

IMPROVING SWALLOW FUNCTION IN
PROGRESSIVE DYSPHAGIA ASSOCIATED WITH
HUNTINGTON'S DISEASE

By

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CHAPTER I

INTRODUCTION

Individuals with Huntington's disease, a genetic and fatal disease, typically develop dysphagia, a swallowing disorder, at some point in their battle with the disease. It is crucial these individuals attain a solution to their swallowing difficulties. Most approaches to the treatment of Huntington's disease are pharmacological in nature. Although pharmacological remediation is beneficial and often necessary, there are substantial adverse reactions associated with drugs. The medications currently available lack extensive research as to enduring effects; moreover, they mask the symptoms resulting from the disease, rather than providing actual improvement in various disorders.

A less aversive treatment approach is found through the adoption of compensatory strategies to aid in the symptomatic relief of the movement disorder. Symptomatic relief, through pharmacological or compensatory treatments, provides only a temporary reduction in abnormal movement. Compensatory strategies vary according to the symptoms from which the individual suffers. While compensatory strategies provide symptomatic relief in many cases, there is no true remediation of the associated muscular weakness. As is the case with pharmacological therapy, compensatory strategies mask the symptoms of the disease with no actual remediation of the affected physiology.

The general population understands the importance of exercise. Physical exercise enables individuals to maintain, and/or improve the function of targeted musculature. Understanding both the importance and the benefits of exercise has spawned the formulation of treatment in individuals with Huntington's disease. As further discussed in a review of the literature, studies, while limited, show promise in maintaining and even improving the integrity of musculature involved in speech through the implementation of strengthening exercises in individuals with Huntington's disease. The majority of the musculature involved in speech production is identical to that involved in the process of swallowing. Based on this knowledge, it is recommended the exercises noted to improve speech production be implemented in an attempt to rehabilitate those suffering from dysphagia.

The primary intent of this study was to examine the effects of strengthening exercises deemed appropriate for vocal, oral-motor, and respiratory rehabilitation to the swallowing process. This study employed oral-motor, respiratory, and pharyngeal strengthening exercises to improve swallow function. The strength, range of motion, and coordination of the structures innervated by cranial nerves V, VII, IX, X, XII which influence speech and swallow function were measured and compared both before and after a four-week long implementation of the aforementioned treatment exercises. The discussion of the results will be based upon both objective and subjective measures of comparison.

CHAPTER II

REVIEW OF LITERATURE

Huntington's disease is a devastating genetic disorder caused by a mutation of the gene on the short arm of chromosome four that results in progressive deterioration of the central nervous system control of the body. Males and females are affected alike, and the typical age of onset occurs in the afflicted individuals late 30's; however, age of onset has occurred from early childhood to late adulthood (Dawson, Kristijanson, Toye, & Flett, 2004). Characteristics of the disease include emotional and cognitive changes along with physical impairments. Death befalls the individual within 10 to 20 years of the initial onset of these symptoms.

Personality changes affect impulsiveness, depression, and mood swings, while changes in cognition typically affect short-term memory and problem solving. These are often the presenting characteristics associated with the insidious onset of the disease (Dawson et al., 2004). The physical impairments affecting the individual diagnosed with Huntington's disease are grave. Motor decline is noted through involuntary movements in the form of chorea, as well as impaired voluntary movements such as bradykinesia, disturbances in gait, dysarthria, and dysphagia. Treatment, while available for the characteristics of Huntington's disease, fails to hinder the inevitable progression that ultimately ends the individual's life (Dawson et al., 2004).

Dysphagia

Dysphagia refers to difficulties with feeding as a result of abnormalities in the swallowing process (Logemann, 1998). Swallowing is a complex procedure consisting of three primary phases: oral, pharyngeal, and esophageal. Together these three phases work through voluntary and involuntary neuromusculature to produce a smooth, fluid swallowing process in normal individuals. It is essential that these three phases of the swallow function appropriately due to their mandatory coordination with one another. Abnormalities within any or all phases of the swallowing process may result in dysphagia. The sequelae of dysphagia include: malnutrition, penetration of the bolus to the vocal folds, aspiration of the bolus below the vocal folds and resultant aspiration pneumonia, and asphyxiation (Kagel & Leopold, 1992).

The understanding of the complexity of the three intricate phases of swallowing is critical when assessing dysphagia and associated disorders. The oral phase consists of mastication of the bolus in preparation for its propulsion into the cavity of the oropharynx. This act of propelling the bolus into the oropharynx initiates the contraction of the tongue and the striated muscles of mastication. This voluntary preparation and propulsion of the bolus into the anterior portion of the oropharynx triggers an involuntary, reflexive swallow.

The initiation of the involuntary swallow reflex begins the second, or pharyngeal, phase of the swallowing process. As the bolus enters into the anterior portion of the cavity of the oropharynx, the velum rises while the hyoid bone and larynx move superiorly and anteriorly. The epiglottis covers the trachea, and the vocal folds adduct to further protect the airway, preventing aspiration. The tongue then pushes the bolus

posteriorly into the pharynx, and the walls of the pharynx begin peristaltic movement to aid in propelling the bolus downward. The movement of these structures allows the bolus to pass through the pharynx and aids in the opening of the upper esophageal sphincter.

Peristaltic movement permits the passing of the bolus through the opened upper esophageal sphincter into the esophagus, initiating the esophageal phase of the swallow. The lower esophageal sphincter opens during this phase of the swallow, and from the esophagus the bolus enters the stomach. This completes the complex, yet predominantly involuntarily, process of swallowing (Logemann, 1998). As revealed within the three phases, swallowing requires intact and appropriate functioning of voluntary and involuntary musculature alike. Abnormalities in the functioning of these voluntary or involuntary groups result in dysphagia.

The type of dysphagia the individual experiences may be classified as neurologic or non-neurologic, depending upon the source of the abnormalities. Non-neurologic dysphagia is often the result of illness or surgery, and it typically indicates a positive prognosis. Neurologic dysphagia, however, stems from various etiologies, often stroke and progressive neuromuscular diseases, and generally indicates a poor prognosis (Logemann, 1998). Without appropriate attention to the array of ramifications, dysphagia could threaten the lives of individuals with progressive neurological diseases, such as Huntington's disease.

Dysphagia often presents itself in later stages of the course of Huntington's disease. All characteristics of the disease negatively impact the individual and his or her family, but the ramifications of severe dysphagia are often fatal. Individuals suffering

from dysphagia secondary to Huntington's disease advance their risk of death due to cachexia, aspiration, which increases risks of aspiration pneumonia, and asphyxiation (Kagel & Leopold, 1992). This alarming fact supports the critical need for focal attention on the relation between Huntington's disease treatment and maintenance of swallow safety.

HD Subtypes and Dysphagia Characteristics

Huntington's disease affects each individual uniquely, and, as a result, the swallowing abnormalities experienced differ depending upon the motor impairments of a given individual. Some patients experience forms of severe hyperkinesia, while others experience forms of rigid bradykinesia. Just as the subtypes of their disease differ, so do the abnormalities of their swallow.

Kagel and Leopold (1992) attempted to pinpoint the similarities and differences across the motor classifications of the disease through a clinical assessment of swallow function. Clinical assessment of the swallow revealed those individuals with the hyperkinetic type of Huntington's disease demonstrated an uncoordinated and repetitive swallow, and a longer period of elevation of the larynx. Individuals with the hyperkinetic type of Huntington's disease also exhibited respiratory and lingual forms of chorea. Those with the rigid bradykinetic type of Huntington's disease expressed rigidity of the mandible, excessive coughing on solid foods, choking on thin liquids, and lingual chorea (Kagel & Leopold, 1992).

Impairments in voluntary and involuntary movements are highly individualized in individuals with Huntington's disease; however, there are alarming similarities when

comparing the abnormalities of the swallow. Consistent abnormalities often occur at the preparatory and oral phases of the swallow, likewise, they are also noted at the pharyngeal phase (Hamakawa, et al., 2004). Abnormalities at the preparatory and oral phases are often associated with individual's involuntary flailing of the limbs and postural instability secondary to chorea. The abnormalities associated with the oral and pharyngeal phases may coincide with both respiratory and lingual forms of chorea.

The inability to voluntarily control motor movements of the limbs and tongue, along with the inability to coordinate the muscles of respiration impairs an individual's ability to coordinate the preparatory, oral, and pharyngeal phases of swallowing. These impairments lead to impulsive and/or premature transfer of the bolus from the anterior oral cavity into the posterior oral cavity, and from the posterior oral cavity into the pharynx. Abnormalities in volitional control and coordination of the musculature may lead to insufficient mastication, hurried eating, also known as tachyphagia, and pooling of residue at the level of the valleculae and/or the pyriform sinuses, along with penetration or aspiration (Hamakawa et al., 2004). All of these ramifications of dysphagia, unfortunately, contribute to the decline of the individual's health, and, ultimately, if unaddressed, may lead to death.

Treatment

The similarities noted in the analysis of the swallow in individuals with Huntington's disease allow for the development of beneficial treatment; however, the treatment must ultimately be tailored to suit the needs of the individual. Treatment approaches for these individuals have historically incorporated compensatory strategies

through behavior modification, introduction of alternative equipment for eating and positioning, and alteration of food consistency (Bilney, Morris, & Perry, 2003). It is also critical the speech-language pathologist educate the patient and the family (Bilney et al., 2003). By educating and teaching the family and patient, the recommended modifications may reduce tachyphagia, aid in the control and transfer of the bolus from the oral phase to the pharyngeal phase of swallowing, promote and improve the safety of independent feeding, and promote coordination of the musculature.

Kagel and Leopold (1992) reported overall improvements in individuals swallowing abilities when intensive treatment in the form of compensatory strategies was implemented. Frequency of penetration and aspiration was also diminished through controlling the consistency and the portion-size, and implementing an individualized swallow pattern, such as chew-swallow-cough-swallow. Improved swallow patterns persisted a duration of three years for some individuals (Kagel & Leopold, 1992). These data support the implementation of compensatory strategies for the improvement of overall swallowing abilities in individuals with Huntington's disease; however, reports of muscle strengthening therapy and its effects upon maintenance or improvement in swallow safety and speech intelligibility in the progressive dysphagia and dysarthria of Huntington's disease are limited (Giddens, Coleman, & Adams, 2009).

Behavioral management in the form of compensatory strategies provides a non-pharmaceutical form of treatment for individuals with Huntington's disease to alter the inadvertently habituated pathological swallowing patterns (Kagel & Leopold, 1992). Behavioral management techniques should be considered in addition to the pharmaceutical intervention (Bonelli, et al., 2004). Anticholinergic medications working as

dopamine-blockers are often administered to individuals with Huntington's disease, and unfortunately, the side effects often negatively impact voluntary movements including the swallow. Sedation is one of the adverse reactions to antichoreic drugs contributing to the deterioration of the individual's swallow pattern, further increasing the risk of aspiration and asphyxiation (Bonelli et al., 2004). Reactions to pharmaceutical therapy impact individuals with Huntington's disease, and as a result, behavioral modifications may benefit the individual by limiting excessive administration of anti-choreic drugs.

Chorea and dysphagia seem to be two characteristics alarmingly consistent across individuals with Huntington's disease. Respiratory and lingual forms of chorea both affect vocal quality, speech intelligibility, and the associated dysphagia. In an attempt to improve overall speech intelligibility, voluntary phonatory, oral strengthening, and respiratory exercises may be implemented into daily therapy (Giddens et al., 2009). The laryngeal adduction, respiratory, and labial and lingual strengthening exercises improve vital capacity, vocal quality, volume, and speech intelligibility by increasing the tone, strength, and coordination of intrinsic and extrinsic musculature within the head, neck, and chest; however, phonation is the secondary function of these muscles (Aronson, 1990). The primary function of the musculature responsible for speech output is swallow and respiration. As a result, the implementation of these exercises should improve the coordination and strength of the musculature of breathing and swallowing.

Aspiration pneumonia secondary to dysphagia often results in death in individuals with Huntington's disease (Leopold & Kagel, 1985). While non-oral tube feeding is ultimately warranted, oral feeding should be continued as long as possible to maintain quality of life. Vocal and respiratory exercises improve overall speech output; however,

it is hypothesized they will also improve overall coordination and function of swallowing.

Improvement in respiratory function, while improving the driving force upon which speech is produced, also translates to better protection of the cough reflex. Increased strength in vocal fold adduction, while increasing the strength of the voice, also improves the ability of the vocal folds to close during the swallow to further protect the lungs from aspiration of any debris. Strengthening vocal fold adduction also increases the strength of the constrictor muscles of the pharynx, improving propulsion of the bolus posteriorly into the esophagus. Increased strength of the face, lips, and tongue, while improving the accuracy of articulation of speech, also improves mastication ability and the ability to move the bolus from the front to the back of the oral cavity during the transition from the oral to the pharyngeal phase of the swallow. It also improves tongue base retraction, initiating hyolaryngeal excursion, which triggers vocal fold adduction, further protecting the lungs, and the closing off of the airway through the movement of the epiglottis. The current study looks at the intense implementation of oral-motor, respiratory, and glottal adduction exercises as a form of behavioral management in dysphagia therapy for individuals with Huntington's disease.

CHAPTER III

METHODOLOGY

The purpose of this study was to examine the effects of oral-motor, pharyngeal, and respiratory strengthening exercises on the rehabilitation of the swallowing process in individuals with Huntington's disease. The study was conducted as a simple pre-test, post-test design following a four-week implementation of selected strengthening exercises.

The specific research questions addressed were as follows:

- 1) Do oral-motor, pharyngeal, and respiratory strengthening exercises improve the strength, range of motion, and coordination of the structures innervated by cranial nerves V, VII, IX, X, and XII?
- 2) Do oral-motor, pharyngeal, and respiratory strengthening exercises improve and/or maintain:
 - a. the participant's perception of swallow safety in individuals with Huntington's disease?
 - b. the clinician's perception of swallow safety in individuals with Huntington's disease?

Subjects

Study participants were recruited from the Oklahoma City region Huntington's disease support group. All participants were consented and screened according to a protocol approved by the Institutional Review Board at Oklahoma State University. Objective, non-invasive measures of oral-motor function, swallowing function, and mental status were obtained for baseline measures through the following tests:

- Mini-Mental Status Examination (MMSE): a brief screening measure used to determine the overall cognitive functioning of the participant. Areas regarding orientation, registration, attention and calculation, recall, and language were tested and scored for a maximum composite score of 30. Average functioning for most adult results in a composite score between 24-30 (Folstein, M. Folstein, S., McHugh, 1975).
- Functional Outcome Swallowing Scale (FOSS): a dysphagia staging scale used for participants to self-rate their swallowing severity. The scale ratings range from 0, which is asymptomatic oral feeding, to 5, which is non-oral feeding (Salessa, 2000).
- Barbara Sonies Oral Mechanism Examination: a comprehensive physiological examination of structure, strength, coordination, and range of motion of oral-motor, pharyngeal, and respiratory structures with their respective cranial nerve innervation (Sonies et al., 1987).
- Informal bedside evaluation: a dysphagia screening following precise presentation of consistencies in the following order: thin liquids via cup, pudding-thick liquid via spoon, followed by a solid requiring mastication. The

administrator noted any overt discrepancies in swallowing function, such as successive swallows per bite, difficulty initiating volitional swallow, coughing, choking, and/or gagging.

- Omron automated sphygmomanometer: a blood pressure screening used as a precautionary measure.

The FOSS, the Barbara Sonies Oral Mechanism Examination, and the informal bedside evaluation were re-administered at the conclusion of the study to note physiological changes.

Based on the previous measures, participants were screened and deemed ineligible for inclusion in the study due to any of the following:

- 1) Unacceptable mental performance as noted on the MMSE through a composite score of <20 . Acceptable mental performance was necessary in determining the ability of each participant to voluntarily participate in the study and to understand and perform the target exercises.
- 2) Self-rating of swallowing severity as >3 as noted on the FOSS. This precautionary measure eliminated those participants reporting severe forms of swallowing dysfunction determined unsafe to further participate in the study.
- 3) Any sign of audible or silent aspiration as noted by the administrator during an informal bedside swallow screening.

Following ineligibility determined by the FOSS and/or the informal bedside evaluation, the participant was provided a referral for a formal swallow evaluation.

In addition to these exclusionary measures, participants were deemed ineligible for inclusion in laryngeal adduction exercises secondary to any of the following:

- 1) History of hypertension unresponsive to medication.
- 2) Current blood pressure registering greater than 140/90 mmHg as noted by the administrator on an Omron automated sphygmomanometer.
- 3) Current or past use of cardiovascular medication.
- 4) History of cerebrovascular accident.
- 5) Chronic, daily headaches.
- 6) History of chest pain or myocardial infarction.

Treatment Procedures

A small sample size was included in the study, secondary to rarity of the disease. The small sample size was also the result of non-compliance by two individuals and ineligibility by two other individuals. One individual was deemed ineligible secondary to severe dysphagia, and the other individual was deemed ineligible secondary to a swallow self-rating >3 on the FOSS. Both individuals were referred to a local physician for further assessment and referral. Five of the nine participants fulfilled the requirements for inclusion in the study, and were introduced and trained in the use of strengthening exercises by the administrator. Selected exercises targeted the strengthening of the following muscle groups: labial and lingual, pharyngeal, and respiratory. Oral-motor exercises consisted of repetitive actions involving range of motion and resistance training. Pharyngeal exercises targeted the strengthening of vocal fold musculature, as well as musculature involved in pharyngeal constriction. Respiratory exercises were aimed at maintaining efficient air expenditure and increasing overall vital capacity by strengthening the thoracic and abdominal musculature. Upon

introduction of these exercises, the participants were provided with detailed instructions of each of the exercises. These exercises were performed both individually and in a group format prior to implementation of a vigorous home program. The participants were instructed to implement the strengthening exercises one to two times daily.

Statistical Procedures

Statistical analysis was performed on the pre-test and post-test numerical data generated from the Barbara Sonies Oral Mechanism Examination and the Functional Outcome Swallowing Scale on all five qualifying participants. A one-tailed *t*-test analysis using the *Statistical Package for the Social Sciences* (SPSS) software was used to determine statistical significance. The one-tailed *t*-test analysis was selected to determine the presence of any statistically significant improvement in strength and/or coordination of the structures innervated by cranial nerves V, VII, IX, X, and XII, and/or any improvement in the participants' perceptions of individuals swallow safety.

CHAPTER IV

FINDINGS

The purpose of this study was to determine any improvement in swallow function in individuals with Huntington's disease following implementation of oral-motor, pharyngeal, and respiratory strengthening exercises. This study was a pre-test, post-test design following a four-week treatment period.

A one-tailed *t*-test analysis was performed on the pre-test and post-test data of all five participants on the Barbara Sonies Oral Mechanism Examination and the Functional Outcome Swallowing Scale (FOSS). This analysis was selected to determine whether or not there was any significant improvement in swallow function, and/or in the functioning of structures innervated by cranial nerves V, VII, IX, X, and XII, which influence both speech and swallow production. The objective data was analyzed using the *Statistical Package for the Social Sciences* (SPSS) to determine statistical significance.

Barbara Sonies Oral Mechanism Examination Analysis

The mean score for the baseline results of the Barbara Sonies Oral Mechanism Examination was 4.10, while the post-treatment mean score was 2.40. This decrease in mean scores following the implementation of exercises indicates improvement in the

strength, range of motion, and coordination of structures innervated by cranial nerves V, VII, IX, X, XII. The results from the one-tailed dependent *t*-test analysis on the Barbara Sonies Oral Mechanism Examination indicated a statistically significant increase in function ($p < .048$) from baseline measures to post-treatment data (see Table 1 located in the Appendices).

FOSS Analysis

The mean score for the baseline results of the FOSS was 2.00, while the post-treatment mean score was 1.80. This decrease in mean scores following the implementation of exercises indicates improvement; however, the results of the one-tailed *t*-test analysis on the pre-test and post-test data of all five participants on the FOSS indicated no statistical significance ($P < .4075$) (see Table 2 located in the Appendices).

Informal Bedside Evaluation Analysis

The informal bedside evaluation provided purely qualitative data concerning the integrity of the swallow function of each individual. A precise order of presentation of bolus consistencies was administered to each participant prior to implementation of treatment, as well as subsequent to implementation of treatment. Any abnormality in swallow, such as successive swallows following one bite, difficulty initiating volitional swallow (dry or with bolus), coughing, choking, and/or gagging was documented for each individual. Baseline data documentation indicated three of the five participants demonstrated difficulty initiating a volitional swallow. The remaining two participants demonstrated no difficulties in swallow function throughout the entirety of the baseline

evaluation. Results from the post-treatment informal bedside evaluation indicated four of the five participants demonstrated no difficulties in swallow function throughout the entirety of the post-treatment evaluation. One of the five participants demonstrated difficulties with swallow function during the post-treatment evaluation as indicated by successive swallows for one bite, and coughing. These results indicate maintenance and/or improvement in swallow function following implementation of the treatment exercises in four of the five participants.

Discussion

This study attempted to answer the following questions:

- 1) Do oral-motor, pharyngeal, and respiratory strengthening exercises improve the strength, range of motion, and coordination of the structures innervated by cranial nerves V, VII, IX, X, and XII?
- 2) Do oral-motor, pharyngeal, and respiratory strengthening exercises improve and/or maintain:
 - a. the participant's perception of swallow safety in individuals with Huntington's disease?
 - b. the clinician's perception of swallow safety in individuals with Huntington's disease?

Improvement in Oral-Motor, Pharyngeal, and Respiratory Structures

It was hypothesized that oral-motor, pharyngeal, and respiratory strengthening exercises would improve overall strength, range of motion, and coordination of the

structures innervated by cranial nerves V, VII, IX, X, and XII which influence speech and swallow production as indicated by results from the Barbara Sonies Oral Mechanism Examination. A statistically significant increase in function was noted in the comparison of the pre-test and post-test examination. The hypothesized improvement was noted in strength, range of motion, and coordination specifically in structures innervated by cranial nerves V, IX, X, and XII.

The structures innervated by cranial nerves V, IX, X, and XII that evidenced improvement in function included the: lips, tongue, pharynx, and respiratory system. Improvement in the tongue was noted in extension and retraction, stability throughout all movements, and overall range of motion. A perceptible improvement was noted in the participants' voice production, suggesting improvement in the pharynx. An improvement in vocal function was evidenced by increased volume, indicating an increase in respiratory and laryngeal strength. Tremor was also perceived to be possibly reduced. The participants' increased voice production also suggested improvement in the respiratory system. An increase in the overall length of extended phonation time was noted, indicating an increase in strength and coordination. This increase in overall phonation time required an increase in strength of the respiratory system to increase the respiratory capacity, along with an increase in coordination to regulate the overall breath expenditure.

Improvement in Swallow Function

It was hypothesized that oral-motor, pharyngeal, and respiratory strengthening exercises would improve and/or maintain the participants' perception of swallow safety,

as indicated by the FOSS, as well as the clinician's perception of swallow safety in individuals with Huntington's disease as indicated by the informal bedside evaluation. Although the participants' mean perception of swallow safety improved, comparison of the pre-test and post-test FOSS scores failed to demonstrate statistical significance. Results from the informal bedside evaluation, however, may cast doubt on the validity of the FOSS self-ratings. Comments from the participants during the post-treatment bedside swallow evaluation, as well as the clinician's perception of swallow function conflicted with the findings from the FOSS.

The pre-treatment bedside swallow evaluation revealed that three of the five participants demonstrated difficulty coordinating the initiation of a volitional swallow prior to implementation of the oral-motor, respiratory, and pharyngeal exercises. Each of these individuals was able to initiate a volitional swallow upon second attempt. The results of the pre-test informal bedside evaluation on the remaining two individuals were unremarkable.

Following a four-week implementation of the oral-motor, respiratory, and pharyngeal exercises, no difficulties in coordination and initiation of the volitional swallow were noted by the clinician during the post-test informal bedside evaluation in four of the five participants. It should be noted that during the post-treatment informal bedside evaluation, one of the five participants required two successive swallows to clear the pudding-thick consistency, and two successive coughs were noted following a drink of water from the cup. This participant reported severe allergies for which he was administered monthly allergy shots. The participant reported consistent coughing one-week following the allergy shots. Although the participant reported receiving the

monthly allergy shots three days prior to post-test collection, it was unclear whether the participant's coughing was secondary to allergy shots, or penetration/aspiration of the liquid bolus.

A discrepancy in FOSS self-ratings was also observed in regard to participant comments following the post-treatment informal bedside evaluation. Following completion of the post-treatment informal bedside evaluation, the researcher asked each participant if they noticed any change in their swallow function. Four of the five participants reported improved swallow function in the form of less coughing and choking during mealtimes, and overall improved coordination. The one participant reporting deterioration in swallow function attributed the difficulty to current allergy shots. This information again casts doubt onto the reliability and validity of the self-ratings of the FOSS.

A potential confound to the study presented itself in the form of a dopamine antagonist used to treat movement disorders, Tetrabenazine. Adverse reactions include, but are not limited to: sedation, depression, anxiety, and dysphagia (Bonelli et al., 2004). These reactions are concomitant in Huntington's disease, making it difficult to distinguish adverse reactions to pharmacological therapy from symptoms of Huntington's disease. Two participants began self-administering mid-study, and a third participant was self-administering titrated doses of Tetrabenazine prior to and during the course of the study. The potential confound of Tetrabenazine was likely negated by the two remaining participants who elected to avoid the medication. The two participants who did not administer Tetrabenazine were treated as a control group and compared with the two participants who began Tetrabenazine mid-study. Independent (two-group) t-tests were

performed on the Sonies and the FOSS differences scores between pre- and post-treatment for the two participants beginning Tetrabenazine and the two who did not. Neither the Sonies nor the FOSS difference scores demonstrated statistical significance ($p < 0.753$ and $p < 0.861$, respectively). Confounds to controlled clinical trials by way of non-compliance through self-administered anti-chorea medications are common due to the quickly progressing, incurable, and fatal nature of Huntington's Disease (Landwehrmeyer, et al., 2007). The potential for Tetrabenazine to act as a confounding variable in this study, however, appears to have been averted.

Summary

The statistical analyses performed on the quantitative data of this study failed to reveal an expected association between a significant improvement in function of the oral-motor, pharyngeal, and respiratory structures following strengthening exercises, and an improvement in the participants' perceptions of the safety of their swallow. Statistically significant improvement in function noted on the Barbara Sonies Oral Mechanism Examination ($p < .048$) was not observed on the FOSS ($p < .4075$). The statistical significance noted in the data from the Barbara Sonies Oral Mechanism Examination suggests an improvement in structure, strength, and range of motion of the facial and oral musculature. While no statistical significance was noted in the data from the FOSS, the qualitative data obtained from the informal bedside evaluation suggests an improvement in overall swallow function in a majority of the participants.

CHAPTER V

CONCLUSION

Dysphagia is a well-documented ramification of the genetic and progressive Huntington's disease. Treatment of this disease is often pharmacological and/or compensatory in nature. While beneficial, and often necessary, these treatment approaches result in compounding adverse reactions; and, more importantly, rather than providing true remediation, they simply mask the symptoms of the disease. Treatment approaches in the form of physical exercises have demonstrated promise in improving the strength, and thus, slowing the deterioration, of target musculature in individuals with Huntington's disease. The effects of the implementation of physical exercises targeting the musculature involved in the swallowing process have yet to be documented.

The purpose of this study was to document any improvement in swallow function following the implementation of oral-motor, pharyngeal, and respiratory strengthening exercises in individuals with Huntington's disease. It was hypothesized that the aforementioned exercises would improve overall strength, range of motion, and coordination of the structures innervated by cranial nerves V, VII, IX, X, and XII. In addition, it was hypothesized that those same exercises would improve and/or maintain, not only the participants' perception of swallow safety, but also the clinician's perceptions of swallow safety.

This study was conducted as a classic pre-test, post-test design following a four-week implementation of oral-motor, pharyngeal, and respiratory strengthening exercises. Nine individuals were screened for participation. Two individuals were dropped from the study secondary to non-compliance with the treatment regimen. One individual was deemed ineligible secondary to the severity of the clinician's perception of swallow safety, and another individual was deemed ineligible secondary to the severity of the participant's perception of swallow safety. Five participants between the ages of 40 and 62 completed the study protocol.

Those participants deemed eligible for inclusion were administered the Barbara Sonies Oral Mechanism Examination, the FOSS, and an informal bedside evaluation at baseline. Each participant was provided strengthening exercises targeting the following groups of musculature: facial, labial, lingual, pharyngeal, and respiratory. The clinician provided the participants detailed instruction on the implementation of each exercise. Following the instruction, each participant performed each of the exercises individually, as well as in a group format to ensure the accuracy of their practice. Participants were then instructed to perform each exercise at least one time daily for the four-week treatment period. Following the four-week treatment period, each participant was again administered the Barbara Sonies Oral Mechanism Examination, the FOSS, and an informal bedside evaluation, and results were documented as post-test data.

The primary findings of the current study were that:

- 1) The oral-motor, pharyngeal, and respiratory strengthening exercises appeared to improve the strength, range of motion, and coordination of the structures innervated by cranial nerves V, VII, IX, X, and XII as indicated by the

statistically significant results from the comparison of pre-test and post-test Barbara Sonies Oral Mechanism Examination.

- 2) The oral-motor, pharyngeal, and respiratory strengthening exercises
 - a. did not appear to improve and/or maintain the participants' perceptions of swallow safety as indicated by the comparison of results from the pre-test and post-test FOSS. Although the mean FOSS score indicated an improvement in the participants' perceptions of their swallow safety, no statistical significance was demonstrated. These findings did conflict, however, with the participants' reports during the informal bedside evaluation.
 - b. appeared to improve and/or maintain the clinician's perception of swallow safety in individuals with Huntington's disease as indicated by the comparison of results from the pre-test and post-test informal bedside evaluation.

Statistical analysis indicated significant improvement among Huntington's disease participants on the Barbara Sonies Oral Mechanism Examination ($P < .048$) following only a four-week implementation of oral-motor, respiratory, and pharyngeal strengthening exercises. This improvement leads us to infer an increase in strength and range of motion, ultimately resulting in an improvement in coordination of the structures innervated by cranial nerves V, VII, IX, X, and XII. These findings were also recognized and reported by the participants following the four-week implementation of the strengthening exercises.

No statistical significance was indicated upon analysis of the FOSS ($p < .4075$). Although it leads us to infer no improvement in swallow function following implementation of oral- motor, respiratory, and pharyngeal strengthening exercises, it is imperative to discuss the cognitive deficits associated with individuals with Huntington's disease. Reliability and validity of the FOSS as an outcome measure for this population may be suspect secondary to these cognitive impairments.

Progressive cognitive impairments associated with Huntington's disease include impairment in attention, immediate and short-term memory, along with executive function skills (Ho et al., 2003). The self-rating scale on the FOSS requires individuals to comprehend the symptomatic swallowing scale ranging from (0) to (5), recall swallow function over the previous six months, and classify their outcome based on this information. Accurately classifying one's swallow function according to these measures requires appropriate attention, comprehension, and immediate recall of the symptomatic scale, short-term recall of individual swallow function over the course of the previous six months, along with the adequate executive function skills through the appropriate categorization of their symptoms into a corresponding rating on the scale. Although the participants were screened for cognitive function, the discrepancy between self-report on the FOSS and comments relayed by the participants during the informal bedside swallow examination may indicate that the cognitive deficits associated with Huntington's disease rendered the FOSS scores invalid. In fact, based on the cognitive deficits associated with individuals with Huntington's disease, the accuracy of self-ratings may be considered suspect. The FOSS may lack the sensitivity necessary for individuals with Huntington's disease.

Limitations

Although a potential confound of the study by the drug Tetrabenazine appears to have been avoided, one of the individuals that refrained from self-administration of the drug was administered allergy shots during the four-week treatment period. The ramifications of these immunizations on swallow function are unknown, but may have been negligible.

The paucity of quantitative data for swallow function may have prevented the realization of an association between significant improvement in oral motor function and significant improvement in swallow function. It was difficult to generate genuinely objective instruments from which data could be collected. Further study utilizing a modified barium swallow study to more objectively measure swallow function would allow the researcher to completely view the pharyngeal structures. In this procedure, barium, a radio-opaque substance, is infused in food and liquid of varying textures and consistencies. As the individual swallows under X-ray, the barium-infused bolus is followed through the oropharyngeal cavity, thus leading to an accurate identification of abnormalities in swallow function. Any changes would be noted upon comparison of the pre-test and post-test video data.

Finally, the small sample size included for this study may have contributed to the lack of significant findings in swallow improvement through use of exercises. Although the original sample size consisted of nine participants, two of the individuals were not included secondary to non-compliance, and the remaining two individuals were deemed ineligible through baseline screening protocol. The rarity of Huntington's disease also

places severe limitations on the number of individuals available for participation in any study focused on the disease.

Statistically significant improvement in the strength, range of motion, and coordination of the structures innervated by cranial nerves V, VII, IX, X, XII following a four-week implementation of oral-motor, respiratory, and pharyngeal strengthening exercises was realized. It would seem intuitive that an improvement in many of the structures involved in the swallow process would have translated to a perception of significantly improved swallow function. No such improvement was observed with the self-report of swallow function; however, this may have been secondary to an insensitivity of the utilized instrument to the compromised cognitive abilities accompanying Huntington's disease. As such, this study was unable to irrefutably accept the hypothesis that oral-motor, respiratory, and pharyngeal strengthening exercises improve swallow function. One may infer from the outcome of the informal bedside evaluation in four of the five participants unreliability in the self-ratings of swallow function. These results indicate the dire need for an objective swallow-screening tool sensitive to the ramifications of Huntington's disease.

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APPENDICES

TABLE 1

One-Tailed Dependent *t*-Test Table for Barbara Sonies Oral Mechanism Examination in Progressive Dysphagia for Individual's with Huntington's Disease

	Mean	Std. Deviation	df	One-Tailed Dependent <i>t</i> -test
Pre-Sonies	4.10	3.362		
Post-Sonies	2.40	1.817	4	.048

TABLE 2

One-Tailed Dependent *t*-Test Table for Functional Outcome Swallowing Scale (FOSS) in Progressive Dysphagia for Individual's with Huntington's Disease

	Mean	Std. Deviation	df	One-Tailed Dependent <i>t</i> -test
Pre-FOSS	2.00	.707		
Post-FOSS	1.80	1.643	4	.4075

TABLE 3

Two-Tailed Independent *t*-Test Table for Effects of Tetrabenazine on Barbara Sonies
Oral Mechanism Examination in Progressive Dysphagia for Individual's with
Huntington's Disease

	Mean	Std. Deviation	df	Two-Tailed Independent <i>t</i> -test
Sonies without Tetrabenazine	2.50	1.414	2	.746
Sonies with Tetrabenazine	1.75	2.475	1.590	.753

TABLE 4

Two-Tailed Independent *t*-Test Table for Effects of Tetrabenazine on Functional
Outcome Swallow Scale (FOSS) in Progressive Dysphagia for Individual's with
Huntington's Disease

	Mean	Std. Deviation	df	Two-Tailed Independent <i>t</i> -test
FOSS without Tetrabenazine	.00	2.828	2	.860
FOSS with Tetrabenazine	-.50	2.121	1.855	.861

FIGURE 1

Functional Outcome Swallowing Scale

Stage Symptoms

- 0) Normal function and asymptomatic
- 1) Normal function with episodic or daily symptoms of dysphagia
- 2) Compensated abnormal function manifested by significant dietary modifications or prolonged mealtime (without weight loss or aspiration)
- 3) Decompensated abnormal function with weight loss of <10% of the body weight over 6 months due to dysphagia; or daily cough, gagging, or aspiration during meals
- 4) Severely decompensated abnormal function with weight loss of >10% of body weight over 6 months due to dysphagia; or severe aspiration with bronchopulmonary complications. Non oral feeding for most nutrition
- 5) Non oral feeding for all nutrition

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FIGURE 2

Barbara Sonies Oral Mechanism Examination

Speech-Language Pathology Oral Motor Checklist

NAME: _____ DATE: _____
 AGE: _____ PROTOCOL: _____
 SEX: _____ DIAGNOSIS: _____

CRANIAL VII FACIAL

<u>Peripheral-whole face</u>	(0)	(1)	(2)
1. symmetry	normal(0) _____	asymmetrical(1) _____	
2. wrinkles forehead	normal(0) _____	abnormal(1) _____	
3. winks both eyes	normal(0) _____	abnormal(1) _____	
4. winks right eye	normal(0) _____	abnormal(1) _____	
5. winks left eye	normal(0) _____	abnormal(1) _____	
6. eyes closed, resistance to opening	normal(0) _____	abnormal(1) _____	

CRANIAL V TRIGEMINAL

<u>Central-lower face V</u>	<u>Normal</u>	<u>Abnormal</u>
7. lip pendancy at rest	normal(0) _____	drooping(1) _____
8. elevates upper lip	yes(0) _____	no(1) _____
9. smiles evenly	yes(0) _____	no(1) _____
10. retracts lower lip(ee)	yes(0) _____	no(1) _____
11. close mouth & pucker lips	yes(0) _____	no(1) _____ asymmetry (2) _____
11.1 pucker & retract lips 3 times in a series	yes(0) _____	no(1) _____
12. protrudes lower lip (pouts)	yes(0) _____	no(1) _____
13. bilabial seal of lips	yes(0) _____	no(1) _____
14. nasal respiration with cheeks inflated	yes(0) _____	no(1) _____

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Name: _____

- 15. labial spill of saliva reported
no(0) _____ yes(1) _____ night only(2) _____
- 16. labial spill of saliva observed
no(0) _____ yes(1) _____

CRANIAL IX GLOSSOPHARYNGEAL

- | | <u>Normal</u> | <u>Abnormal</u> |
|--|---------------|---------------------------------------|
| 17. dysphagia history | no(0) _____ | yes(1) _____ |
| 18. swallow 3 ml H ₂ O upright | yes(0) _____ | no(1) _____ |
| 19. pharyngeal gag reflex | yes(0) _____ | no(1) _____ |
| 20. on "ah" constricts pharyngeal wall to midline | yes(0) _____ | no(1) _____ |
| 21. on "ah" uvula deviates | no(0) _____ | yes(1) _____
R(1) _____ L(2) _____ |
| 22. raises posterior tongue on /k/ | yes(0) _____ | no(1) _____ |
| 23. velar gag reflex | yes(0) _____ | no(1) _____ |
| 24. nasality | no(0) _____ | yes(1) _____ |
| 25. nasal emission (air through nose on speaking-cleft palate) | no(0) _____ | yes(1) _____ |

Cranial X VAGUS

- | | <u>Normal</u> | <u>Abnormal</u> |
|----------------------------------|---------------|-----------------|
| 26. dysphonia (unilateral) | no(0) _____ | yes(1) _____ |
| 27. aphonia (bilateral) | no(0) _____ | yes(1) _____ |
| 28. other voice quality deficits | no(0) _____ | yes(1) _____ |

Barbara C. Series, Ph.D.

Name: _____

CRANIAL XII HYPOGLOSSAL

	<u>Normal</u>	<u>Abnormal</u>	
29. protrudes tongue	yes(0) _____	deviation (1) _____ unsteady (2) _____	tremors (3) _____
29.1 protrudes/retracts tongue in series of 3	yes(0) _____	no(1) _____	slow or awkward (2) _____
30. elevates tongue tip to upper incisors	yes(0) _____	no(1) _____	
30.1 rapid raising/lowering of tongue tip behind upper incisors (3x)	yes(0) _____	no(1) _____	
30.2 rapid raising & lowering of tongue tip behind upper and lower incisors (3x)	yes(0) _____	no(1) _____	
31. elevates tongue tip to upper lip external	yes(0) _____	no(1) _____	
32. tongue strength: tip	normal(0) _____	weak(1) _____	
33. tongue strength: right side	normal(0) _____	weak(1) _____	
34. tongue strength: left side	normal(0) _____	weak(1) _____	
35. widens and flattens tongue tip	yes(0) _____	no(1) _____	
36. atrophy of tongue	no(0) _____	both sides(1) _____	R(2) _____ L(3) _____
37. tongue tip localization right upper	yes(0) _____	no(1) _____	
38. tongue tip localization right lower	yes(0) _____	no(1) _____	
39. tongue tip localization left upper	yes(0) _____	no(1) _____	
40. tongue tip localization left lower	yes(0) _____	no(1) _____	

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Name: _____

- 40.1 touches corners of mouth rapidly 5 x in series yes(0)____ no(1)____ uses Jaw(2)____
- 40.2 circles tongue around upper and lower lips yes(0)____ no(1)____ other(2)____
- 41. tongue positional stability normal reflex(0)____ decreased resistance(1)____
- 42. sleep interrupted by shortness of breath or choking no(0)____ yes(1)____
- 43. snore at night no(0)____ yes(1)____

CRANIAL V. TRIGEMINAL

- 44. mass of masseter muscle clenched normal(0)____ diminished(1)____
- 45. mass of temporalis muscle clenched normal(0)____ diminished(1)____
- 46. right side mandible, raise vs. resistance normal(0)____ diminished(1)____
- 47. left side mandible, raise vs. resistance normal(0)____ diminished(1)____
- 48. jaw opening vs. pressure normal(0)____ weak(1)____
- 49. TMJ click or slipping no(0)____ yes(1)____
- 50. lower jaw deviates on opening no(0)____ R(1)____ L(2)____
- 51. inter incisal distance over 40mm(0)____ under 40mm (1)____
- 52. "ah" 1.____ 2.____ 3.____ (time in sec)
- 53. /p/ _____ /10 seconds
- 54. /t/ _____ /10 seconds
- 55. /k/ _____ /10 seconds

upper dental arch 1/3 to 1/2 of lower
closed - all are good
some closed - open bite
functional - no apparatus
1st Arch may be very close to 2nd arch
occlusion, dental usual
aligner, ortho or space
 Barbara C. Sonies, Ph.D. *member to*
look at corners for bite evaluation
orthodontic

Name: _____

56. /p t k / _____ /10 seconds

57. articulation normal(1) _____ mild(2) _____ moderate(3) _____ severe(4) _____

58. fluency normal(1) _____ mild(2) _____ moderate(3) _____ severe(4) _____

59. oral sensation:

tongue	(0) _____	(1) _____
lips	(0) _____	(1) _____
face	(0) _____	(1) _____

FIGURE 3

Informal Bedside Evaluation

Step 1: Have participant produce dry swallow feel neck for laryngeal elevation.

Step 2: Have participant produce sharp, dry cough and listen for vocal quality.

Step 3: Give participant a spoonful of water while feeling neck for appropriate laryngeal elevation. Have participant say “ahh” and listen for clear vocal quality with absence of wet, gurgle.

Step 4: Give participant a sip of water while feeling neck for appropriate laryngeal elevation. Have participant say “ahh” and listen for clear vocal quality with absence of wet, gurgle.

Step 5: Give participant a pudding-thick consistency liquid from a spoon while feeling neck for appropriate laryngeal elevation. Have participant say “ahh” and listen for clear vocal quality with absence of wet, gurgle.

Step 6: Give participant a cracker (solid). Have participant masticate and swallow while feeling neck for appropriate laryngeal elevation. Have participant say “ahh” and listen for clear vocal quality with absence of wet, gurgle.

VITA

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Scope and Method of Study: This study examined the effects of oral-motor, respiratory, and pharyngeal strengthening exercises on dysphagia in individuals with Huntington's disease. In a pre-test, post-test design, five participants voluntarily implemented the aforementioned exercises daily for a four-week period. The function of the oral-motor, pharyngeal, and respiratory structures was measured both at baseline and at study completion. In addition, participants provided a self-rating of their swallow function prior to and subsequent to implementation of the selected exercises. Swallowing function was also examined through an informal bedside evaluation and documented by a clinician at baseline and at conclusion of the study.

Findings and Conclusions: A statistically significant improvement in the function of the oral-motor, pharyngeal, and respiratory structures was noted. No statistically significant improvement was noted in the participants self-rating of their swallow function; however, four of the five participants appeared to maintain and/or improve swallow function as reported by the individual and as noted on the informal bedside evaluation by the clinician. In conclusion, the null hypothesis could not be rejected. It could not be concluded that the selected exercises improved dysphagia based upon the participants self-rating of swallow function. However, as a statistically significant improvement in oral-motor function was realized, the findings raise concerns as to the sensitivity of swallow-screening measures for individuals with Huntington's disease. It is critical that an objective swallow-screening measure be developed sensitive to the ramifications of Huntington's disease and various other disorders affecting cognition.

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