is conducting research on how swallowing has effected your life. Are you willing to participate in such a study?"*

## APPENDIX B: DYSPHAGIA QUESTIONNAIRE

### Dysphagia Questionnaire

Code:

Background Information	Question	
1	What is your gender?	<input type="checkbox"/> Male <input type="checkbox"/> Female
2	Which age category fits you?	<input type="checkbox"/> 20-34 years old <input type="checkbox"/> 35-54 years old <input type="checkbox"/> 55-64 years old <input type="checkbox"/> 65-74 years old <input type="checkbox"/> 75-84 years old <input type="checkbox"/> 85-90 years old
3	When were you diagnosed with dysphagia?	<input type="checkbox"/> 1-4 months ago <input type="checkbox"/> 5-7 months ago <input type="checkbox"/> 8-12 months ago <input type="checkbox"/> More than 1 year ago <input type="checkbox"/> I don't know <input type="checkbox"/> No response
4	Which condition caused the dysphagia?	<input type="checkbox"/> Stroke <input type="checkbox"/> Traumatic Brain Injury <input type="checkbox"/> Bell's Palsy <input type="checkbox"/> GERD <input type="checkbox"/> Xerostoma <input type="checkbox"/> Other: _____ <input type="checkbox"/> I don't know <input type="checkbox"/> No response
5	Do you experience any of the following symptoms with your dysphagia?	<input type="checkbox"/> Pain while swallowing <input type="checkbox"/> Not being able to swallow <input type="checkbox"/> Difficulty swallowing liquids <input type="checkbox"/> Sensation of food sticking in throat or chest <input type="checkbox"/> Sore throat <input type="checkbox"/> Drooling <input type="checkbox"/> Hoarse vocal quality <input type="checkbox"/> Regurgitation of food <input type="checkbox"/> Heartburn/ acid reflux <input type="checkbox"/> Loss of appetite <input type="checkbox"/> Persistent cough <input type="checkbox"/> Short of breath <input type="checkbox"/> I don't know <input type="checkbox"/> No response

**Current  
Eating Status**

Question		
6	What is your current diet?	<input type="checkbox"/> Regular solids <input type="checkbox"/> Mechanical soft foods <input type="checkbox"/> Pureed foods <input type="checkbox"/> Thin liquids <input type="checkbox"/> Nectar thick liquids <input type="checkbox"/> Honey thick liquids <input type="checkbox"/> NPO (none per oral) <input type="checkbox"/> Alternative feeding (i.e., PEG, NG) <input type="checkbox"/> I don't know <input type="checkbox"/> No response
7	What techniques or suggestions are recommended for you to use?	<input type="checkbox"/> Chin tuck <input type="checkbox"/> Head turn <input type="checkbox"/> Small bites/ sips <input type="checkbox"/> Eat and swallow slowly <input type="checkbox"/> Take sips of liquid between bites of food <input type="checkbox"/> Thoroughly chew food before swallowing <input type="checkbox"/> I don't know <input type="checkbox"/> No response
8	Do you need assistance when eating?  If yes, who provides the assistance?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response  <input type="checkbox"/> Spouse <input type="checkbox"/> Sibling(s) <input type="checkbox"/> Parent(s) <input type="checkbox"/> Child(ren) <input type="checkbox"/> Friend(s) <input type="checkbox"/> Other:
9	Are there foods you enjoy, but are unable to eat due to your dysphagia?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response
10	Do you eat less because of your dysphagia?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response

**Daily Life with  
Dysphagia**

	Question	
11	Do you think eating should be enjoyable?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response
12	Is eating still enjoyable with dysphagia?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response
13	Which do you feel applies to you regarding meal time?	<input type="checkbox"/> Content during meal time <input type="checkbox"/> Avoid eating with others <input type="checkbox"/> Embarrassed during meal time <input type="checkbox"/> Feelings of anxiety or panic during meal time <input type="checkbox"/> I don't know <input type="checkbox"/> No response
14	Does dysphagia make your life less enjoyable?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response
15	What areas of your life have been most impacted by dysphagia?	<input type="checkbox"/> Social interaction <input type="checkbox"/> Career <input type="checkbox"/> Finances <input type="checkbox"/> Hobbies <input type="checkbox"/> Other: _____ <input type="checkbox"/> I don't know <input type="checkbox"/> No response

**Personal Life  
with  
Dysphagia**

	Question	
16	Do you think dysphagia is treatable?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I don't know <input type="checkbox"/> No response
17	How have you emotionally reacted to your dysphagia diagnosis?	<input type="checkbox"/> Content <input type="checkbox"/> Frustrated <input type="checkbox"/> Embarrassed <input type="checkbox"/> Depression <input type="checkbox"/> I don't know <input type="checkbox"/> No response
18	Are you currently receiving speech-language therapy services for dysphagia?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response
	If yes, how long have you been receiving treatment?	<input type="checkbox"/> 1-4 months ago <input type="checkbox"/> 5-7 months ago <input type="checkbox"/> 8-12 months ago <input type="checkbox"/> More than 1 year ago <input type="checkbox"/> I don't know

19	Have you spoken to a relative about your dysphagia?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> No response
	If yes, who?	<input type="checkbox"/> Spouse <input type="checkbox"/> Sibling(s) <input type="checkbox"/> Parent(s) <input type="checkbox"/> Child(ren) <input type="checkbox"/> Friend(s) <input type="checkbox"/> Other: _____
	If no, why not?	<input type="checkbox"/> Embarrassed <input type="checkbox"/> Afraid <input type="checkbox"/> It can't be treated.

20. Additional Comments: Is there anything else you would like other people to know about living with dysphagia?

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