Anticipated compliance and quality of life measures for individuals consuming thickened liquids: Perceptions of taste, texture, palatability, and enjoyment given beverage appearance

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Under the supervision of Jerry Hoepner, Ph.D.

This study addressed: (a) effect appearance has on perceived taste, texture, palatability, and enjoyment of thickened liquids, (b) predicted effects of thickened liquids on compliance and quality of life based on duration of time the individual is asked to consume the liquid, (c) quality of life factors related to thickened liquid consumption. The effect of appearance on perceived taste and enjoyment of thickened liquids has little empirical evidence, despite being a common treatment for dysphagia. Additionally, the effect thickened liquids have on quality of life has not been well-studied. Thickened juice was presented in masked/un-masked trials. Participants were prompted to taste each juice and rate a number of factors (taste, texture, etc.). Afterwards, participants were asked to predict their anticipated compliance to drink thickened liquids for a specified duration (1 week, 3 years, etc.). Participants were asked to rate their anticipated quality of life based on the duration of thickened liquid intake. Finally, participants were asked to describe the extent drinking thickened liquids would have on their life.

Presentation of thickened liquids, specific to masking, was shown to have an insignificant effect. Ratings of anticipated compliance as a function of duration were found to have significant multivariate effect. Ratings of anticipated quality of life as a function of duration were found to have significant multivariate effect. Themes from qualitative interviews on quality of life, included: compliance issues, social participation barriers, routine/convenience factors, and enjoyment changes. Results of this study demonstrate increased need for support surrounding compliance issues and reduction of social participation barriers. Qualitative and quantitative data validate each other, suggesting strong triangulation.

May 4th, 2017

Thesis Advisor | Date

DEDICATION

This research study is dedicated to my Grandfather, John Geisner. He was a man of great character and strength, who valued honesty and hard-work. While nearing the end of his life, he faced swallowing difficulties. Consequently, he was asked to consume thickened liquids, which negatively impacted his quality of life. As I shared this experience with others, I noticed other individuals were experiencing the same dilemma. My hope is that this study can improve or lead to improving the lives of individuals with dysphagia.

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CHAPTER ONE

LITERATURE REVIEW

Dysphagia is the sensation that liquids or solids are difficult to swallow (Leonard & Kendall, 2014). Dysphagia is the medical term for "difficulty swallowing" and the consequences are potential impairments to safety, inadequacy of intake, and diminished quality of life. Neurogenic disorders are the most common etiologies resulting in dysphagia (Leonard & Kendall, 2014). Additionally, 75% of oropharyngeal dysphagia cases have a neurological cause (White, O'Rourke, Ong, Cordato, & Chan, 2008). Common neurological causes of dysphagia include, but are not limited to: stroke, dementia, Parkinson's disease, Amyotrophic Lateral Sclerosis (ALS), traumatic brain injury (TBI), multiple sclerosis, cerebral palsy, and neuromuscular disorders (Gonazalez-Fernandez & Daniels, 2008; Leonard & Kendall, 2014; White et al., 2008). In order to ensure safe oral intake, often thickened liquids are prescribed by a Speech-Language Pathologist (SLP) (Leonard & Kendall, 2014; Martino, Pron, & Diamant, 2004). Without thickened liquids, the patient could potentially aspirate, meaning food and/or liquid would enter the trachea and contact lung tissue (Aspiration, n.d.). There are differing opinions on appropriateness and utility of thickened liquids, and the potential effects thickened liquids have on swallowing safety and aspiration pneumonia reduction. However, recommending thickened liquids in a common practice among SLPs for individuals with swallowing disorders. Individuals post-stroke are at an increased risk for developing aspiration pneumonia (Gonazalez-Fernandez & Daniels, 2008). When thickened liquids are used, a more cohesive bolus, which is defined as a mass of food or liquid, is created and aspiration is less likely due to the thicker consistency (Loret, Walter, Pineau, Peyron, Hartmann, & Martin, 2011). Thickened liquids are less easily deformed in nature than liquids of normal viscosities and are more likely to move through the digestive tract easily without falling into the airway (Leonard & Kendall, 2014).

Despite their perceived importance and use in everyday interventions for dysphagia, there is little empirical evidence on the effect of appearance on the taste of thickened liquids, texture, palatability, and enjoyment of thickened liquids. Additionally, the effect thickened liquids have on the quality of life of patients' with dysphagia has not been well-studied. This study will address the following:

- The effect appearance has on perceived taste, texture, palatability, and enjoyment of thickened liquids.
- The perceived degree thickened liquids affect quality of life with respect to a specific prescribed duration of time the individual is advised to consume thickened liquids (e.g., 1 month, 6 months, etc.)

Elderly adults frequently experience changes to swallowing function that necessitate short-term or long-term diet modifications. Smithard, O'Neill, and Park (2008) found the prevalence of dysphagia in the elderly to be between 12% and 60% in the USA and Europe. Daniels, Brailey, Priestly, Weisberg, and Foundas (1998), Kidd, Lawson, Nsbitt, and MacMahon (1993), and Mann, Hankey, and Cameron (1999) found 64-90% of conscious stroke patients in the acute stage had dysphagia, with aspiration in 22-42% of cases. The wide variety of etiologies and diverse continuum of severity for dysphagia may result in the wide and unspecific range of incidence and prevalence when describing dysphagia. Additionally, Smithard et al. (1998) found an increased risk of mortality and morbidity in individuals post-stroke with swallowing problems.

Altered liquid viscosity is a dietary modification used to ensure safe oral intake and to minimize oral-pharyngeal signs and symptoms associated with dysphagia. Liquids can be thickened in a variety of manners, including hand mixing of liquids with a powder thickening agent and pre-thickened, homogenized beverages. Thickened liquids are prepared to match a variety of viscosities, including pudding, honey, and nectar consistencies. A thin, or unaltered, viscosity is also a potential liquid consistency.

A standardized measurement system is not readily used among clinicians, staff, and family members who prepare thickened liquids for patients (Nicosia & Robbins, 2007). Although some standardized scales do exist, such as "the line spread test" (Nicosia & Robbins, 2007) and "the syringe test," (International Dysphagia Diet Standardization Initiative, 2016) both are seldom used clinically, leaving gaping differences and inconsistencies in the thickened liquids patients are served. Likewise, consistent terms for determining viscosity levels do not exist. Nectar-, honey-, and pudding-thick terms are commonly used. However, several other categorizing terms exist in the literature surrounding dysphagia and thickened liquids, including syrup-thick, spoon-thick (Castellanos, Butler, Gluch, & Burke, 2004; Cichero, 2013).

Determination of appropriate consistency is the role of speech and language pathologists. Note that sometimes occupational therapists, nurses, physicians, and dieticians play a role in determining a patient's dietary recommendations. Once appropriate consistencies for safe consumption are determined, orders are made and the patient is asked to consume that particular consistency. Sometimes liquid consistencies vary for consumption during and outside of mealtime or vary by nature of liquid (e.g., water versus other liquids). Several potential issues surround consumption of altered/thickened liquids, including meeting hydration needs[1], perceived quality/palatability of thickened liquids, and compliance, which could vary depending upon duration of need for thickened liquids (Adeleye and Rachal, 2007; Murray, Miller, Doeltgen, and Scholten, 2014; Whelan, 2001). The present investigation will focus on perceptions of quality/palatability, compliance issues, and associated quality of life issues.

Prevalence of Dysphagia/Thickened Liquid Use

Dysphagia effects 300,000-600,000 people annually (Sura, Madhavan, Carnaby, & Crary, 2012). Approximately 15% of the elderly population is affected by dysphagia (Sura et al., 2012). Castellanos, Butler, Gluch, and Burke (2004) conducted a study that examined the prevalence and use of thickened liquids in skilled nursing facilities. Their results showed a mean of 8.3% of residents were receiving thickened liquids. Of those, 60% were on "nectar/syrup" thick, 33% were on "honey" thick, and 6% were on "pudding/spoon" thick. Few studies have investigated the prevalence of dysphagia and thickened liquid use in other settings, such as hospitals, rehabilitation facilities, group homes, independent home use, and other related institutions.

Another challenge for individuals hospitalized post-stroke is that those who were on a diet that included thickened liquids were shown to consume significantly less liquids than the recommended standards (Murray et al., 2014). Indeed, Thirty-seven to seventy-eight percent of adults are diagnosed with dysphagia post-stroke, which puts those individuals

[1] For a detailed discussion of hydration issues refer to Murray, Miller, Doeltgen, and Scholten (2014), and Whelan (2001).

at risk for dehydration (Murray et al., 2014); depending upon type and severity of stroke, there is a substantial discrepancy in incidence. Thickened liquid consumption can many times worsen the effects of dehydration, which are already hard to regulate for the elderly population (Murray et al., 2014).

Murray et al. (2014) investigated the thickened liquid intake of hospitalized adults post-stroke. Their participants included 64 adults with dysphagia who were hospitalized after having a stroke. They found the mean daily intake of thickened liquids included 781 mL, 519 mL, and 1274 mL for hospitals, acute settings, and rehab settings, respectively. The recommended daily fluid intake is between 2600-3000 mL and 2100-2200 mL for men and women, respectively. However, patients who are hospitalized are generally ill and therefore will not consume the recommended daily amount. Therefore, hospitals set goals for patient fluid intake. The hospital goal utilized in Murray et al. (2014) study was 1500-1600 mL. When considering the reduced hospital goal for daily fluid intake, the participant's thickened liquid intake was far less. Whelan (2001) conducted a study that examined the thickened liquid intake of 24 patients hospitalized post-stroke. He found that individuals who were prescribed a diet of thickened liquids were offered fluid half as much as those who were receiving liquids of normal consistencies (Whelan, 2001). Potential reasons for this were discussed and included less priority given to patients on thickened liquids by staff and lack of understanding about the importance and rationale for thickened liquids among patient family members and staff (Whelan, 2001).

Few studies have identified the prevalence of dysphagia across age groups. Roden and Altman (2013) conducted a literature review of articles that identified the prevalence of dysphagia and examined it across age groups. Approximately two-thirds of the literature on dysphagia prevalence is written about adults who are 50 and older (Roden & Altman, 2013). Traumatic brain injury (TBI) is also another common etiology of dysphagia, which may necessitate a modified diet including thickened liquids. Prevalence estimates show 20-70% of patients with traumatic brain injuries are effected by dysphagia (Leonard & Kendall, 2014). Again, due to the diversity in severity and type of TBIs, incidence and prevalence varies significantly. Unlike stroke, TBI effects individuals across the age span. Older adolescents (ages 15-19 years) and older adults (ages 65 and older) are most likely to acquire a traumatic brain injury (Faul, Wald, & Coronado, 2010). Current literature shows an increased need for attention to dysphagia interventions, including improving thickened liquids and quality of life of those affected by dysphagia across the age spans, but particularly elderly adults.

Taste and Palatability Issues

Precursors that Effect Taste.

Manufacturers of thickening agents and/or pre-thickened liquids indicate that the thickening agents do not alter the flavor of the liquid (Thick-It ®: Dysphagia Nutrition Solutions, 2016; Thick & Easy ®: Hormel Health Labs). However, decreased fluid intake in individuals with dysphagia has been linked to the altered taste and texture of thickened liquids McGrail & Kelchner, (2014), Crary and Groher (2003), along with Macqueen, Taubert, Cotter, Stevens, and Frost (2003) found individuals dislike consuming thickened liquids. Specifically, Macqueen et al. (2003) studied eight patients between the ages of 71-93, with mild-moderate dysphagia who evaluated the taste of five-commercial powdered thickeners. Six of the eight patients stated they did not like using the powdered thickener (Macqueen et al., 2003). However, specific reasons for their distaste were not investigated (Macqueen et al., 2003). Logemann (2008) conducted a study that evaluated dysphagia interventions for individuals with dementia or Parkinson's disease. She reported a majority of the 711 participants favored the chin-tuck compensatory strategy to reduce risk of aspiration, rather than a modified diet consisting of honey-thickened liquids.

Prior to categorizing and making conclusive statements about perceived taste of thickened liquids, the factors affecting perceived taste must be considered. Nalcaci and Baran (2007) identified factors associated with self-reported halitosis (SRH), a general term used to describe a detectable odor in expired air, and perceived taste disturbance (PTD) in elderly populations. They found the factors most strongly associated with SRH and PTD were: subjective oral dryness, tongue coating, inadequate oral hygiene practice, and partial and/or complete denture wear (Nalcaci & Baran, 2007).

Likewise, the rheological properties of food thickeners (i.e., viscosity, homogeneity, flow/how it pours, texture, persistence – how long it maintains desired consistency/under what temperatures or conditions), preparation methods (e.g., stirred versus homogenized, and the way foods are served (warm, cold) must be considered before making conclusions about the perceived taste and related factors of thickened liquids. Viscosity refers to "the property of resistance to flow in a fluid or semifluid" state (Viscosity, n.d.). Homogeneity refers to the state of being homogeneous- "consisting of parts that are the same or uniform in structure or composition" (Homogeneous, n.d.). Hospitals, skilled nursing facilities, and other healthcare environments in which thickened liquids are served employ diverse protocols for thickened liquid preparations.

Similarly, preparation and serving techniques can vary substantially in patients' homes and/or are dependent upon instructions from professionals (i.e., SLP, OT, and dietician). Some institutions utilize pre-thickened "ready-to-serve" packaged portions of specific beverages. Others utilize powders which are mixed with a certain amount of the respective liquid to create the desired thickness level. Table 1 identifies common thickening agents for pre-thickened and powder-based thickeners.

Table 1. Thickening Agents

Thickener
Xanthan Gum
Guar Gum
Locust Bean Gum
Starch
Carageenan

(Cichero, 2013)

Taste Differences of Thickeners.

Goldberg & Heiss (2013) examined the differences in taste, texture, and palpability of apple juice thickened with starch- and gum-based agents. Researchers presented both starch- and gum-based thickened apple juice to participants. Participants included 15 female graduate students between the ages of 22 and 26 with no medical conditions related to dysphagia. There was one masked trial and one un-masked trial for both starch and gum based thickeners. Participants rated each beverage for taste, texture, and palatability using a 10-cm visual analog scale. Taste was the primary determinant for palatability for starch thickeners. Taste was the primary determinant for palatability when the gum-based thickener when un-masked. When masked, texture was the primary determinant for palatability. These results indicate appearance and presentation of thickened liquids could effect a patient's perceived taste.

Rheological Characteristics of Thickeners.

As discussed previously, rheological characteristics of specific foods are important to characterize factors that affect an individual's perceived taste and respective enjoyment of a food or liquid. Rheological properties delineate from the term "rheology" which is defined as "a science dealing with the deformation and flow of matter" (Rheology, n.d.). Adeleye and Rachal (2007) compared the rheological properties of ready-to-serve liquids (i.e., pre-thickened) versus liquids created with powdered mixing agents (i.e., instant food thickeners) at different temperatures for use with individuals with dysphagia. They found the honey and nectar consistency, commercially pre-packaged thickeners (CPPT) to be more viscous (e.g., thicker) than the instant food thickeners (IFT) beverages at both warm and cold temperatures.

Additionally, CPPT beverages were almost always more viscous than the nationally predefined requirement standards. In this case, IFT beverages more often complied with these standards. With that being said, IFT beverages are contingent upon the person mixing them. Specifically, each person has subjective "thickness standards;" one person could thicken a beverage to a slightly different consistency than another person. This study shows there are significant differences in the rheological characteristics between food thickeners, which persist across temperatures (Adeleye & Rachal, 2007).

A consistent standardization system between food thickeners does not exist, which could contribute to problems from medical, physiological, and emotional standpoints for patients who are required to consume these altered consistencies. If a thickened liquid is more viscous than standards require, perceived taste and palatability could be affected, which could potentially impact quality of life measures for a patient with dysphagia. Germain, Dufresne, and Ramaswamy (2005) found thickened liquids were not necessarily consistent with the Bostwick consistency levels, a standardized, scientific procedure for measuring viscosity. The Bostwick consistency levels are determined by a Bostwick consistometer, which is a device that measures the thickness of a substance using a long trough with 0.5 cm graduations on the bottom. In order to measure the thickness consistency, a liquid substance is loaded into the consistometer and is allowed to spread throughout the trough for a specified amount of time. After the time period has elapsed, the thickness is determined by reading the cm graduations to which the liquid spread to (Bostwick Consistometer, 2014). This study provides further evidence that the standardization of thickened liquids is not well-defined at this point in time. Krystyjan, Sikora, Adamczyk, and Tomasik (2011) studied the rheological properties of xantham gum and potato starch used to thicken caramel sauce. They noted in their article "texture is one of the most essential properties characterizing a food product and its quality" (Krystyjan et al., 2011, p. 22). As the thickened liquids have an altered texture, as compared to non-thickened liquids, the perceived taste of the beverage is likely to be altered as well.

Taste Preferences.

Several studies have investigated the role thickened liquids play in perceived taste. Macqueen, Taubert, Cotter, Stevens, and Frost (2003) conducted a study that investigated the commercial thickening agent preference of patients. They asked eight participants, above the ages of 70 years with dysphagia to rate commercial thickening agents. Additionally, they investigated whether the drink flavor used influences taste and preference among thickened liquids. They found no significant taste or preference among the three drink flavors. However, researchers found significant differences in taste and preference among the three different thickeners used. Their results suggest that the thickening agent used influences palatability more than the actual drink used. Matta, Chambers, Garcia, and Helverson (2006) investigated the specific sensory characteristics of commercially thickened beverages. They utilized five "highly trained" descriptive sensory analysis panelists with no diagnosis of dysphagia and unspecified ages as their participants. Eight beverages mixed with four commercial thickeners were included. They found all thickener types suppressed the main beverage flavor. The thickeners added some off-flavors (bitter, sour, etc.) in some beverages. Starch thickeners were grainier. Gum based thickeners were more slick. Pelletier (1997) compared the consistency and taste of five commercial thickeners. The study evaluated five commercial thickeners on the basis of consistency and their impact on taste. The participants were four volunteers from the facility, including: administrative staff, dietary staff, and Speech Language Pathology staff. The thickeners were judged using a numerical rating scale. They found no thickener was superior within the "taste" condition. Certain thickened liquid brands were found superior within different conditions of thickness levels and beverage used, such as apple juice.

Temperature.

The role temperature plays in the taste perception of thickened liquids has not been investigated thoroughly. Horwarth, Ball, and Smith (2006) investigated taste preferences for nectar-thick hot and cold beverages using two commercially prepared thickeners and one non-commercially prepared natural thickener. They thickened both fruit juice and hot cocoa with natural thickeners and commercially prepared thickeners. The natural thickeners included applesauce for the fruit juice and pudding for the hot cocoa. They found significant differences in taste ratings of both commercially prepared thickeners and between one of the commercially prepared thickeners and the non-commercially prepared natural thickener. However, temperature of the beverage was not specifically analyzed, but rather compared across both beverage types.

Research Aims

Past research has examined factors that affect taste, commercial thickener taste preferences of patients with dysphagia, rheological characteristics of liquid thickeners, and temperature. To the author's knowledge, no past studies have examined the effects of visual perceptions (i.e., seeing the thickened liquid – clarity, color, etc.) on taste-palatability perceptions. Likewise, no past studies have identified perceived effects of thickened liquid taste-texture-palatability on compliance or quality of life on individuals with dysphagia. The present investigation seeks to address the following questions:

- How does the appearance of a beverage affect the consumer's perceived taste, texture, palatability, and enjoyment?
- How does the consumption of thickened liquids affect the participant's anticipated quality of life?
- How does the expected duration (e.g., length of time) of thickened liquids affect the consumer's anticipated compliance and quality of life?

As there has been limited empirical evidence even broadly related to the questions of this investigation, directional hypotheses have not been formed. Rather, the hypotheses were intentionally open-ended, so as not to substantively bias any results or interpretations in the qualitative or quantitative sections. Because of the complex, multi-factor quantitative and qualitative design, a pilot study was conducted to help solidify methods for this thesis.

Pilot Study

A pilot study was conducted to preliminarily examine the effects appearance and temperature of honey-thick apple juice have on perceived taste, texture, palatability, and enjoyment. In addition, participants' expected compliance based on the duration that thickened liquids were prescribed was also studied, as well as potential/expected effects on quality of life as a result of consuming thickened liquids.

Eight female graduate students studying Communication Sciences and Disorders at the University of Wisconsin- Eau Claire participated in the pilot study. Participants were asked to taste the honey-thickened apple juice and rate it on a nine-point rating scale based on: taste, texture, palatability, and enjoyment from *dislike extremely* to *like extremely* (see appendix A). Afterwards they were asked to describe the beverage. Next, they were instructed to predict their anticipated compliance and quality of life based on a prescribed duration of thickened liquids (i.e., one glass of thickened liquids, one week, one month, three months, one year, and the remainder of their life). Anticipated compliance ratings were predicted using a nine-point rating scale from *not at all compliant* to *extremely compliant* (see appendix B). Participants predicted their estimated quality of life using a nine-point rating scale and respective quality of life graphic (see appendix C).

Results of the pilot study showed participants rated taste and enjoyment higher when beverages were warm, but texture and palatability were rated better when beverages were cold (in unmasked conditions). Presentations of masked and un-masked juices, as well as temperature conditions were counter-balanced and within-subject design was implemented. For masked conditions, participants rated taste, palatability, and enjoyment higher when beverages were warm, but texture higher when beverages were cold. Regarding appearance, participants rated taste, texture, palatability and enjoyment higher when the liquid was masked, for the warm beverage condition. For the cold beverage condition, participants rated palatability better when the beverage was un-masked, and rated texture higher when the beverage was masked. Taste and enjoyment were rated equally for masked and un-masked beverages, for the cold beverage conditions. For specific data see Table 2.

Table 2. Pilot Study Perception Ratings for Masked & Unmasked Trials.

	Room Temperature						Chilled					
Unmasked Juice						Average						Average
	Taste	3	9	6	6	6	Taste	5	7	5	6	5.8
	Texture	2	6.5	5	5	4.6	Texture	2	3.5	7	7	4.9
	Palatability	4	7	4	5	5	Palatability	5	3	7	7	5.5
	Enjoyment	2	5	6	5	4.5	Enjoyment	2	3	5	7	4.25
Masked Juice						Average						Average
	Taste	6	9	5	6	6.5	Taste	4	7	5	7	5.75
	Texture	5	6.5	4	6	5.4	Texture	2	4	8	8	5.5
	Palatability	6	7.5	6	6	6.4	Palatability	3	3	6	7	3.75
	Enjoyment	5	5	5	7	5.5	Enjoyment	1	3	5	8	4.25

Results of compliance estimates showed a gradual decrease in compliance as duration increased. In other words, generally participants said they would be less compliant the longer they had to consume thickened liquids. However, a slight increase in anticipated compliance was noted for the last duration condition- that being “the remainder of life.”

Generally, participants estimated they would be more compliant if they had to consume thickened liquids for the rest of their life than their previous estimates (i.e., one glass, one week, one month, etc.). During this time, participants made qualitative comments, such as: "I would get used to it." Results of quality of life estimates showed a gradual decrease as the duration of consumption of thickened liquids increased. For specific data on compliance and quality of life ratings see Table 3.

Table 3. Pilot Study Compliance and Quality of Life Ratings for Thickened Liquid Durations.

	Degree of Compliance									Quality of Life								
1 Glass									Average									Average
	2	3.5	6	3.5	9	5	7	6	5.25	5	8	6	5	8	9	7	8	7
1 week									Average									Average
	1	5	5	2	7	4	7	3	4.25	2	5	5	3	6	5	6	5	4.6
3 months									Average									Average
	1	2.5	5	3	7	6.5	6	3	4.25	2	3	6	3	6	6.5	6	3	4.4
1 year									Average									Average
	1	2	3	2	5	4	4	2	2.9	2	2	3	5	5	7	4	1	3.6
Remainder									Average									Average
of Life	1	7	3	5	5	2	4	2	3.6	2	6	3	5	5	3	3	1	3.5

Following collection and preliminary analysis of pilot data, final methods of data collection and analysis were determined.

CHAPTER TWO

METHODS

Participants

The sample consisted of 43 people between the ages of 60 and 90 years of age (mean = 70.6 years of age). Participants were recruited via fliers in community locations (i.e., coffee shops, university) and the local senior center. Inclusion criteria were as follows: (1) chronological age over 60, (2) no current or past diagnosis of dysphagia, and (3) no current or past profession as a Certified Nursing Assistant (CNA), Registered Nurse (RN), Occupational Therapist (OT), dietician/nutritionist, or Speech-Language Pathologist (SLP). For specific demographic information of participants, see Table 4. See table 5 for self-reported estimates of daily liquid intake and see table 6 for self-reported perceptions of oral dryness.

G*Power was used to determine the number of participants required to detect a medium effect size with 80% power at $p = .05$ is 36 for MANOVA analyses of taste, texture, palatability, and enjoyment for masked vs. unmasked beverage.

The same program indicated that 24 participants were needed to detect a medium effect size with 80% power at $p = .05$ for the repeated measures ANOVA analysis of compliance and quality of life as a function of duration (Faul, Erdfelder, Lang, and Buchner, 2007).

Table 4. Participant Demographics.

Participant	Age	Gender	Occupation	Relation to Person with Dysphagia	Current or Previous Tobacco User	Liquid Intake *see table 5*	Dentures	Oral Dryness *see table 6*
1	60	F	Insurance Agent	No	No	3	No	D
2	61	F	Special Education Teacher	No	Yes	3	No	C
3	80	M	Owner of Construction Company	Yes	No	3	No	D
4	64	M	Lumber Yard Manager	Yes	Yes	3	No	D
5	60	M	Engineer	No	No	4	No	D
6	74	F	Customer Service	Yes	No	3	No	D
7	62	M	Labor	Yes	Yes	3	Yes-upper	C
8	67	F	Secretary	No	No	2	No	D
9	81	F	Elementary Teacher	Yes	No	2	No	D
10	82	M	Physician	Yes	No	3	No	D
11	61	M	Audiologist	Yes	No	2	No	D
12	65	F	Teacher	Yes	No	2	No	D
13	60	F	Marketing/Business Writing	No	No	4	No	D
14	76	F	Administrative Assistant	Yes	Yes	2	No	D
15	66	F	SPED Para-professional	No	Yes	3	No	C
16	62	F	None	No	No	4	No	D
17	68	F	Bookkeeper	No	No	2	No	C
18	60	F	Elementary Teacher's Aide	No	No	2	No	C
19	67	F	Para-Professional	No	No	1	No	D
20	67	M	Lawyer	Yes	No	2	No	D
21	67	F	University Professor	No	No	3	No	D
22	76	F	None	Yes	No	3	No	D
23	78	M	Elementary Teacher	No	Yes	3	Yes-upper	B
24	68	M	Engineer	No	No	3	No	D
25	66	F	Homemaker	No	No	2	No	D
26	65	F	Insurance Agent	No	No	4	No	B
27	70	M	Banker	No	No	2	No	D
28	70	F	Teacher/Business Owner	Yes	No	4	No	D

29	61	M	Home Builder	Yes	No	5	No	D
30	69	M	None	No	Yes	2	No	C
31	69	F	None	Yes	Yes	2	No	D
32	60	M	Financial Advisor	Yes	Yes	5	No	D
33	62	F	College Administrator	No	Yes	4	No	C
34	89	F	Registered Nurse (out of field for 30+ years)	Yes	Yes	2	No	D
35	88	M	Physician	No	Yes	3	No	B
36	60	F	Registered Nurse	No	No	3	No	D
37	79	F	Librarian	No	No	2	Yes- upper & partial lower	C
38	67	M	Construction Sales	No	No	2	No	B
39	78	M	University Professor	No	Yes	4	No	D
40	86	F	Labor	No	No	3	No	D
41	91	F	Secretary	Yes	No	2	No	C
42	79	M	Sales	No	No	4	No	C

Table 5. Participant Rating Scale for Self-Reported Daily Liquid Intake Estimates.

Liquid Intake	
1	8-16 oz.
2	17-36 oz.
3	37-52 oz.
4	53-68 oz.
5	69 oz. +

Table 6. Participant Rating Scale for Self-Reported Perceptions of Oral Dryness.

Oral Dryness	
A	Extremely Dry
B	Somewhat Dry
C	A Little Dry
D	Not Dry at All

An exception to the inclusion criteria was one participant, a Registered Nurse, retired from the field for 30+ years. Another exception to the inclusion criteria was another Registered Nurse, employed in a sub-specialty un-related to dysphagia and thickened liquid use. Both participants' knowledge of thickened liquid use was pre-screened, ultimately showing no awareness or knowledge of thickened liquids. Therefore, the participant's data was included in analysis.

One participant opened the lid of the masked juice, upsetting masking presentation procedures. Therefore, her data on ratings of taste, texture, palatability, and enjoyment for masked-trials were not included in analyses.

After data collection was complete, the primary investigator ensured each participant's cognition was within an average range, using the Adult Functional Communication Measures (FCM) of Attention, Problem Solving, and Memory (American Speech-Language-Hearing Association, 2013). An assigned rating of level five or above was considered to be within the range of normal attention, problem solving, and memory and therefore correlated to an overall estimate of participant cognition. See table 3, 4, and 5 for ratings. All participants received ratings of five or above, indicating average cognition. Therefore all qualitative interview data was included in analyses.

Table 7. Functional Communication Measures- Attention.

Level 1	Attention is nonfunctional. The individual is generally unresponsive to most stimuli.
Level 2	The individual can briefly attend with consistent maximal stimulation, but not long enough to complete even simple living tasks.
Level 3	The individual maintains attention over time to complete simple living tasks of short duration with consistent maximal cueing in the absence of distracting stimuli.
Level 4	The individual maintains attention during simple living tasks of multiple steps and long duration within a minimally distracting environment with consistent minimal cueing.
Level 5	The individual maintains attention within simple living activities with occasional minimal cues within distracting environments. The individual requires increased cueing to start, continue, and change attention during complex activities.
Level 6	The individual maintains attention within complex activities and can attend simultaneously to multiple demands with rare minimal cues. The individual usually uses compensatory strategies when encountering difficulty. The individual has mild difficulty or takes more than a reasonable amount of time to attend to multiple tasks/stimuli.
Level 7	The individual's ability to participate in vocational, avocational, or social activities is not limited by attentional abilities. Independent functioning may occasionally include the use of compensatory strategies.

Table 8. Functional Communication Measures- Memory.

Level 1	The individual is unable to recall any information, regardless of cueing.
Level 2	The individual consistently requires maximal verbal cues or uses external aids to recall personal information (e.g., family members, biographical information, physical location, etc.) in structured environments.
Level 3	The individual usually requires maximal cues to recall or use external aids for simple routine and personal information (e.g., schedule, names of familiar staff, location of therapy areas, etc.) in structured environments.
Level 4	The individual occasionally requires minimal cues to recall or use external memory aids for simple routine and personal information in structured environments. The individual requires consistent maximal cues to recall or use memory aids for complex and novel information (e.g., carry out multiple steps activities, accommodate schedule changes, anticipate meal times, etc.), plan and follow through on simple future events (e.g., use calendar to keep appointments, use log books to complete a single assignment/task, etc.) in structured environments.
Level 5	The individual consistently requires minimal cues to recall or use external memory aids for complex and novel information. The individual consistently requires minimal cues to plan and follow through on complex future events (e.g., menu planning and meal preparation, planning a party, etc.).
Level 6	The individual is able to recall or use external aids/memory strategies for complex information and planning complex future events most of the time. When there is a breakdown in the use of recall/memory strategies/external memory aids, the individual occasionally requires minimal cues. These breakdowns may occasionally interfere with the individual's functioning in vocational, avocational, and social activities.
Level 7	The individual is successful and independent in recalling or using external aids/memory strategies for complex information and planning future events in all vocational, avocational, and social activities.

Table 9. Functional Communication Measures- Problem Solving.

Level 1	Problem solving skills are nonfunctional in all situations or settings regardless of cueing or additional time given. The individual does not recognize a problem given any level of cueing. 1:1 supervision is required.
Level 2	The individual is able to solve rote problems (i.e., picking up a cup, if knocked over) in immediate environment. With consistent, maximal cues/assistance and additional time, the individual is able to recognize problems, generate appropriate solutions and/or carry out steps to complete simple problem solving tasks in structured environments. However, problem solving attempts are rarely accurate and 1:1 supervision is required.
Level 3	The individual usually requires moderate cues/assistance and additional time to recognize problems, generate appropriate solutions and/or carry out steps to complete simple problem solving tasks in structured environments, although accuracy may vary. Close supervision is required.
Level 4	The individual occasionally requires minimal cues/assistance to complete simple problem solving tasks in structured environments. Additional time may be needed to recognize problems, generate appropriate solutions and carry out steps to solve problems. Distant supervision may be required to complete simple problem solving tasks. The individual demonstrates emerging problem solving skills for complex problem solving tasks. With consistent, maximal cues/assistance and additional time, he/she is able to identify salient features of complex problems, but rarely self-monitors effectiveness of performance and/or uses strategies when encountering difficulty. Close supervision may be required during complex problem solving tasks.
Level 5	The individual demonstrates functional problem solving skills in routine daily activities. He/she rarely requires minimal cueing/assistance or additional time to recognize problems, identify various solutions and carry out steps to complete simple problem solving tasks.
Level 6	Problem solving skills are functional in most settings, but some limitations in problem solving are still apparent in vocational, avocational, and social activities. The individual rarely requires minimal cueing/assistance or additional time to generate multiple solutions and carry out steps to complete complex problem solving tasks. He/she usually self-monitors effectiveness of performance and uses strategies when encountering difficulty.
Level 7	The individual's ability to successfully and independently participate in vocational, avocational, and social activities is not limited by problem solving skills. Independent functioning rarely requires more than a reasonable time to complete complex problem solving tasks. The individual independently self-monitors effectiveness of performance and uses strategies when needed.

Participants were pre-screened based on inclusion criteria, as well as other related criteria using a questionnaire (see appendix D). Participants completed the questionnaire independently. Clarification on content of the questionnaire was provided by clinician when requested by participant. The first portion included demographic information, including: age, gender, presence of swallowing difficulties and dysphagia diagnosis in themselves or in friends/family members (self-reported or diagnosed by physician, as previous experiences and exposure may alter their responses), and smoking status (current, past, or non-smoker, as a history of smoking may impact taste perceptions). The second portion related to eating and related habits, including: water intake, presence or absence of partial and/or complete denture wear, degree of oral dryness, oral hygiene practices, and food allergies.

Materials

Apple juice was selected as the beverage, due to its commercially available status and general familiarity among the participants. A pre-thickened juice was utilized (Hormel *Thick & Easy* ® pre-thickened apple juice, honey consistency), as to avoid instrumentation bias and aid in standardization across the sample. Masked juices were presented in 12 oz. Styrofoam *Dixie* ® *Perfectouch* ® *Grab' N Go* ® disposable travel coffee cups with lids. Unmasked juices were presented in 9 oz. plastic *Solo* ® *Clear Cups.* Qualitative interview data were collected via two Sony-brand, model ICD-SX712 and ICD- SX733 digital voice recorders.

Procedures

Thickened apple juice was presented, within-subjects, in masked and un-masked trials. Presentations of the masked/un-masked juices were randomized to avoid sequencing effects. Randomization was ensured and juice order was determined using the "Random Sequence Generator" (Random.org, 2017). Masked juices were presented in a disposable, Styrofoam coffee cup with black-colored lid. Un-masked juices were presented in clear, plastic, disposable cups. Participants were informed they would be tasting thickened apple juice and were prompted to taste the respective juice. Afterwards they were asked to rate the juice for (a) taste, (b) texture, (c) palatability, and (d) enjoyment on a nine-point rating scale from *dislike extremely* to *like extremely* immediately after tasting the juice (see appendix A). Next, they were prompted to taste the opposite masked/un-masked version of their first juice. Again, they were asked to rate the juice for the above listed factors on the nine-point rating scale from *dislike extremely* to *like extremely.*

Following this task, participants were asked to predict their degree of compliance to drink thickened liquids for a specified duration. Specific durations presented include: (a) 1 glass of thickened liquids on 1 occasion, (b) 1 week of all liquids thickened – including liquids at meal time and outside of meals, (c) 3 months of all liquids thickened – across meal and non-meal contexts, (d) 1 year of all liquids thickened, and (e) thickened liquids for the remainder of their life. Compliance ratings were collected via a 9-point rating scale from *not at all compliant* to *extremely compliant* (see appendix B).

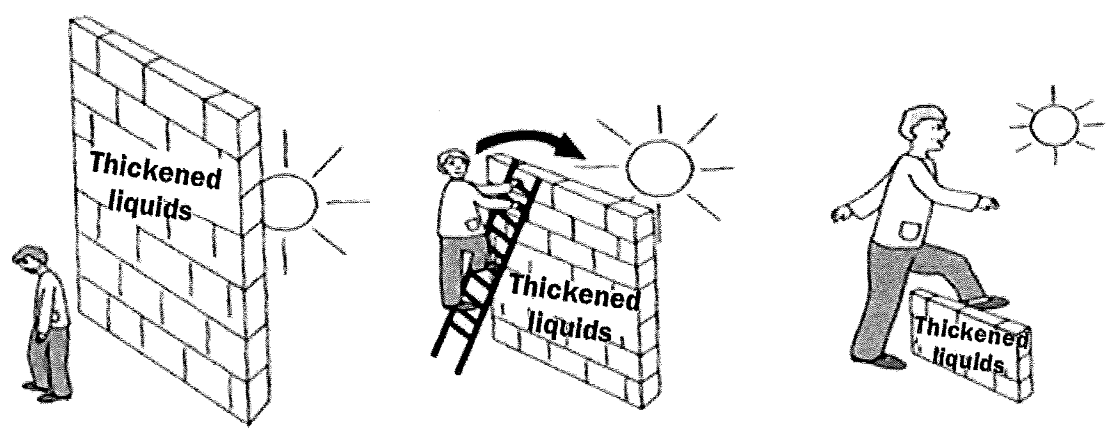
Participants were then asked to "describe the extent drinking thickened liquids would have on [their] life." Follow-up questions were administered to address specific areas, including: social, convenience/daily routine, types of liquid, and enjoyment. Follow-up questions were administered in the order listed in table 10. Researchers used the prompt, "Can you tell me more about that?" to respond to un-clear or ambiguous participant statements. In the case, the participant's statement to question D involved content related to consumption/willingness to thicken alcoholic beverages, researchers did not administer question E. Digital recordings of qualitative interviews were transcribed by the primary investigator and a research assistant for use in qualitative analyses.

Table 10. Follow-Up Qualitative Interview Questions.

Sub-Section		Question
Social	A	Would drinking thickened liquids restrict your likelihood to go out to different social contexts?
	B	Who would you feel comfortable drinking thickened liquids in front of vs. who would you not feel comfortable drinking thickened liquids in front of?
Convenience/Daily Routine	C	How, if at all, would it [drinking thickened liquids] affect your daily routine?
Types of Liquid	D	Think about all the liquids you consume in your life. What are some that you would be willing to thicken and what are some you would not be willing to thicken?
	E	Would you thicken an alcoholic beverage, such as a beer or mixed drink?
Enjoyment	F	How, if at all, would thickening your liquids effect your enjoyment of the beverage?

Order of durations were randomized per participant, as to avoid sequencing effects. Duration order were again randomized using the “Random Sequence Generator” (Random.org, 2017). Participants were informed prior to predicting their compliance ratings that only their liquids would be thickened, and they would still be able to eat all other, non-liquid foods by mouth. After selecting a compliance rating for each duration, participants were also asked to rate their perceived quality of life based on the duration of thickened liquid intake. Quality of life was depicted using a 9-point rating scale, and a respective graphic (see appendix C). The graphic used was modified from the "wall question" on the Assessment for Living with Aphasia (ALA) published by the Aphasia Institute (2015). The conventional purpose of the "wall question" is to assess overall quality of life, as related to aphasia- a neurological language disorder common among individuals post- stroke or –traumatic brain injury. The question is depicted by three graphics on a rating scale. The graphic was modified to include "thickened liquids" instead of "aphasia," see Figure 1.

Figure 1. Wall Question- Thickened Liquids.



The quality of life measures were again randomized per participant, along with their respective duration, to avoid sequencing effects, using the "Random Sequence Generator" (Random.org, 2017). Participants were familiarized with the graphic and asked to rate their perceived quality of life on a nine-point rating scale placed below the figure 1 graphic, the far left side of the scale representing a large effect on quality of life and the far, right side of the scale representing a small effect on quality of life. Wall image and scale adapted from the Assessment for Living with Aphasia with permission from the Aphasia Institute.

Analyses

Data were collected through mixed quantitative and qualitative measures. Quantitative data was analyzed using IBM Statistical Package for the Social Sciences (SPSS), version 24. Participant ratings of taste, texture, palatability, and enjoyment for both masked and un-masked juices were analyzed using a doubly multivariate repeated measures MANOVA (SPSS general liner model). Participant ratings of anticipated compliance and quality of life for respective durations (1 glass, 1 week, 3 months, 1 year, remainder of life) were analyzed using repeated measures ANOVAs (SPSS general linear model). Ratings of anticipated compliance and quality of life were analyzed in succession with gender factors and participant's relation to person with dysphagia.

Qualitative analyses of interview responses used Strauss and Corbin's (2008) method of non-hierarchical open and axial coding. Strauss and Corbin (2008) define open coding as "breaking data apart and delineating concepts to stand for blocks of raw data" and axial coding as "crosscutting or relating concepts to each other" (Strauss & Corbin, 2008; p. 195).

Interview responses were recorded, transcribed, organized, and analyzed within an Excel Spreadsheet. Codeable statements were determined by responses to the open-ended prompt (i.e., "Describe the extent drinking thickened liquids would have on your life") and each sub-section questions (i.e., social, convenience/daily routine, types of liquids, enjoyment). See table 10 for sub-section questions. Participant statements were printed and divided into individual slips of paper, based on responses to respective question. Responses to each question were placed into categories based on the central meaning. For example, participant statements, which central meaning related to compliance issues, were placed into a category titled "compliance." Afterwards, each category was subdivided into further sub-categories. Themes were drawn from categories and subcategories. By creating themes, underlying meanings of data are linked.

During the first round of data analysis, the primary investigator independently placed participant statements to the open-ended prompt and sub-section questions into respective categories using the open coding technique (Strauss & Corbin, 2008). The following two rounds of data analysis involved the primary investigator and two coding assistants. The coding assistants were two undergraduate students who responded to a call for transcribers. They were trained on the coding process by the primary investigator. During the second round of data analysis, the coding assistants jointly reviewed participant statements and ensured they were placed in the most appropriate category based upon the open coding technique (Strauss & Corbin, 2008). When coders disagreed upon category placement, a discussion ensued and a consensus was negotiated. The primary investigator and coding assistants jointly developed operational definitions for each category to further clarify the content of each category. During the last round of data analysis, participant statements were again jointly reviewed and ensured they were placed in the correct category (i.e., that previous coding schemes still made sense in a separate review, given operational definitions). The primary investigator and the coding assistants generated subcategories, using the axial coding technique, based on the more specific content of participant statements in each category (Strauss & Corbin, 2008). This iterative process assured integrity of the coding process by reviewing the coding schemes over the course of multiple meetings. Further, the drilling down process of axial coding ensures inclusion of unique data points. Along with comparisons to quantitative data, the iterative vetting process facilitates triangulation and improves rigor of qualitative codes.

Themes generated across categories and subcategories provided information related to the consumption of thickened liquids and related outcomes. Barriers and facilitators to compliance with thickened liquid consumption were identified.

CHAPTER THREE

RESULTS

Quantitative Results

Analysis of ratings of taste, texture, palatability, and enjoyment as a function of masking were found to have an insignificant multivariate effect, $F(4, 37) = 1.526, p = .215, \eta_p^2 = .142$. Although not found to be significant, mean ratings of taste, texture, palatability, and enjoyment show slightly favorable ratings for the unmasked juice for taste and enjoyment factors and the masked juice for texture factors and palatability factors. For specific data on mean ratings, see table 11.

Table 11. Participant Ratings of Masked and Unmasked Juice.

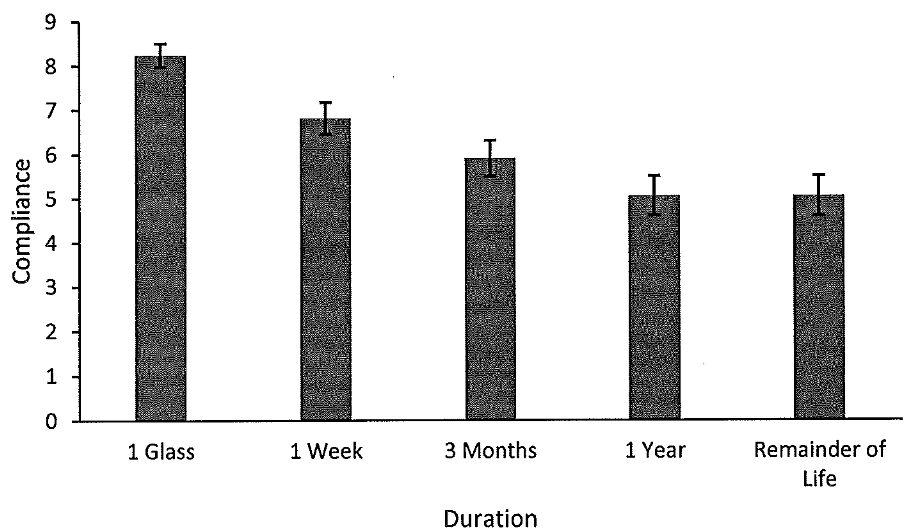
Ratings	Masking	Mean	Standard Deviation
Taste	Unmasked	6.56	1.534
	Masked	6.12	1.873
Texture	Unmasked	5.66	2.093
	Masked	5.90	1.960
Palatability	Unmasked	5.90	1.855
	Masked	6.07	1.664
Enjoyment	Unmasked	5.29	2.182
	Masked	5.12	2.182

Note: Ratings ranked from 1 = dislike extremely; 9 = like extremely.

Ratings of anticipated compliance as a function of duration were found to have a significant multivariate effect. Assumptions of Mauchly's Test of Sphericity were violated and corrections via Greenhouse-Geisser were applied, indicating a significant difference in compliance as a function of duration, $F(2.35, 96.31) = 33.51, p = .001, \eta_p^2 =.462$. Within-subjects contrasts indicated a significant linear pattern, such that compliance was negatively affected by duration, $F(1, 38) = 54.02, p < .001, \eta_p^2 =.587$. Additionally, the within-subjects quadratic contrast was significant, $F(1,38) = 13.09, p =$

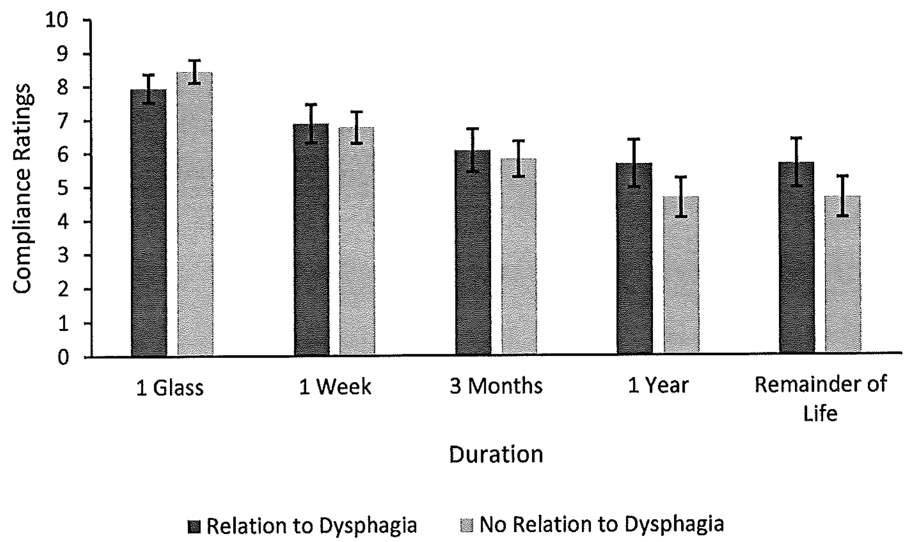
.001, $\eta_p^2 = .256$. Compliance was highest for one glass, relatively high for one week, and then decreased sharply for the following durations. See figure 2. The significant linear and quadratic contrasts converged indicated that, as duration increased, ratings of anticipated compliance decreased.

Figure 2. Ratings of Anticipated Compliance as a Function of Duration.



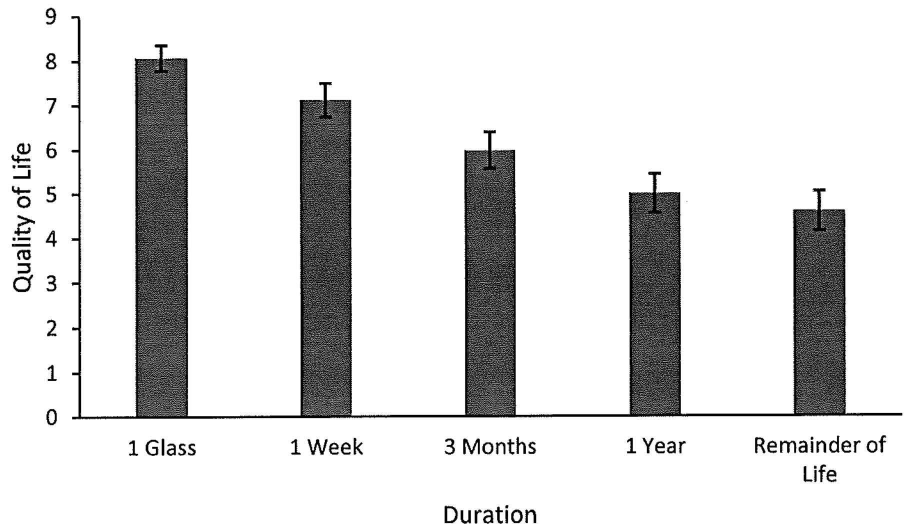
Ratings of anticipated compliance as a function of duration were also analyzed in succession with gender and relationship to dysphagia (e.g., if the participant knew someone with dysphagia) treated as independent between-subjects variables. The Gender X Duration interaction for compliance was not significant, indicating that the main effect of duration on compliance was not moderated by gender, $F(4, 35) = 1.01, p = .415, \eta_p^2 = .104$. However, the Duration X Relationship to Dysphagia interaction was found to be marginally significant when Greenhouse-Geisser corrections were applied, $F(2.41, 91.70) = 2.862, p = .052, \eta_p^2 = .070$. Only the linear within-subjects contrast was significant, $F(1, 38) = 4.693, p = .037, \eta_p^2 = .110$. Please see figure 3. Participants who knew someone with dysphagia made higher ratings of compliance, with the exception of the first duration (1 glass), than those who did not know someone with dysphagia.

Figure 3. Anticipated Compliance as a Function of Duration, Considering Relationship to Dysphagia.



Ratings of anticipated quality of life as a function of duration were found to have a significant multivariate effect. Assumptions of Mauchly's Test of Sphericity were violated and corrections via Greenhouse-Geisser were applied indicating a significant difference in quality of life as a function of duration, $F(4, 96.26) = 33.054, p < .001, \eta_p^2 = .465$. See figure 4. Within-subjects contrasts indicated a significant linear pattern, such that quality of life was negatively correlated with duration, $F(1, 38) = 58.30, p < .001, \eta_p^2 = .605$. Quality of life steadily decreased as duration increased.

Figure 4. Ratings of Anticipated Quality of Life as a Function of Duration.



Ratings of anticipated quality of life as a function of duration were also analyzed in succession with gender and relation to dysphagia as variables. The Gender X duration interaction for quality of life was significant, indicating that the main effect of duration on quality of life was not moderated by gender, $F(4, 35) = .709, p = .591, \eta_p^2 = .075$. Initially, the Relation to Dysphagia X Duration interaction for quality of life was significant. However, after applying Greenhouse-Geisser corrections for violating Mauchly's Test of Sphericity, the Relation to Dysphagia X Duration interaction was not significant, indicating that the main effect of duration on quality of life was not moderated by relationship to dysphagia, $F(2.53, 96.26) = 1.689, p =.182, \eta_p^2 = .043$.

Qualitative Data Results

A total of 242 statements, from 42 participants were coded; because three statements were double coded, a total of 245 codes were identified. Overall barriers to thickened liquid consumption were elicited with the open-ended prompt (i.e., describe the extent drinking thickened liquids would have on your life). Follow-up questions codes were divided for analysis. Codes were organized based on participant responses to interview questions. Question-categories included the broad open-ended prompt, and follow-up question which were divided into the following question-subcategories: social, daily life factors, types of liquid, and enjoyment; respective categories and subcategories were identified per each question subcategory. Codes surrounding "types of liquids" were separated into "general beverages" and "alcoholic beverages" to provide content in further detail. Categories and subcategories were identified for consumption of alcoholic beverages. However, general statistics were provided based of willingness to thicken for "general beverages."

Overall Barriers to Thickened Liquid Consumption

A total of 41 participant statements were elicited by the open-ended prompt (i.e., describe the extent drinking thickened liquids would have on your life). This question yielded three categories, including ***decrease liquid consumption, compliance***, and ***ambiguous***. Distribution of categories and subcategories of responses is provided in table 12. The category ***decrease liquid consumption*** accounted for 12% of responses to the open-ended prompt (n =5 statements). Statements in this category made direct reference to a probable decrease in liquid consumption if the participant needed to consume thickened liquids (e.g., "I might not drink as much"). Within this category, subcategories identified included: general health concerns (n = 3; 60% of category) such as any indications that intake could have impacts on overall health, and length of consumption (n = 2; 40% of category), which referred to increased time needed to consume thickened liquids. The second category, **compliance issues**, included 32 statements (78% of responses to open-ended prompt). Within this category, subcategories identified included: compliance dependent upon context (n = 5; ≈ 15.6% of category), which referred to a change in compliance based on situational factors (i.e., social gatherings, restaurants, etc.). A second subcategory, compliant included 8 statements (25% of category), which referred to indications the individual would comply with recommendations to consume thickened liquids. A third subcategory, compliant but unappeased included 12 statements (37.5% of category), which referred to indications in which the individual verified compliance, but made statements of negativity involving thickened liquid consumption. A final, fourth, subcategory, uncompliant consisted of 7 statements (≈ 21.9% of category), which referenced indications the individual would not comply with recommendations to consume thickened liquids for part or all of the duration they are were asked to consume. The last category, ambiguous, included four statements (≈ 9.8% of category) and was made up of statements in which the central meaning or communicative purpose of the utterance was unclear.

Table 12. Distribution of Overall Barriers to Thickened Liquid Consumption.

	Categories	**Subcategories**	**Exemplar**
Overall Barriers to Thickened Liquid Consumption	Decrease Liquid Consumption (5)	General Health Concerns (3)	"It would be hard to get enough liquid [every day]. It would be about getting the right amount of liquids."
		Length of Consumption (2)	"It would take forever to drink. I think I would drink less."
	Compliance Issues (32)	Compliance Dependent Upon Context (5)	"It would be really hard to go out and have any kind of meal."
		Compliant (8)	"It wouldn't bother me at all."
		Compliant but Unappeased (12)	"It would be annoying, but I would do it for my health."
		Uncompliant (7)	"There is no quality of life then, so why do it?"
	Ambiguous (4)		

Social

Two categories were created based on responses to social questions. Social questions included: (a) would drinking thickened liquids restrict your likelihood to go out to different social contexts? and (b) who would you feel comfortable drinking thickened liquids in front of vs. who would you not feel comfortable drinking thickened liquids in front of? These questions yielded two categories, including ***social settings*** *and* ***social partners***. Distribution of categories and subcategories of responses in provided in table 13. The category of ***social settings*** accounted for 50% of responses to social, follow-up questions (n = 41). Statements in this category made direct reference to participation effects specific to social settings. Within this category, subcategories identified included: large impact/withdrawal (n = 7; ≈17.1% of category), which referenced indications thickened liquid consumption would cause social withdrawal or significantly affect participation in social settings, minor impact (n = 7; ≈17.1% of category), which referred to a small impact on social participation, no impact (n = 17; ≈41.5% of category), which made reference to no effect on social participation, participation dependent upon context (n = 7; ≈17.1% of category) which made direct reference to specific contexts in which social participation would be enhanced or decreased (e.g., large gatherings vs. small), and convenience barrier (n = 3; ≈ 7.3% of category) which referenced decreased participation in social settings due to inconvenience of thickened liquid consumption. The second category **social partners** included 41 statements (50% of responses to social, follow-up questions) and yielded two subcategories. The first being: comfortable (n = 29; 71% of category), such indicated complete comfortability consuming thickened liquids in front of any social partner. The second subcategory being: comfortability dependent upon social partner (n = 12; 29% of category), indicating comfortability with consumption of thickened liquid in the presence of select social partners (i.e., family/friends vs. strangers).

Table 13. Social Participation Factors Related to Thickened Liquid Consumption.

Social- (82)	Categories	Subcategories	Exemplar
	Social Settings (41)	Large Impact/ Withdrawal (7)	"It would be very difficult in a social situation."
		Minor Impact (7)	"Grabbing the powder and throwing it in your drink might be a little awkward; knowing me I wouldn't care too much."
		No Impact (17)	"It would not restrict me."
		Participation Dependent Upon Context (7)	"In a smaller group, where people would see that I was drinking thickened liquids and nobody else was; that would bother me."
		Convenience Barrier (3)	"If I'm out is it up to me to thicken it? That would [be] a big barrier for me."
	Social Partners	Comfortable (29)	"If I were to drink them, I could do it in front of anyone."
		Comfortability Dependent Upon Social Partner (12)	"Family would be fine. Friends- it depends on who they are and how much they know about you."

Daily Life Factors

The overarching category of "daily life factors" was created based off participant responses to the "convenience/daily routine" follow-up question: "How, if at all, [would drinking thickened liquids] effect your daily routine?" This question yielded two categories, including ***routine factors,*** and ***convenience factors***. Distribution of categories and subcategories of responses is provided in table 14. The category of ***routine factors*** accounted for 61% of responses (n = 23). Statements in this category made direct reference to effects on daily routine. Within this category, subcategories identified included: no effect (n = 14; ≈ 60.9% of category), such indicated no change in routine as a result of thickened liquid consumption, minor effect (n = 7; ≈ 30.4% of category), which indicated a slight change in routine as a result of thickened liquid consumption, and large effect (n = 2; ≈ 8.7% of category), such referenced a significant change in routine as a result of thickened liquid consumption. The second category, ***convenience factors*** included 15 statements (39% of responses to questions). Within this category, three subcategories were identified, including preparation barrier (n = 6; 40% of category), which referenced an inconvenience related to length of time and/or materials needed to prepare thickened liquids, availability barrier (n = 7; ≈ 46.7% of category), which indicated inconvenience related to planning factors and/or availability at common retailers (i.e., grocery stores, restaurants), and length of consumption (n = 2; ≈ 13.3% of category), which, again, referred to increased time needed to consume thickened liquids.

Table 14. Daily Life Factors Related to Thickened Liquid Consumption.

Daily Life Factors-(38)	Categories	Subcategories	Exemplar
	Routine Factors (23)	No Effect (14)	"It would not likely affect my routine."
		Minor Effect (7)	"It would affect [my routine] some."
		Large Effect (2)	"It would affect my routine quite a bit."
	Convenience Factors (15)	Preparation Barrier (6)	"The preparation of it [would be inconvenient]."
		Availability Barrier (7)	"I think it [would] be the logistics in having something that I could drink available at all times."
		Length of Consumption (2)	"[It] would take me longer to drink a thickened liquid."

Enjoyment

The overarching category of "enjoyment" was created based upon responses to the "enjoyment" follow-up question, stating: "How, if at all, would drinking thickened liquids effect your enjoyment of the beverage?" This question yielded three categories, including ***enjoyment changes, enjoyment dependent upon other factors,*** and ***ambiguous.*** Distribution of categories and subcategories of responses is provided in table 15. The category of ***enjoyment changes*** accounted for 72.5% of responses to the question (n = 29 statements). Within this category, subcategories identified included: <u>increase in enjoyment</u> (n = 2; ≈ 6.9% of category), which referenced an increase in enjoyment of respective beverages as a result of it being thickened, <u>decrease in enjoyment</u> (n = 23; ≈79.3% of category), such indicated a decreased in beverage enjoyment due to it being thickened, and <u>no effect on enjoyment</u> (n = 4; ≈ 13.8% of category), which indicated no effect on beverage enjoyment due to thicken liquid consumption. The category

enjoyment dependent upon other factors accounted for 17.5% of responses to the question (n = 7 statements) and included the following subcategories: taste (n = 5; ≈ 71.4% of category), such indicated enjoyment is dependent upon the preservation of original beverage taste, despite addition of thickener, and method/mode of intake (n = 2; ≈ 28.6% of category), such referenced a change in thickened liquid beverage enjoyment based on mode of transport to mouth (i.e., spoon, straw, cup, etc.). The last category, ***ambiguous***, accounted for 10% of responses to question 1 (n = 4 statements) and was made up of statements in which the central meaning or communicative purpose of the utterance was unclear.

Table 15. Enjoyment Factors Related to Thickened Liquid Consumption.

Enjoyment (40)	**Categories**	**Subcategories**	**Exemplar**
	Enjoyment Changes (29)	Increase in Enjoyment (2)	"I'd kind of enjoy if I could thicken some things."
		Decrease in Enjoyment (23)	"It would affect [enjoyment] a lot."
		No Effect on Enjoyment (4)	"It probably wouldn't be that big of an effect."
	Enjoyment Dependent Upon Other Factors (7)	Taste (5)	"It all comes down to taste."
		Method of Intake (i.e., spoon, straw, etc.) (2)	"If you could drink it through a straw versus just out of the cup [would change it]."
	Ambiguous (4)		

Types of Liquid

Overarching categories for "types of liquid" were based on participant responses to "types of liquid" follow-up questions: (a) Think about all the liquids you consume in your life. What are some that you would be willing to thicken and what are some that you would not be willing to thicken? and (b) Would you be willing to thicken an alcoholic beverage, such as a beer or mixed drink? Participant responses were subdivided into main categories, based on their content, including: (1) general beverages, and (2) alcoholic beverages.

General Beverages

Categories and subcategories were not obtained in the general beverage category. Rather, frequency counts per participant report were analyzed.

Table 16. Reported Willingness to Thicken Beverage Types.

Beverages	Yes	No	Maybe
Water	7	15	0
Juices	24	2	0
Coffee	0	21	3
Milk	9	9	1
Tea	0	4	0
Tomato Juice	0	2	0
Broth/Soup	5	0	0
Soft Drinks	1	9	0
Hot Chocolate	1	0	0

Alcoholic Beverages

Within this main category, three categories were yielded, including ***willingness/unwillingness, not applicable,*** and ***ambiguous.*** Distribution of categories and subcategories of responses is provided in table 17. The category ***willingness/unwillingness*** accounted for ≈ 87.2% of responses to the questions (n = 34 statements). Within this category, three subcategories were identified; the first being: <u>would thicken alcohol</u> (n = 12; ≈ 35.3% of category), which referenced an interest in thickening alcoholic beverages. The second subcategory, <u>would not thicken alcohol</u> (n = 18; ≈ 52.9% of category), indicated no interest in thickening alcoholic beverages. The last subcategory, <u>potentially thicken alcohol</u> (n = 4; ≈ 11.8% of category), made reference to willingness to thicken alcohol based on trials and perceptions of enjoyment. The second category, ***not applicable***, accounted for ≈ 5.1% of the category (n = 2 statements) and included responses stating they did not consume alcohol, therefore the question did not apply. The last category, ***ambiguous***, accounted for ≈ 7.7% of responses to question 1 (n = 3 statements) and was made up of statements in which the central meaning or communicative purpose of the utterance was unclear.

Table 17. Factors Related to the Consumption of Thickened Alcoholic Beverages.

Alcoholic Beverages (39)	**Categories**	**Subcategories**	**Exemplar**
	Willingness/Unwillingness (34)	Would Thicken Alcohol (12)	"I'd be willing to thicken Leinenkugel's beer."
		Would Not Thicken Alcohol (18)	"I wouldn't want to thicken beer."
		Potentially Thicken Alcohol (4)	"I think I'd have to try [thickened alcohol] to find out."
	Not Applicable (2)		"It doesn't really relate to me because I don't drink [alcohol]."
	Ambiguous (3)		

CHAPTER FOUR

DISCUSSION

Overview

The present investigation sought to address the following questions: (a) how does the appearance of a beverage affect the consumer's perceived taste, texture, palatability, and enjoyment? (b) how does the expected duration (e.g., length of time) on thickened liquids affect the consumer's anticipated compliance and quality of life? (c) how does the consumption of thickened liquids affect the participant's anticipated quality of life?

As there has been limited empirical evidence even broadly related to the questions of this investigation, directional hypotheses were not formed. Rather, the hypotheses were intentionally open-ended, so as not to substantively bias any results or interpretations in the qualitative or quantitative sections. The primary investigator acknowledges that personal experiences and professional knowledge undoubtedly influence interpretations of data. In order to reduce the influence of investigator bias and given the lack of prior empirical evidence for directional hypotheses, predictions regarding the impact of presentation, duration, and other factors were not formed.

Implications

Quantitative Data.

Participant ratings of taste, texture, palatability, and enjoyment for masked and unmasked juices were not significantly different, suggesting the appearance of thickened liquids does not affect the persons' perceptions of taste, texture, palatability, and enjoyment. This suggests that professionals involved in serving thickened liquids (e.g., dietary aids or kitchen staff, speech-language pathologists, or related disciplines) do not need to alter the serving mode by transferring the thickened liquids to another serving container to address these quality factors. To the investigator's knowledge, this is the first empirical evidence regarding serving presentation for thickened liquids. In spite of the insignificant relationship, professionals should be sensitive to individual variability regarding presentation preference.

Predictions of compliance by older individuals without dysphagia indicate that compliance is likely to decline as duration increases. In examining compliance as a function of duration (i.e., 1 week, 1 year, etc.) there was a significant multivariate effect among participant ratings, after corrections for violating sphericity were applied. As duration increased, ratings of anticipated compliance decreased. Therefore, Speech-Language Pathologists who write orders for patients to consume thickened liquids for longer durations can assume the patient is less likely to be compliant. Consequently, increased patient support should be provided and/or alternative treatment methods should be explored.

Few previous investigations have addressed compliance with thickened liquid consumption. Whelan (2001) found that compliance in consuming thickened liquids was reduced post- acute stroke, which led to decreased oral hydration. Conclusions urged hospital staff to ensure adequate fluid intake for patients consuming thickened liquids, including provisions for supplementary fluids when necessary. Rosenvinge and Starke (2005) investigated the effectiveness of practice policy changes to improve compliance among individuals consuming thickened liquids. After implementation of a "dysphagia compliance group," which consisted of medical professionals most related to swallowing recommendations (i.e., SLPs, nurses, dietetics, catering departments, physicians), and a "dysphagia/nutrition link nurse" program, which consisted of a 2-hr training for nurses caring for individuals with dysphagia, improvements in patient compliance increased from 48-64%, suggesting increased support related to dysphagia and thickened liquid consumption can improve the compliance of patients.

The anticipated compliance ratings of participants who knew an individual with dysphagia (either closely or distantly), were marginally significantly different as a function of duration, after corrections for violating sphericity were applied. Therefore, these participants reported increased anticipated compliance as duration increased, as compared to participant's who did not know someone with dysphagia. The underlying reason for this relationship-based implication is unclear. It could be hypothesized, participants who had a relation to dysphagia, had an increased familiarity related to the importance and need for thickened liquids and therefore made higher ratings. However, this needs to be investigated further. For instance, the specific nature of these relationships, duration of the dysphagia, resolution or management of the dysphagia, nor the roles participants from this study had in interacting with that individual with dysphagia was not explored. To the investigator's knowledge, this is the first empirical evidence regarding differences in compliance ratings when considering relationship to dysphagia as a factor.

Quality of life as a function of duration was also found to have a significant multivariate effect among participant ratings, even after corrections for violating sphericity were applied. As duration increased, participant ratings of quality of life decreased. Therefore, when professionals anticipate an individual will need to consume thickened liquids for an extended period of time, steps should be taken to address quality of life factors. Several investigations, including Gillespie and colleagues (2004) and Radford and colleagues (2004) have examined quality of life effects, specific to swallowing difficulties within populations with dysphagia following head and neck cancer. Both studies used questionnaires to assess the quality of life of patients, pre- and post-cancer treatment. Gillespie and colleagues (2004) found participants reported quality of life measures 25-40% worse than populations without head and neck cancer. Radford and colleagues (2004) found participants reported significant decreases, post-cancer treatment, in the following quality of life domains: appearance, activity, recreation, swallowing, chewing, and speech. While implications are somewhat different, the impact of dietary restrictions has been investigated in other populations. Lee and Newman (2003) examined factors negatively affected by Celiac Sprue, given a gluten-free diet restriction. Factors impacted most significantly included dining out, travel, and impact on family. The study reported a variety of other lifestyle factors that were impacted as well. Similarly, Zarkadas et al (2006) found that adults with Celiac Sprue identified access to foods, avoiding restaurants, and avoiding travel as frequent restrictions which affected quality of life. The study also found that better dietary instruction improved quality of life ratings. Flockstra-de Blok and colleagues (2008) developed a quality of life scale for examining dietary restrictions related to food allergies. The scale shares a number of perceived restrictions on quality of life that are similar to those identified in this investigation (e.g., cannot eat certain foods, affects the people you are eating with, affects dining out, feel like you have to explain to others, affects social activities). However, to the investigator's knowledge, this is the first empirical evidence to be conducted regarding quality of life issues as a function of specific durations of time consuming thickened liquids.

Qualitative Data.

Overall Barriers to Thickened Liquid Consumption.

Major barriers related to thickened liquid consumption were identified via the open-ended prompt (i.e., describe the extent drinking thickened liquids would have on your life). Two major categories were identified: ***decrease in liquid consumption*** and ***compliance issues.*** For ***decrease in liquid*** consumption, participants expressed concern regarding maintaining hydration while consuming thickened liquids; whether it was due to perception factors (i.e., taste, texture, palatability, enjoyment) or the length of time it takes to consume thickened liquids. Additionally, a second category ***compliance issues*** identified major concerns related to patient follow-through. Sixty-two percent of respondents noted they would comply with orders to consume thickened liquids; with less than half of those individuals having absolutely no problems with compliance, and over half willing to comply, but mentioning difficulty/unhappiness and doing so.

Understanding major barriers to thickened liquid consumption, can prompt professionals to provide increased support and resources to individuals consuming thickened liquids. In specific, by providing resources on how to maintain hydration; detailing exact amount of thickened liquids needed, per day, for adequate hydration. Rosenvinge and Starke (2005) provide evidence to support the effectiveness of policy changes and programs which can support patient compliance and hydration. Murray and colleagues (2013) demonstrate the intake of patients consuming thickened liquids was lower than recommended standards of fluid intake; citing protocols and increased monitoring of thickened liquid intake should be implemented via increasing offers of fluid, free-water protocols, and use on non-oral supplementary fluid. Specific to increasing opportunities offering fluids, Robinson and Rosher (2002) demonstrated the effectiveness of a hydration program, a beverage cart, in a skilled nursing facility; increasing patient hydration and number of bowel movements, and decreasing the use of laxatives and patient fall incidents.

For patients who have expressed concerns surrounding compliance, professionals can provide education on the consequences of non-compliance (i.e., silent aspiration, potential pneumonia) to ensure patients are making an informed decision. (Gonazalez-Fernandez & Daniels, 2008). Karagiannis and Karagiannis (2014) demonstrate free thin-water access (Frazier Rehabilitation Center free water protocol), while consuming thickened liquids, improved patient hydration and significantly increased quality of life.

Social Factors.

Based on participant responses to social questions, the categories of ***social settings*** and ***social partners*** were identified. Participant responses in these categories related to degrees of difficulty for social participation, specific to contextual factors: social settings and communication/social partners. The largest percentage (41%; n = 17) of respondents in this category noted drinking thickened liquids would not impact their social participation specific to the social setting; suggesting thickened liquid consumption does not limit the social participation of adults ages 60 years and older. However, professionals should recognize that less than half of the respondents (34%; n = 14) noted thickened liquid consumption would significantly or minimally impact their social participation. Similarly, Farri and colleagues (2007) surveyed the quality of life of participant, between 40-80 years of age, who had undergone surgeries which resulted in dysphagia. A majority of participants self-reported an active-social life, prior to onset of dysphagia, resulting in emotional fragility, decrease in self-esteem, limitations to social relationships, and tendency for isolation after onset of dysphagia. Professionals working with individuals with dysphagia will need to provide resources to support social participation, which may include, but are not limited to self-advocacy and support groups.

Daily Life Factors.

Based on responses to the daily life factors question, the categories ***routine factors*** and ***convenience factors*** were identified. In the ***routine factors*** category, participants made judgements about the degree to which their daily routine would be effected. A majority (61% of category; n = 14) stated thickened liquid consumption would have no effect on their routine. Seventy-one percent (n = 30) of participants were past the average retirement age of 62.9 (Munnell, 2015). Therefore, it can be hypothesized thickened liquid consumption would be less likely to affect the routine of participants, due to the flexible nature of retirement. Professionals should identify patients, pre-retirement, who are consuming thickened liquids and provide appropriate supports/resources if a significant impact on routine is suspected; including planning preparation of thickened liquids and information on commercially prepared thickeners. Lee and Newman (2003) identified a less significant impact on work (approximately 41%), for individuals with Celiac Disease, than other factors such as dining out and travel, although identified as a factor. Within the ***convenience factors*** category, participants made statements related to the inconvenience of consuming thickened liquids. Similarly, reduced ease of access to gluten-free products was identified by Lee and Newman (2003) and Zarkadas and colleagues (2006). In the current study, preparation and availability of thickened liquids were identified as the main barriers to convenience. Specific to preparation, professionals should account for the cognitive functioning of the person preparing thickened liquid (i.e., patient or caregiver). When appropriate, demonstrations on thickening procedures should be employed to ensure correct viscosity of liquid. Specific to availability, patients and caregivers should be educated on where to obtain thickened liquids. Commercial thickening agents are less readily available than gluten free foods, which can be found in many grocery stores. Further, pre-thickened liquids are even more difficult to access and often must be purchased in bulk. While educating, professionals should be sensitive to socio-economic status and access to transportation; providing resources that offer discounted supplements, such as *The Aging and Disability Resource Center* (Wisconsin Department of Health Services, 2017) and information on public transportation. To the investigator's knowledge, this is the first study to report barriers to daily life factors (routine and convenience) related to thickened liquid consumption.

Enjoyment Factors.

This theme was created based off responses to the enjoyment question. Three categories were identified, including: ***enjoyment changes, enjoyment dependent upon other factors,*** and ***ambiguous.*** Within the ***enjoyment changes*** category, an overwhelming majority (79%; n = 23) of participants reported a decrease in beverage enjoyment due to it being thickened. Professionals should help patients identify beverages, specific to individual preferences, which are most appealing when thickened. In doing so, clinicians are able to support a basic level of beverage enjoyment, potentially contributing to quality of life factors. Within the category, ***enjoyment dependent upon other factors***, participants made statements on enjoyment related to taste and method of intake. Specific to taste, participants noted if the addition of the thickener distorted the taste of the beverage, enjoyment would decrease. Additional research on rheological characteristics of thickeners should be conducted to further clarify perceptions of taste change due to addition of thickener. Clinician and patient could co-identify typical beverages that meet viscosity requirements (i.e., naturally nectar-thick juices; yogurt-juices, etc.) which have the potential to better support their enjoyment of said beverage. Specific to method of intake, participants statements which referenced a change in enjoyment specific to the utensil used to consume (e.g., spoon, straw, cup, etc.). Clinicians should explore patient's preferred method of intake when serving thickened liquids to support increased enjoyment. Additionally, future research should be conducted on method of intake to identify major themes among utensil used, beverage type, and enjoyment ratings. To the investigator's knowledge, this is the first study to report barriers to enjoyment as a result of thickened liquid consumption.

Types of Beverages.

General Beverages: Frequency counts related to beverages preference (see table 16) can be used as general, thickened-liquid preference assumptions. Seventy-five percent of oropharyngeal dysphagia cases have a neurological cause; which can include but are not limited to stroke, dementia, Parkinson's disease, Amyotrophic Lateral Sclerosis (ALS), traumatic brain injury (TBI), multiple sclerosis, cerebral palsy, and neuromuscular disorders (White, O'Rourke, Ong, Cordato, & Chan, 2008; Gonazalez-Fernandez &

Daniels, 2008; Leonard & Kendall, 2014; White et al., 2008). Concomitant changes to speech, language, and cognition are also common for individuals with dysphagia. Data on general, thickened liquid preferences may be useful in contexts where patients are unable to effectively communicate their beverage preferences. By having a base knowledge of what types of thickened beverages adults without dysphagia prefer (i.e., juices, etc.), clinicians can provide better options for patients consuming thickened liquids.

Alcoholic Beverages: Approximately half of respondents (53%; n = 18) said they would not be willing to thicken alcohol. For some individuals, social activities may be associated with alcohol consumption (e.g., restaurants, etc.), which could restrict participation for an individual who needs to consume thickened liquids or reduce likelihood of compliance.

To the investigator's knowledge, this is the first study to report data on willingness to thicken beverage types and barriers to alcohol consumption as a result of consuming thickened liquids.

Limitations

One limitation of the study was the sample size. Although ratings of perception factors (i.e., taste, texture, palatability, and enjoyment) as a function of masking, in addition to ratings of anticipated compliance and quality of life as a function of duration were well-powered, a larger sample size would have allowed for increased validity.

Another limitation was that participants were individuals without dysphagia. Due to limited knowledge related to thickened liquids and dysphagia, participants may have had a difficult time making predictions on how their life would be effected as a result of dysphagia and thickened liquid consumption. However, the participant population was chosen because there is a high prevalence of dysphagia in that age group. While they did not have dysphagia at the time of this investigation, they may experience dysphagia in the future. Thus, their perceptions and perspectives on intake of thickened liquids are valuable. Another related limitation was that participants came in with different levels of knowledge related to dysphagia and thickened liquids (i.e., some knew more than others). Therefore, this could have impacted the variability in their responding to questions. One way to control for this factor would be to have had a pre-test/quiz which determined prior knowledge related to dysphagia and thickened liquid. Additionally, having participants watch a standardized informational video about swallowing disorders and thickened liquids would have allowed for more consistent responding due to equal background knowledge.

Another limitation was the use of apple juice as the presentation liquid. Participants had different degrees of enjoyment/preference related to apple juice, prior to making ratings. To further clarify, one participant could describe a "love" for apple juice; whereas another may have described "dread/loathing." This factor was difficult to account for and may have influenced their individual ratings of taste, texture, palatability, and enjoyment.

Conclusion

A variety of significant factors related to thickened liquid consumption were identified in this investigation. Those most prevalent include the significant linear and quadratic relationships between participant's anticipated compliance to consume thickened liquids and duration of thickened liquid consumption, as well as the significant relation linear relationship between participant's anticipated quality of life and duration of thickened liquid consumption. Information derived from this study provides insights into the clinical management of individuals who require thickened liquids. Results indicate prevalent factors in which to attend to and those that are not important (i.e., serving container). It is essential professionals evaluate the education they provide patients, specifically education supporting compliance. Overall and specific barriers to thickened liquids consumption were identified. Overall barriers included: compliance factors and hydration concerns. Specific barriers included social, enjoyment, and daily life factors. Medical professionals should evaluate ways to support access and reduce barriers to compliance in the community. Data related to general individual preferences for thickened beverages was compiled, and preliminary barriers related to the consumption of alcohol and relation to thickened liquids was examined. Data on general, thickened liquid preferences should be used in contexts where patients are unable to effectively communicate their beverage preferences, due to concomitant changes in speech, language, and cognition. Outcomes of qualitative and quantitative data support one another, suggesting strong triangulation. Quantitative data were supported through strong statistical power and qualitative data were derived from a rigorous, multi-coder and multi-round manual coding process.

Future research could address quality of life and enjoyment factors related to the consumption of pureed foods. Additionally, investigations on quality of life for individuals with dysphagia of: varying type, severities, etiologies, and durations of time should be examined to more specifically evaluate the individual barriers. Continued research on appearance factors related to serving and presenting thickened liquids to patients should be conducted; specifically, using neutral beverage types (i.e., water) to assess individual perception factors. Further examination of differences in compliance ratings, as a result of knowing someone with dysphagia should be investigated to further clarify the reason for this relationship.

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APPENDIX A

Perceptions Rating Scale

Dislike Extremely	1	2	3	4	5	6	7	8	9	**Like Extremely**

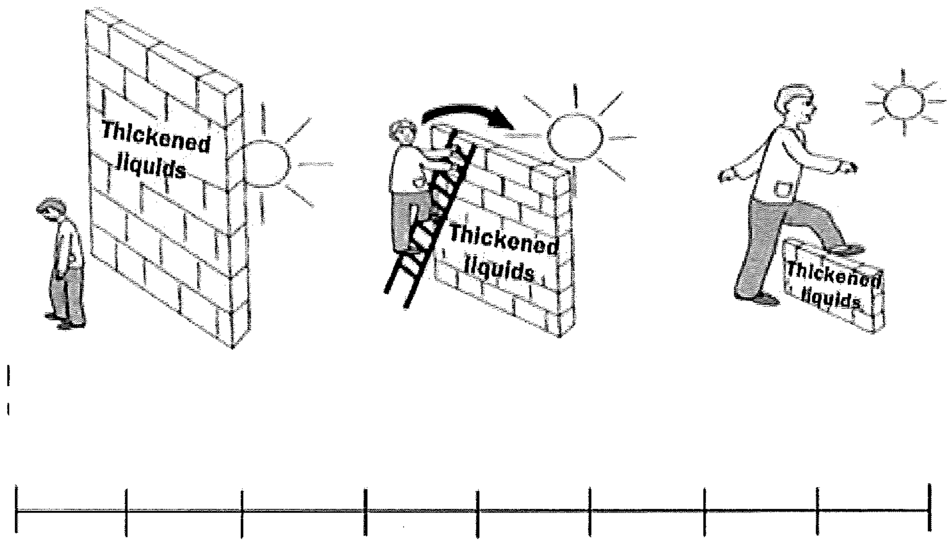
APPENDIX B

Compliance Rating Scale

Not at all Compliant	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**Extremely Compliant**

APPENDIX C

Quality of Life Rating Scale



APPENDIX D

Demographic Questionnaire

Participant #:____

Demographic Information:

Age: ________________

Gender:

- ☐ Male
- ☐ Female
- ☐ Other

Please list your current or past profession/career:

____

Do you currently or have you ever worked as a:

Certified Nursing Assistant (CNA)?

- ☐ Yes
- ☐ No

Registered Nurse (RN)?

- ☐ Yes
- ☐ No

Occupational Therapist (OT)?

- ☐ Yes
- ☐ No

Dietician/Nutritionist?

- ☐ Yes
- ☐ No

Speech Language Pathologist (SLP)?

- ☐ Yes
- ☐ No

Do you have swallowing difficulties, a diagnosis of dysphagia?

- ☐ Yes
- ☐ No

Do you know someone (e.g., family, friend, etc.) with swallowing difficulties or a diagnosis of dysphagia?

☐ Yes
☐ No

Do you currently use tobacco products?

☐ Yes
☐ No

*If yes, please list quantity and frequency of consumed product, per day:

____

Did you use tobacco products previously?

☐ Yes
☐ No

*If yes, please list the duration you consumed the product (i.e. 1 year, 5 years, etc.):

____

____

______

Health Conditions:

Do you have or have you had any of the following?

☐ Head Injuries
☐ Asthma
☐ Allergies
☐ Vision difficulties (Do you wear glasses? Yes ☐ No ☐)
☐ Hearing difficulties (Do you wear hearing aids? Yes ☐ No ☐)
☐ Diabetes
☐ Pneumonia
☐ Heart Trouble
☐ High or low blood pressure
☐ Stroke
☐ Recent or unplanned weight loss
☐ Cancer (If so, please list type and how it was treated:
___________________________)
☐ Other:
____

Eating & Related Habits:

Please estimate your consumption of liquid intake per day: (note: 8 oz. = 1 cup)

☐ Less than 16 oz.
☐ 17 oz. – 36 oz.

- ☐ 37 oz. – 52 oz.
- ☐ 53 oz. -68 oz.
- ☐ 69 oz. +

Do you have dentures?

- ☐ Yes
- ☐ No

*If yes:

Do you have a(n):

- ☐ Upper Denture
- ☐ Lower Denture
- ☐ Both

How would you rate your degree of oral dryness?

Extremely Dry	*Somewhat Dry*	*A Little Dry*	*Not Dry at All*
☐	☐	☐	☐

How often do you brush your teeth/ clean your dentures per day?

- ☐ 0
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 3+

Please list any food allergies you have:

____

____

APPENDIX E

Response Template to Participant Emails- Version 1

Hello _______________,

Dr. Jerry Hoepner and Jill Utz, a graduate student in the Department of Communication Sciences and Disorders at the University of Wisconsin- Eau Claire are conducting a study exploring the perceptions of individuals consuming thickened-liquids, as related to appearance, compliance, and quality of life factors. The primary purpose of this research is to improve the quality of life of individuals effected by swallowing disorders.

You are invited to participate in this study if you are 60 years of age or older. We are examining the preferences, perceptions, compliance ratings, and quality of life ratings of individuals consuming thickened liquids. While you receive no direct benefits, research outcomes may guide future clinical practices and future research studies in the area of swallowing disorders/dysphagia.

If you agree to participate, a research investigator will meet with you at the UW-Eau Claire's Center for Communication Disorders Clinic or a community location. Upon meeting, you will be asked to fill out a questionnaire which overviews basic demographic information (i.e., age, gender, food allergies, etc.). Afterwards, you will be asked to taste and rate a thickened liquid, often used in the treatment of individuals with swallowing disorders. Additionally, you will be asked to estimate your perceived compliance and quality of life based on a hypothetical scenario in which you are asked to consume thickened liquids for a specific duration of time. Lastly, you will be asked to answer an interview question related to the impact consuming thickened liquids would have on your life. This process will last approximately 15-30 minutes. It will be audio recorded for later data analyses.

Your participation is entirely voluntary. If you agree to participate, you may choose to not answer any given questions, and you may withdraw your consent and discontinue your participation at any time. Your identity will be kept confidential. Transcripts of your interviews will be de-identified and associated with a number. Only the investigators will be aware of your identity. All audiotapes and forms will be kept in a secure place. If data from this study are presented or published, it will be as group data; your identity will not be divulged in any way.

If you have any additional questions about the purpose of this research, contact Dr. Jerry Hoepner, Department of Communication Sciences and Disorders, HSS 117 University of Wisconsin- Eau Claire, Eau Claire WI 54702, telephone 715-836-3980.

If you have any questions about the treatment of human subjects in this study you may call or write Dr. Michael Axelrod, Chair, Institutional Review Board for the Protection of Human Subjects, Schofield 17, University of Wisconsin- Eau Claire, WI 54702, telephone 715-836-2373.

Sincerely,

Jill Utz, B.S.
Student Researcher
Graduate Student Clinician
University of Wisconsin- Eau Claire
utzjl@uwec.edu

APPENDIX F

Response Template to Participant Emails- Version 2

Hello _________________,

Thank you for your interest in this study. We appreciate your involvement.

I would be happy to set up a time to meet with you to participate in the study. Options for meeting places include: The Center for Communication Disorders, 239 Water St # 113, Eau Claire, WI 54703, or a community location.

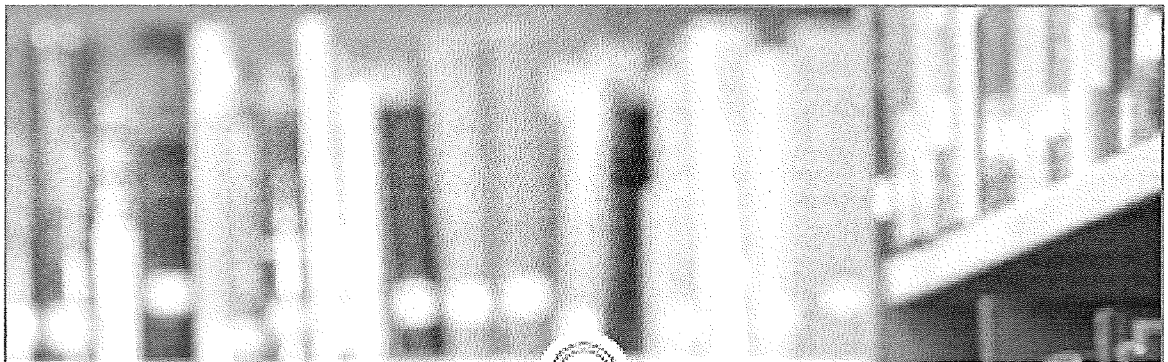
Please let me know your preference for meeting location and your available dates and times for the meeting.

Sincerely,

Jill Utz, B.S.
Student Researcher
Graduate Student Clinician
University of Wisconsin- Eau Claire
utzjl@uwec.edu

APPENDIX G

Recruitment Flier



Research Participant Opportunity

Are you 60 years of age or older?

Are you looking to participate in a research opportunity that will potentially improve the lives of individuals effected by swallowing disorders?

If you answered yes to these questions, you are invited to participate in this study. Dr. Jerry Hoepner and Jill Utz, a graduate student in the Department of Communication Sciences and Disorders at the University of Wisconsin- Eau Claire are conducting a study exploring the perceptions of individuals consuming thickened-liquids, as related to appearance, compliance, and quality of life factors. The primary purpose of this research is to improve the quality of life of individuals effected by swallowing disorders.

We are examining the preferences, perceptions, compliance ratings, and quality of life ratings of individuals consuming thickened liquids. While you receive no direct benefits, research outcomes may guide future clinical practices and future research studies in the area of swallowing disorders/ dysphagia.

If you have any questions about the purpose of this research, contact: Dr. Jerry Hoepner
Department of Communication Sciences and Disorders
715-836-[illegible]
HSS [illegible]
University of Wisconsin- Eau Claire

Phone: 715-836-4186
E-mail: UTZJL@uwec.edu

Jill Utz
Phone: 715-836-4186
E-mail: UTZJL@uwec.edu

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Phone: 715-836-4186
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Jill Utz
Phone: 715-836-4186
E-mail: UTZJL@uwec.edu

APPENDIX H

Consent Form

Title of Investigation: Anticipated compliance and quality of life measures for individuals consuming thickened liquids: Perceptions of taste, texture, palatability, and enjoyment given beverage appearance.

Name of the Principal Investigator: Jill Utz

This document is to certify that I, ________________________________, hereby freely agree to participate as a volunteer in a research study as an authorized part of the educational and research program of the University of Wisconsin- Eau Claire under the supervision of Dr. Jerry Hoepner.

- The research project has been fully explained to me by ______________, and I understand this explanation, including what I will be asked to do. A copy of the procedures of this investigation and a description of any risks, discomforts and benefits associated with my participation has been provided and discussed in detail with me.
- I have been given an opportunity to ask questions, and all such questions and inquiries have been answered to my satisfaction.
- I understand that I am free to decline to answer any specific items or questions in interviews or questionnaires.
- I understand that all data will remain confidential with regard to my identity.
- I understand that the risks of this study are equal to or less than the everyday risks of potential aspiration or choking in a community environment.
- I certify that to the best of my knowledge, I have no physical or mental illness or weakness that would increase the risk during participation in this investigation.
- I understand that participation in this research project is voluntary and not a requirement or a condition for being the recipient of benefits or services from the University of Wisconsin-Eau Claire or any other organization sponsoring the research project.
- I understand that the approximate length of time required for participation in this research project is 15-30 minutes.

- I understand that if I have any questions concerning the purposes or the procedures associated with this research project, I my call or write:

  Jill Utz

  105 Garfield Avenue, 715.836-4186, UTZJL@uwec.edu

  Dr. Jerry Hoepner, Department of Communications Sciences and Disorders, HSS 117, University of Wisconsin- Eau Claire, WI 54702, telephone 715-836-3980.

- I understand that it will not be necessary to reveal my name in order to obtain additional information about this research project from the principal investigator(s).

- I understand that if I have any questions or concerns about the treatment of human subjects in this study, I may call or write:

  Dr. Michael Axelrod, Chair

  Institutional Review Board for Protection of Human Subjects

  Schofield 17

  University of Wisconsin Eau Claire

  Eau Claire, Wisconsin 54702

  Telephone: 715-836-2373

  Although this person will ask my name, I understand that all inquiries will be kept in the strictest confidence.

- I UNDERSTAND THAT I AM FREE TO WITHDRAW MY CONSENT AND DISCONTINUE MY PARTICIPATION AT ANY TIME.

____ _______________

Signature of Subject Date

____ _______________

Signature of Investigator Date

APPENDIX I

Cover Letter

Prospective Research Participant:

Dr. Jerry Hoepner and Jill Utz, a graduate student in the Department of Communication Sciences and Disorders at the University of Wisconsin- Eau Claire are conducting a study exploring the perceptions of individuals consuming thickened-liquids, as related to appearance, compliance, and quality of life factors. The primary purpose of this research is to improve the quality of life of individuals effected by swallowing disorders.

You are invited to participate in this study if you are 60 years of age or older. We are examining the preferences, perceptions, compliance ratings, and quality of life ratings of individuals consuming thickened liquids. While you receive no direct benefits, research outcomes may guide future clinical practices and future research studies in the area of swallowing disorders/dysphagia.

If you agree to participate, a research investigator will meet with you at the UW-Eau Claire's Center for Communication Disorders Clinic or a community location. Upon meeting, you will be asked to fill out a questionnaire which overviews basic demographic information (i.e., age, gender, food allergies, etc.). Afterwards, you will be asked to taste and rate a thickened liquid, often used in the treatment of individuals with swallowing disorders. Additionally, you will be asked to estimate your perceived compliance and quality of life based on a hypothetical scenario in which you are asked to consume thickened liquids for a specific duration of time. Lastly, you will be asked to answer an interview question related to the impact consuming thickened liquids would have on your life. This process will last approximately 15-30 minutes. It will be audio recorded for later data analyses.

Your participation is entirely voluntary. If you agree to participate, you may choose to not answer any given questions, and you may withdraw your consent and discontinue your participation at any time. Your identity will be kept confidential. Transcripts of your interviews will be de-identified and associated with a number. Only the investigators will be aware of your identity. All audiotapes and forms will be kept in a secure place. If data from this study are presented or published, it will be as group data; your identity will not be divulged in any way.

If you have any additional questions about the purpose of this research, contact Dr. Jerry Hoepner, Department of Communication Sciences and Disorders, HSS 117 University of Wisconsin- Eau Claire, Eau Claire WI 54702, telephone 715-836-3980.

If you have any questions about the treatment of human subjects in this study you may call or write Dr. Michael Axelrod, Chair, Institutional Review Board for the Protection of Human Subjects, Schofield 17, University of Wisconsin- Eau Claire, WI 54702, telephone 715-836-2373.

Sincerely,

Jill Utz, B.S.

____

Student Researcher

APPENDIX J

General Structure of Qualitative Interviews

Examiner Prompt:	Describe the extent drinking thickened liquids would have on your life.
Participant Response:	It would affect my life a lot. I would have a hard time drinking the liquids every day. It would be hard to get enough liquids.
Examiner Prompt:	Would drinking thickened liquids restrict your likelihood to go out to different social contexts?
Participant Response:	Potentially. I think it might be embarrassing to drink the thickened liquids out in public, like at a restaurant or bar.
Examiner Prompt:	Who would you feel comfortable drinking thickened liquids in front of vs. who would you not feel comfortable drinking thickened liquids in front of?
Participant Response:	Definitely family and close friends. Beyond that, I don't think I'd be very comfortable.
Examiner Prompt:	How, if at all, would it [drinking thickened liquids] affect your daily routine?
Participant Response:	I would have to remember to plan ahead to make them. I would also have to know where you can buy them, specifically if I have to make an extra trip to get them.
Examiner Prompt:	Think about all the liquids you consume in your life. What are some that you would be willing to thicken and what are some you would not be willing to thicken?
Participant Response:	I would be willing to thicken juices, soda, and milk, but I wouldn't thicken coffee, water, or tea.
Examiner Prompt:	Would you thicken an alcoholic beverage, such as a beer or mixed drink?
Participant Response:	Potentially. I'd have to try it and see what it is like before I decide.
Examiner Prompt:	How, if at all, would thickening your liquids effect your enjoyment of the beverage?