Using Spaced Retrieval with External Aids to Improve Use of Compensatory Strategies
During Eating for Persons with Dementia

Dissertation

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Abstract

Spaced Retrieval (SR) is a memory training strategy that is used to aid persons with dementia in retaining novel information over expanding intervals of time. Spaced Retrieval has been used successfully to train persons with dementia to remember a variety of information and some researchers have successfully begun to pair this training strategy with external memory aids to provide support for persons with dementia when there is difficulty learning with verbal cues only. One application of SR that continues to have little support in the literature is the use of SR in persons with dementia with a coexisting dysphagia. The development of SR to train persons with dementia has proven to be very successful and fortunately, the strategy is easily implemented in the clinical setting and is low cost. Its use can help to maintain independent functioning, thereby improving quality of life for persons with cognitive impairments.

In this study SR and an external memory aid were used to teach five nursing home residents diagnosed with dementia and a coexisting dysphagia to use compensatory strategies (i.e., chin tuck, alternation of liquids and solids, lingual/finger sweep) at mealtime for oral intake. The purpose of this study was to (a) determine if SR, when paired with an external memory aid, is an effective technique to teach persons with dementia to use compensatory swallowing strategies; and (b) to learn if SLPs naïve to the study aims would judge post-training sessions as improved, or safer, in comparison to

baseline sessions; thereby validating the changes due to SR training to use external aids during meals.

Results indicated there was a treatment effect of SR training with the use of a visual aid for two to three behaviors for each of five participants. These study outcomes paired with social validation ratings demonstrated that persons with dementia could learn compensatory swallowing behaviors for safety during oral intake.

Dedication

I dedicate this work to my parents John R. and Wendy Benigas. Their love, encouragement and support throughout my education have not gone unnoticed.

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First and foremost, I would like to praise God for providing me the opportunity to grow and for granting me with a strong will to persevere to the finish line. I would like to thank my husband, Jonathan W. Hunt, who met me only several weeks into my doctoral program. He supported me, kept me from taking everything too seriously and loved me throughout the craziness of the entire adventure.

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Chapter 1: Introduction

Clinicians treating persons with dementia have often found the treatment of self-feeding, or eating, and swallowing disorders to be a challenge. Maintaining the respiratory health, in addition to nutritional and hydration needs of the person are a high priority to decrease the potential for additional medical concerns and further cognitive deficits. Studies exploring eating and swallowing impairments in persons with dementia have primarily been conducted within institutional settings (Priefer & Robbins, 1997). Turley and Cohen (2009) have reported that more than 51% of long-term care residents are affected by dysphagia. Changes in liquid volume and viscosity and modification of food have been the most commonly practiced treatments for nursing home residents with dementia (Groher & McKaig, 1995). Environmental changes to improve oral intake of persons with dementia have also been shown to be effective (Brush, Meehan & Calkins, 2002; Calkins & Brush, 2003; Roberts & Durnbaugh, 2002). Studies specifically addressing non-nursing home populations with dementia are very limited in regards to effective treatments that may differ from the ones used in skilled nursing facilities. Treatments addressing swallowing deficits for other populations without memory and cognition impairments, such as people with Parkinson's disease, head and neck cancer or who have suffered a stroke, provide strong data that support rehabilitation or the use of

compensatory efforts (Logemann et al., 2009; Robbins et al., 2005; Robbins et al., 2007; Welch, Logemann, Rademaker, & Kahrilas, 1993). Nevertheless, studies yielding similar results for persons with dementia are fewer in number because such treatments are difficult to apply due to memory and cognition impairments of persons with dementia. Evidence for treatment options to avoid modification of liquid and food is lacking for persons with dementia and a coexisting dysphagia in all settings. The purpose of this study was to evaluate an effective treatment approach for eating and swallowing problems of persons with dementia.

Dementia

Dementia is a progressive deterioration of cognitive abilities and functional impairments, which impacts behavior, personality, and physical and sensory functioning (Grand, Caspar & MacDonald, 2011). The behavioral symptoms required for a dementia diagnosis include (a) memory impairment and related changes in another cognitive domain such as language, abstract thinking, judgment, or executive functioning, that are; (b) sufficiently severe to cause impairment in social and occupational functioning and that reflect; (c) a decline from a previously higher level of functioning (*DSM-IV*; American Psychiatric Association, 1994). A progressive decline in these three criteria over time result in a range of problems including word finding, problem solving, reasoning, participation in activities of daily living, social isolation and problems related to eating and swallowing. The types of problems with eating behaviors seen over the progressive decline of dementia include memory (cognitive) problems such as difficulty following a recipe to prepare food in initial stages, progressing to difficulty with social

conversation during mealtime or forgetting to eat altogether. In later stages sensory, cognitive and motor deficits appear as a person may lose the ability to automatically accept a bolus, which is a small rounded amount of food, from a utensil or may not be able to detect food in the oral cavity making chewing and swallowing more difficult and increasing the risk of choking or aspirating. These changes in eating behaviors require an intervention that addresses the sensory, cognitive and motor changes of the person with dementia.

Impairments in the autonomic nervous system (ANS), which cause involuntary reactions, may also impact swallowing because the pharyngeal and esophageal stages of swallowing are coordinated by the ANS. Disruptions in these phases can result in an impaired or absent swallow reflex or difficulty in movement of the bolus from the pharynx to the stomach either from a lack of salivation or from impaired involuntary muscle control. Walsh and Unwin (2011) reported that autonomic dysfunction is most commonly found in dementia with Lewy bodies (DLB) and Parkinson's with dementia with approximately 62% of patients with DLB experiencing significant autonomic failure.

Cognition: Memory

The main characteristics of dementia, memory loss and cognitive impairment, underlies many of the concerns that arise during eating and swallowing. Memory impairments have been described as difficulties with (a) encoding and registering information, or new learning; (b) storing information; (c) accessing and retrieving the information (Aggarwal, Wilson, Beck, Bienias, Bennett, 2005). The most typical

memory problems of persons with dementia include difficulties learning new information; this is required for perceiving the environment through the senses, understanding the information and then encoding the information for storage and retrieval. Subtle signs of difficulty with memory and cognition appear in the early stages of dementia. Short-term memory deficits cause forgetfulness and possible decline in socialization; problems with retrieval from long-term memory cause difficulty with word finding. Because of new learning problems, people with dementia may not be able to learn and recall compensatory swallowing strategies if eating or swallowing problems develop (Morris, 1994; Neath & Surprenant, 2003). As dementia progresses, increasing problems with encoding and retrieval occur making it difficult to understand language and to use language to communicate and negative behaviors may result from these impairments. In later stages deficits in sensory memory make recognition (e.g. food, cups, utensils, smells) difficult.

While it is understood that memory impairments result from dementia, it is the decline in these specific cognitive skills that explains why eating and swallowing issues are also impacted. Information related to eating is first received through the sensory system (i.e., visual, auditory, tactile, gustatory, olfactory) in what is referred to as sensory memory. The information is briefly held and can be processed, or encoded, for future use. Deficiencies in the sensory system, such as visual acuity changes, may impact the person's ability to recognize that food has been presented; tactile changes may affect the detection of material pocketed in the buccal cavities; and auditory changes may make listening to mealtime partners when eating in a noisy dining hall difficult. If recognition

happens (e.g., the person sees the food on the utensil), the information is processed in working memory where the information is stored temporarily and manipulated for complex tasks such as comprehension, reasoning and new learning (Baddeley, 2000). Working memory is controlled by the central executive system comprised of three subsidiary systems, referred to as slave systems (see Figure 1). The visuo-spatial sketchpad manipulates and temporarily stores the visual and spatial information and images. The phonological loop is the process of rehearsing and understanding auditory information. Finally the episodic buffer combines the visual, spatial and verbal information into episodes and links the episodes to the central executive system in order to respond appropriately, or to move them to long-term memory. Information in the working memory must either be used immediately or moved to long-term memory (Baddeley, 2000).

The long-term memory involves retrieval processes and permanent storage of unlimited information. This storage is divided into several systems and subsystems. Explicit declarative memory (i.e., semantic, episodic, autobiographical) involves the conscious, verbal and intentional recall of specific past experiences or information and words (Neath & Surprenant, 2003). Implicit non-declarative memory (i.e., emotional, procedural) is described as unconscious and nonverbal and involves encoding new information and specific memories for step-by-step procedures or emotions. This is demonstrated, for example, as the ability to carry out the procedure of eating. People without cognitive deficits eat without conscious awareness or specific instructions to do

any of the movements; food is chewed (repeated movement of the jaw and tongue) and then swallowed (movement of the tongue).

Figure 1. Baddeley's Central Executive Model.

Note. Reprinted from "The Episodic Buffer: A New Component of Working Memory," by A. Baddeley, 2000, *Trends in Cognitive Sciences*, 4(11), p. 417. Copyright 2000 by Elsevier. Reprinted with permission.

Information of past experiences (e.g., multiple episodes of eating over one's lifetime) is retrieved without conscious cognitive effort or recall of a specific learned event (Neath & Surprenant, 2003). This type of memory, procedural memory, includes tasks such as taking a drink when a cup is present or accepting food into the mouth when a bolus is presented on a utensil. Problems with eating can occur when procedural memory is not triggered by sensory cues. For example, Zgoloa and Bordillon (2002) described these

problems as lack of recognition of the environment (e.g., sensory cues associated recognizing the dining room, or the plate and utensils), difficulty remembering to eat (e.g., sensory cues associated with smelling the food), and difficulty making food choices or misrecognition of food (e.g., visual characteristics of the food). In addition, attention deficits may make it difficult to stay seated or to self-feed because of sensory distractions in the environment (e.g., people talking or walking) (Bourgeois & Hickey, 2009).

Sensory deficits contribute to changes in eating behaviors of persons with dementia over the course of their decline. The person's ability to use their senses to recognize an environmental cue is often less impaired in the early stages of dementia and gradually becomes more problematic in later stages. When eating in an unfamiliar dining area, visual cues may not prompt eating, but instead become a distraction. Loud noises and multiple conversations may overload by providing too much stimulation to the auditory system and cause additional distractions from eating (Burton & Torrington, 2007; Calkins & Brush, 2003). Poor presentation of food and disruption of the person's dining routine may all impact a person's oral intake (Roberts & Durnbaugh, 2002). Finally, increased lighting, proper ventilation (Brush, Meehan and Calkins, 2002) and use of contrast enhancement, such as a red tablecloth with white dishes (Brush, Fleder, & Calkins, 2012; Dunne et al., 2004) also contribute to environmental factors important for a good dining experience.

Secondly, sensory deficits may also disrupt the behavior of swallowing. Sensory information is organized and processed through the interaction between the central nervous system (CNS) and the peripheral nervous system (PNS) to produce an

appropriate motor or movement response for successful eating and swallowing. The changes and damage in the CNS or PNS and brain due to dementia may impact either the sensory functions, motor functions, or both that are necessary for swallowing. The resulting symptoms may not be uniform across each person. Six cranial nerves provide innervation for swallowing, each with a motor component or motor and sensory component. The trigeminal nerve (CN V) innervates muscles of mastication (temporalis, masseter, medial, and lateral pterygoid), that which tenses the velum (tensor veli palatine) and assists in laryngeal elevation and excursion. Sensory information and feedback is carried, with the exception of taste. The facial nerve (CN VII) innervates lip and cheek muscles (orbicularis oris, zygomaticus, buccinator) and carries sensory information about taste from the anterior 2/3 of the tongue. The glossopharyngeal nerve (CN IX) innervates the three salivary glands in the mouth, which contributes to bolus formation; the muscle responsible for laryngeal elevation and excursion (stylopharyngeus), mediates sensation from the posterior 1/3 of the tongue and carries sensation from the velum and superior portion of the pharynx. The vagus nerve (CN X) innervates muscles that raise the velum (glossopalatine and levator veli palatine), pharyngeal constrictor muscles, muscles of the larynx, cricopharyngeus muscle and muscles involved in the esophageal stage and respiration. Sensory information is carried from the velum and posterior and inferior portions of the pharynx and is mediated in the larynx. The spinal accessory nerve (CN XI) innervates the muscles, which depress and tense the velum and constricts the pharynx (palatopharyngeus and muscularis uvula). No sensory components are found in this nerve. Finally, the hypoglossal nerve (CN XII) innervates all extrinsic and intrinsic

tongue muscles. No sensory components are found in this nerve (Churney, 1994; Logemann, 1998).

Damage to the cranial nerves may impact the oral preparatory and oral stages when the CNS is not triggered to recognize the presence of the bolus. When the CNS fails to initiate the neuromuscular events needed for swallowing, due to the lack of constant sensory feedback, motor deficits such as difficulty with manipulation of the bolus, ability to maintain the bolus in the oral cavity, difficulty with or absence of mastication, propulsion of the bolus, and clearance of stasis in the oral and pharyngeal cavities ensue. Additionally, CNS damage can impact nonvolitional reflexes such as elevation of the velum, airway closure, pharyngeal transport of the bolus and relaxation of the upper esophageal sphincter. In advanced stages of dementia, further deterioration of the CNS may cause a reappearance of primitive reflexes, such as rooting and sucking. Reappearance is most commonly seen in DLB and Alzheimer's disease (AD) with cardiovascular disease (Links, Merims, Binns, Freedman, & Chow, 2010). Sensory and motor loss cannot be reversed when a degenerative disease in the CNS, such as AD, causes loss. Therefore, sensory approaches to treatment may be ineffective and other options should be considered, such as a cognitive learning approach.

Dysphagia Treatment Approaches

Cognitive deficits associated with dementia contribute to difficulty with implementing compensatory strategies because of difficulty with memory processes associated with understanding and learning the strategies. The treatment objectives of the speech-language pathologist (SLP) should be to identify memory strategies to assist in

treatment and management of the eating or swallowing disorder as the dementia disease progresses. The Medicare National Coverage Determinations Manual (2011) directs that treatment by an SLP is intended to “design all programs to ensure swallowing safety of the participant during oral feedings and maintain adequate nutrition” (p. 4). Therapy programs may be designed to provide direct treatment involving the presentation of food and liquid or indirect treatment involving exercise programs without the use of food or liquid to address and manage the environmental factors, and the sensory, motor and cognitive deficits present. Evidence-based treatments exist to address such needs including environmental (Brush, Meehan & Calkins, 2002; Calkins & Brush, 2003; Hellen, 2002; Roberts & Durnbaugh, 2002), sensory (Lazarus et al. 1993; Morris & Volicer, 2001), motor (Robbins et al. 2005; Robbins et al. 2007) and cognitive treatments (Brush & Camp, 1998b; Roberts & Durnbaugh, 2002; Hellen, 2002).

Environmental and sensory treatments. Many adaptations and strategies to adjust the dining environment have been recommended to meet the needs of persons with dementia and have been shown effective (Abbott et al., 2013). Therefore, clinicians treating this population who demonstrate mealtime difficulties beyond the oropharyngeal dysphagia have been using their clinical expertise to meet the needs of each patient who may each present with a unique set of symptoms.

Modifying the environmental factors to change the atmosphere for a better eating experience and to simultaneously address sensory needs will help to stimulate the senses and elicit procedural memories. Brush, Meehan and Calkins (2002) found that persons with dementia ate more and exhibited fewer problem behaviors during mealtimes when

visual barriers in the dining environment were improved such as increased lighting, controlled glare and improved contrast of the table and food served. Therefore, to promote appropriate oral intake and support independence, Brush and colleagues recommended increasing the visual salience with recommended lighting levels for the activity and presenting visually appealing meals with use of contrasting colors between the foods, plates, placemats and tablecloth. Several studies have shown that oral intake improves with the elimination of visual distractions (nonfood items) from the tables and elimination of auditory distractions in the dining environment such as TV, loud music and conversations between staff members (Calkins & Brush, 2003; Hellen, 2002; Roberts & Durnbaugh, 2002). Addressing sensory (olfactory and gustatory) needs by enhancing the flavors of food with salt, spices, sweeteners, butter and sauces or adding supplements and offering enhanced shakes as snacks has also been shown to improve oral intake (Morris & Volicer, 2001). Simmons and Schnelle (2003) have asserted that overeating should be limited throughout the day, with smaller meals and snacks and hydration breaks. In end stage dementia comfort trays that include a selection of liquids, Jell-O, ice cream or other easily eaten foods the person with dementia may still accept (Bourgeois & Hickey, 2009) may trigger implicit memories of pleasure and other positive emotions.

Directly addressing the sensory needs of persons with dementia by varying sensory input may also improve the motor responses and behaviors needed for eating and swallowing. Heightening sensation in the oral and pharyngeal areas may trigger awareness of the bolus. Changing the bolus characteristics by modifying the volume, viscosity and taste may trigger procedural memory for motor behaviors that alter timing,

strength and extent of muscle activity. Stimulation of oral and pharyngeal structures with thermal, tactile, gustatory and electrical stimulation have been used to modify motor responses, such as reducing the delays in the onset of swallow initiation (Bisch, Logemann, Rademaker, Kahrilas, & Lazarus, 1994; Logemann et al., 1995; Logemann, 1998; Wijting & Freed, 2010). For example, modification of liquid volume and viscosity may make liquid easier to swallow by slowing down the speed of flow of the bolus and may also contribute to heightening sensory awareness (Logemann, 1998). Jacob, Kahrilas, Logemann, Shah, and Va (1989) and Logemann et al. (1992) found that in normal swallow physiology the duration of airway closure and cricopharyngeal opening increase significantly as bolus volume increases and tongue base movement begins significantly later as volume increases. Lazarus et al. (1993) reported that as viscosity increases, longer oral transit times, longer cricopharyngeal opening, duration, and improved oropharyngeal swallow efficiency occurred. Increasing viscosity, or thickening liquids, to compensate for aspiration has become commonplace to help increase safety while drinking (Castellanos, Butler, Gluch, & Burke, 2004). Previously, very little data had existed addressing the efficacy of this method until recently (Logemann et al., 2008; Robbins et al., 2008). Robbins et al. (2008) and Logemann et al. (2008) conducted a randomized, controlled, parallel-design study that compared the effectiveness of chin-down posture, nectar and honey thick consistencies of thickened liquids on the immediate prevention of and three-month cumulative incidence of pneumonia in persons with dementia or Parkinson's disease. Participants aged 50 or older (N = 515) who aspirated thin liquids under videofluoroscopy were examined immediately, randomly assigned to

one of three treatment groups and followed for three months, or until development of pneumonia or until death. Results of Logemann et al. (2008) (Part I) showed that significantly more participants aspirated thin liquids with the chin-down posture than with use of nectar or honey-thick liquid. Likewise, significantly more participants aspirated with nectar-thick liquid than with honey-thick liquid. Overall, more than 50% of the participants with dementia, with or without Parkinson's disease, aspirated on all three interventions. Participants were then randomly assigned to one of three conditions (a) drink all liquids in a chin-down posture (N=259); (b) drink nectar-thick liquid in a head-neutral position (N = 133); and (c) drink honey-thick liquid in a head-neutral position over the next three months (N=123). At the conclusion of the study (Part II), a 3-month cumulative incidence of aspiration pneumonia was 11%, with no significant differences between the groups. However, more participants assigned to the thickened liquids than those assigned to chin-down posture had dehydration, urinary tract infection and fever. Median hospital stay due to pneumonia for participants using honey-thick liquid was 18 days, for participants using the chin-down posture was six days, and for participants using nectar-thick liquid was four days. Overall, no definitive conclusions about the superiority of any of the tested interventions were made; however, the authors encourage clinicians to question the recommendation of very thick liquids without evaluation of all other treatment options.

Little evidence exists for the effects of taste on swallowing (Robbins et al., 2008); however, the presentation of a sour bolus is thought to stimulate the pre-swallow sensory receptors, which alerts the nervous system producing a stronger and faster swallow

(Logemann et al., 1995). Research by Logemann et al. (1995) examined the effects of a sour bolus (50% lemon juice, 50% barium liquid) on pharyngeal swallow measures in two groups of participants with neurogenic dysphagia. While none of the participants were diagnosed with dementia, group one had suffered at least one stroke and group two suffered other neurological damage. Results showed significant earlier oral onset of the swallow for both groups, a significant reduction in pharyngeal swallow delay in group one and in frequency of aspiration in group two with sour when compared to non-sour boluses. There is very little evidence for the effect of temperature and tactile changes on swallowing behavior. Robbins et al. (2008) reported that temperature alone does not yield changes and that studies including the use of carbonated boluses to reducing the amount of residue and reducing aspiration have flawed methodologies calling the results into question.

Finally, neuromuscular electrical stimulation (NMES) has been explored as a means to strengthen and reeducate the muscular system and improve muscular control (Wijting & Freed, 2010). This method has most recently been applied through the neuromuscular electrical stimulation modality by use of specific electrode placement over muscles of the neck and face while traditional motor rehabilitation (e.g., instructions to swallow repeatedly, traditional head lift, or Shaker exercises), is conducted. This technique remains highly controversial because of the limited research to date and much, if not all, of the successful research published has been by the patent holders of the Vital Stimulation device being investigated. Additionally, much of the research has been completed with healthy subjects and many have methodological flaws (Clark, Lazarus,

Arvedson, Schooling, & Frymark, 2009). Wijting and Freed (2010) reviewed more than 30 published articles utilizing the Vital Stimulation modality. None included participants diagnosed with dementia; however, the authors maintain that use of Vital Stimulation with persons with dementia is not a contraindication. They advised that Vital Stimulation be used with caution as occasionally these persons exhibit non-stop verbalization, which could result in aspiration during trials of oral intake. It might be assumed that this modality is not appropriate for persons with dementia due to their confusion and behavior deficits, but further research in this area is needed to determine its potential benefits for persons with dementia.

Environmental and cognitive treatments. Environmental changes that simultaneously address cognition deficits can also help to improve oral intake. Roberts and Durnbaugh (2002) asked 16 expert nurses to identify interventions for 33 common mealtime behaviors for people with dementia. These nurses also identified structural changes needed in the dining room that would be important for quality care. Based on the data collected, an educational program and videotape were developed to train staff in two nursing homes to modify the mealtime environment to improve oral intake of food. Staff demonstrated a significant difference in mean score gains between pretest and posttest scores ($p > .05$) as a result of the training, and increased, but not significantly, the intake of foods with more nutritional value for 26 residents. Roberts and Durnbaugh (2002) identified that providing a consistent environment and seat in the dining room with small tables and chairs may improve comfort. Another positive environmental strategy was to have the meals delivered to the person's room if the person previously

dined alone. Further, they identified that packaging should be opened and food should be served with bones removed. Hellen (2002) proposed offering food choices to create a personalized approach. Such choices can be offered verbally or written on a menu with words and pictures. Cognitive deficits such as confusion, wandering, disorientation and level of alertness may impact the ability of persons with dementia to self-feed. Langmore et al. (1998) identified that self-feeding should be encouraged to reduce the risk of respiratory infection. If self-feeding is difficult, staff can sequence eating activities consistently, offering one item at a time (Gillick & Mitchell, 2002; Hellen, 2002) or by placing a cue card for each step in the eating and swallowing process in front of the person (Brush & Camp, 1998b). If the person is unable to stay seated to self-feed, or if use of utensils is difficult, a diet of finger foods that can be eaten easily and while walking around is suggested (Hellen, 2002; Jean, 1997). Finally, while no research exists to support their use, lids with cups or sports bottles can be used if spilling or pouring of the liquid from the cup frequently occurs.

Compensatory interventions, such as postural changes, may require cognitive skills to learn how to redirect the flow of the bolus through motor movements. Due to the increasing cognitive impairments over time of the person with dementia, the effects of teaching compensatory changes may only be temporary. In the Robbins et al. (2008) and Logemann et al. (2008) studies in which participants with dementia and/or Parkinson's disease were taught to use the chin-down posture, it was reported that some participants required repetition of the instructions or were assisted with gentle pressure on their head to perform the chin-down position. Participants exhibiting learning difficulties were

included only if they were able to achieve the posture following instructions (Logemann et al. 2008; Robbins et al., 2008).

Other postural changes that require cognitive skills to learn them and remember them during eating include (a) head rotation to the weaker side to redirect the flow of the bolus down the stronger side and offers increased airway closure by applying lateral pressure to the larynx (Poertner & Coleman, 1998; Rasley et al., 1993); (b) head lateral flexion to the stronger side which allows gravity to hold the bolus on stronger side of the oral cavity and pharynx (Rasley et al., 1993); (c) head/neck extension which allows gravity to assist with oral clearance, but is inappropriate for delayed pharyngeal swallow or with poor airway protection (Furia et al., 2000); and (d) lying down supine which alters the effect of gravity on pharyngeal residue and requires coughing to clear final residue before sitting back upright (Dejaeger, Pelemans, Ponette, & Vantrappen, 1994; Rasley et al., 1993). To date, there are no studies reporting the effects of training persons with dementia to utilize these compensatory strategies for safe swallowing.

Another compensatory approach is to teach airway protection compensatory maneuvers to assist in an increase in airway protection during swallowing. The maneuvers require the ability to follow sometimes-complex instructions and may not be appropriate options for persons with dementia because of their inability to learn, retain and recall new information. Each will be briefly described.

1. The supraglottic swallow closes the vocal folds before and during the swallow resulting in longer duration of airway protection. The person is instructed to

inhale before beginning the swallow, hold their breath, swallow, and then cough to clear residue (Martin, Logemann, Shaker, & Dodds, 1993).

2. The super-supraglottic swallow is very similar to the supraglottic swallow, but adds force in the sequence through performance of a Valsalva maneuver, which helps to tilt the arytenoids forward, close the false vocal folds, and close the entrance to the airway. The person is instructed to hold breath, bear down, swallow, and then cough to clear residue (Lazarus, Logemann, & Gibbons, 1993). This method is contraindicated in patients with cardiovascular disease or history of stroke (Chaudhuri et al., 2002).

3. The effortful swallow technique increases pressure in the oral cavity and at the base of tongue to reduce pharyngeal residue. Two sets of instructions are acceptable (a) swallow as hard as you can; or (b) squeeze hard with your tongue while you swallow (Hind, Nicosia, Roecker, Carnes, & Robbins, 2001).

4. The Mendelsohn maneuver maintains laryngeal elevation at its highest point, maintains longer UES opening, may decrease residue in the pharynx, and can improve overall coordination of the swallow (Kahrilas, Logemann, Krugler, & Flanagan, 1991). To complete this maneuver, Logemann (1998) advises, “Swallow your saliva several times and pay attention to your neck as you swallow. Tell me if you can feel that something lifts and lowers as you swallow. Now, this time, when you swallow and you feel something lift as you swallow, don’t let your Adam’s apple drop. Hold it up with your muscles for several seconds (pp 221-222).”

5. Masako or the tongue-hold maneuver is not recommended with the use of food during the swallow due to increased vallecular residue. This technique is believed to compensate for reduced base of tongue function by resulting in anterior bulging of the posterior pharyngeal wall and reduces laryngeal residue. The person is instructed to gently bite the anterior portion of the tongue while swallowing (Fujiu & Logemann, 1996).

6. The double swallow or multiple swallow technique may be the easiest to implement during treatment with persons with dementia because it is simple and only requires the person to perform additional swallows. Although no evidence exists to confirm their effectiveness, the use of a double or multiple swallows are common recommendations made during instrumental examinations. A verbal cue or written cue card may be needed to prompt the participant to use additional dry swallows after swallowing the bolus to clear residue from the valleculae and pyriform sinuses.

Similarly, motor exercise interventions can be done without the act of swallowing. That is, exercises to improve muscle strength range of motion, and coordination are practiced without the action of swallowing during the exercise. They are typically reserved for those who exhibit a much more severe dysphagia so they are not exposed to the risk of aspiration. Increased effort, duration and force should be considered with the implementation of these exercises, which target oral, pharyngeal, laryngeal and respiratory musculature. Comparable to motor exercises with swallowing, the ability to follow instructions is required for these exercises and may not be

appropriate options for persons with dementia. Commonly used exercises include: range of motion and tongue strengthening (Lazarus et al., 2003; Robbins et al., 2005), tongue tether (Carroll, Locher, Canon, Bohannon, McColloch, & Magnuson, 2008) respiratory-strengthening (Sapienza & Wheeler, 2006), Shaker (Shaker et al, 2002,) gargling (Veis, Logemann, & Colangelo, 2000), vocal (Sharkawi et al., 2002), and breath hold/airway closure (Martin, Logemann, Shaker, & Dodds, 1993). All listed exercises were discussed by Robbins et al. (2008) and it was determined that lingual exercises and head lifting (Shaker) demonstrated effective changes in muscular strength for swallowing in healthy elderly adults.

Lingual exercises have been shown to be beneficial in tongue strengthening but these exercises also require cognitive skills that are impaired in persons with dementia. Robbins and colleagues (2005, 2007) examined the use of an 8-week lingual resistance program with both healthy adults aged 70 to 89 and stroke participants age 51 to 90. Participants compressed an air-filled bulb between the tongue and hard palate. The training protocol required three sets of ten repetitions, three times a week with increasing effort over an 8-week period. Robbins et al. (2005) found improved lingual pressure generating capabilities, increased pressures generated during swallowing, faster achievement of peak pressures during the swallow post-training and in a few patients who underwent magnetic resonance imaging of the tongue before and after the exercise regimen, an increase in tongue volume (suggesting an alteration in muscle mass counteracting age-related sarcopenia) in healthy elderly participants. Similar results were reported in Robbins et al. (2007) as participants with history of stroke demonstrated

improved lingual pressure generating capabilities, increased pressures generated during swallowing, a significant reduction in overall oropharyngeal residue, significantly increased swallow safety, an increase in tongue volume, a significant decrease in oral transit time post-training and significantly improved quality of life and dietary outcomes. Although this evidence was generated from healthy elderly subjects and those who have suffered a stroke, generalization to the dementia population may be difficult because of their reduced ability to comprehend and follow complex directions.

Head lift, or Shaker exercises, increase hyolaryngeal elevation and targets the muscles involved in elevating the hyoid. The exercise consists of sustained and repetitive movements. The person is asked to lie flat on a bed or the floor without a pillow. First, the person lifts the head, keeping the shoulders flat on the surface, and holds for 60 seconds. Next, the person maintains the same position, but raises and lowers the head, without sustaining the movement (Shaker et al., 2002). Shaker et al. (2002) found that patients who participated in a 6-week program utilizing such exercise exhibited significant improvement in the upper esophageal sphincter opening and a resolution of aspiration after swallowing when compared to those who performed sham exercises. There are no reports in the literature of this technique being used with persons with dementia to date. It is expected that the complexity of the exercise would challenge those with cognitive limitations.

In summary, there is a great need to find effective techniques for teaching persons with dementia many of the above-described swallowing techniques that require cognitive skills. Clinicians and researchers who have explored techniques for teaching persons

with dementia a variety of behaviors unrelated to eating and swallowing have reported that an effective cognitive treatment is the use of external memory aids. Such aids help reduce the level of demand on effortful cognitive processes and self-initiation by providing visual cues to facilitate retrieval of important information. External memory aids such as memory books, written lists, and signs/labels trigger long-term and procedural memory and facilitate participation in conversation, recall of memories and independence in activities of daily living (Bourgeois, 2007).

External Memory Aids

Much research exists to support the use of memory aids for the problem behaviors of persons with dementia. Bourgeois (1990, 1992a, 1992b) first introduced the memory wallet and memory book to enhance the conversational skills for persons with dementia. These aids consisted of 30 pages formatted with a personal picture and a simple, declarative sentence. The aids were later modified to include as few as 12 pages. Bourgeois (1990) trained the caregivers of three participants with middle-stage AD to utilize memory wallets in twice-daily, five-minute conversations. Participants significantly increased the number of factual statements, made more novel comments, and decreased the number of ambiguous, erroneous and preservative utterances throughout the conversational sessions. During three-week and six-week follow-up sessions, maintenance of improved conversational performance was evident. Similarly, memory wallets were shown to have a positive effect in conversation. In Bourgeois (1992a, 1992b) participants had a range of cognitive skills and caregivers were provided with varying amounts of training in the implementation of the memory aids in once-daily

(reduced from twice-daily) conversations. Despite the withholding of training, all participants were observed to make more factual statements and some made fewer ambiguous utterances. Maintenance of such skills was shown up to 30 months for some participants.

Memory aids were then explored to facilitate improved pragmatic skills (e.g., turn taking and topic initiation). Six participants with moderate to severe dementia used their own memory aids to serve as a participant or conversational partner in five-minute conversations. Conversational quality was shown by improved topic maintenance, increased length and number of conversational turns, and decreased nonproductive utterances (Bourgeois, 1993). Bourgeois and Mason (1996) examined the use of memory wallets with staff in an adult day care setting. Volunteers were trained to develop the memory aids and four participants participated in once-daily, five-minute conversations with the volunteers. Conversational outcomes from the participants reflected those of previous studies. Meaningful interactions with volunteers were observed indicating the effectiveness of utilizing volunteers to make and implement memory wallets in adult day-care settings. Memory books, wallets and visual aids have also been successfully used in conversation between nursing home residents and nursing assistants (Hoerster, Hickey & Bourgeois, 2001), in training nursing assistants to utilize memory aids during personal care activities (Allen-Burge, Burgio, Bourgeois, Sims & Nunnikoven, 2001; Burgio et al., 2001; Bourgeois, Dijkstra, Burgio & Allen-Burge, 2001), and to modify repetitive verbalizations (Bourgeois, Burgio, Schulz, Beach & Palmer, 1997). Clinicians who used memory aids with their clients with dementia reported that they often did not remember

to use their aid; Bourgeois and colleagues investigated the addition of a training strategy, Spaced Retrieval (SR), to evaluate its effects on teaching clients to remember to use their memory aid (Bourgeois et al., 2003).

Spaced Retrieval (SR)

Camp (1989) first introduced SR as a memory training strategy for persons with dementia by modifying memory teaching procedures utilized in previous studies (Landauer & Bjork, 1978; Schacter, Rich & Stamp, 1985) by limiting the previously used multiple stimuli to just one meaningful concept. Face-name associations were taught to one person with AD in an adult day care center and challenged the belief that persons with dementia could not learn new information (Camp & Schaller, 1989). Additionally, Camp modified features of the training protocol, including the use of equally timed segments, and the addition of increasing timed segments filled with pleasurable activities (e.g. conversation, games) to prevent active rehearsal. In the initial study and subsequent replications of the study with two people with AD, it was found that the modified procedures enabled the participants to learn and retain face-name associations over relatively long time intervals (Camp, 1989).

History of the spacing effect. Researchers have hypothesized that spacing the repetitions of information being rehearsed into long retention intervals improves performance of recall (Balota, Duchek & Logan, 2007; Neath & Surprenant, 2003). The spacing effect is one principle that underlies the teaching and learning of desired information. Peterson, Wampler, Kirkpatrick, and Saltzman (1963) first observed improved recall outcomes due to spacing recall intervals in healthy adults and Glenberg

(1977) and Balota, Duchek, and Paullin (1989) replicated these effects. Expanding retrieval, a second and similar technique to the spacing effect, was first introduced in the educational setting by Spitzer (1939) and was extended by Landauer and Bjork (1978) with healthy adults. Finally, SR emerged as a way to teach individuals with dementia and has primarily been studied by Camp and colleagues (Camp, 1989).

Spitzer (1939) was the first to investigate recall and retention of novel information in the educational setting. Effects of recall on retention of facts in healthy 6th grade elementary school children in the state of Iowa (N=3605) were examined. The children were divided into nine groups to manipulate test time and number of identical tests. Two of these groups included an expanding retrieval condition separated by days. Regular classroom teachers presented the materials, students read two articles focusing on peanuts and bamboo, and then participated in a 25 question, multiple-choice test to assess knowledge. The expanded retrieval groups were compared to single test groups. Results showed that the expanded retrieval group correctly answered 53% of questions at immediate test and 43% after a 63 day retention interval compared to the single test group answering 25% questions correctly after only a 63 day retention interval.

Landauer and Bjork (1978) extended this work with healthy adults. Participants studied pairs of items on a deck of cards, such as first names with last names, and then took three or four cued recall tests in a continuous paired-associates task. Expanding and equally spaced conditions were then created with the number of trials occurring varying between study trial and repeated test. For example, participants were provided with the first name at one, four and 10 cards versus five, five, and five cards. Performance in the

expanding retrieval condition was compared to an equally spaced condition, and findings indicated that on final test, 30 minutes after the learning phase, expanding retrieval produced approximately a 10% advantage over the equally SR practice.

Use of Spaced Retrieval to support persons with dementia. The effect of expanded retrieval has been examined in persons with cognitive impairments, specifically those diagnosed with dementia. One early controversy was that as a result of encoding difficulties in persons with dementia, new learning could not occur. Yet, research documenting the effects of various modalities to assist individuals with dementia in new learning has invalidated this assumption (Bourgeois et al., 2003; Camp, 2001). As a further extension of Landauer and Bjork's (1978) work, Camp and colleagues explored the method of SR as one way to address the working memory deficit in persons with dementia. The standard protocol for SR requires an individualized, predetermined, exact question be presented for testing, with correct retention being judged as an immediate, predetermined, exact response. Upon success, the same test question is presented at expanding time intervals measured in seconds (e.g., 10s, 20s, 40s, and 60s). Once the item is recalled at 60 seconds the time is doubled with each test trial (e.g., 2-minutes, 4-minutes, 8-minutes, etc.). If the targeted response is not recalled immediately, errorless learning (Wilson, Baddeley, Evans & Shiel, 1994) is utilized by providing the person with the correct response, prompting the person to repeat it, and the time until the next test trial is reduced to the last successful time interval (Brush & Camp, 1998). Hopper et al. (2005) reviewed 15 studies, which included the use of the SR strategy with persons with dementia. The studies included participants with a range of cognitive impairment.

Participants were taught new information or behaviors and 13 of the reviewed studies reported that most participants learned some or all of the targeted information.

Maintenance was demonstrated in 12 studies and generalization in six studies. Hopper et al. (2005) outlined that the expected outcomes of SR training have been described as (a) improvement in acquisition, retention, and generalization of trained information and/or skills; (b) retention of learned information and/or skills from one day to several months following training; (c) generalization of learned information and/or skills to specific contexts and situations; and (d) no change in global cognitive functioning or general memory function as a result of training.

In earlier literature, SR was utilized to improve memory performance in four participants with cognitive impairment and memory loss due to a variety of etiologies, but not a specific diagnosis of dementia (Schacter, Rich and Stamp, 1985). Participants first studied faces and associated characteristics (e.g., names, hometowns, occupations, hobbies) and then utilizing the face cue, engaged in SR practice for the associated characteristics at expanded time intervals. Participants were provided a verbal cue to initiate SR practice. Results illustrated that memory performance for the associated characteristics improved after SR practice relative to baseline performance as measured prior to the introduction of the expanded retrieval strategy. Spaced Retrieval has also been successful with those who have aphasia (Fridriksson, Holland, Beeson & Morrow, 2005), traumatic brain injury (Bourgeois, Lenius, Turkstra & Camp, 2007) and learning disabilities (Sohlberg, 2005).

The use of SR has also been found to be a successful approach to modify behaviors in persons with dementia (Bird, 2001). Two participants with memory loss were taught new behaviors to replace undesired ones. The first participant, with mild Alzheimer's disease (AD), was exhibiting delusions, paranoia, and violence over personal items she believed were stolen. A poster was created, signed by the participant and hung in her room to remind her where her belongings were. Spaced Retrieval was implemented to remind her to look at the poster when she couldn't recall where her belongings were. Staff members of her facility were trained to cue the participant to refer to the poster when she was concerned about her lost possessions. Results showed that the participant stopped asking about her possessions, her paranoia disappeared and her violent behaviors ceased. The second participant, with hypoxic brain damage, who had a fear of soiling himself, was found to be using the restroom obsessively due to his inability to remember that he had already gone. The participant wore a beeper to prompt him to use the restroom whenever it sounded. Initially, the participant associated the beeper to mean he must not use the restroom. This association was unlearned by applying a forced choice procedure with very closely timed spaced trials and SR procedures were implemented to teach the participant the correct association. The participant's wife was trained to provide one verbal cue if needed and the participant began using the restroom once every two hours. His anxiety about toileting only reoccurred when the beeper sounded (demonstrated by rushing to the bathroom) and if he realized he was not wearing the beeper (Bird, 2001). This study is a good example of using Spaced Retrieval, paired with an external memory aid (beeper) to support the desired change in behavior. These

case studies have suggested that the use of an external memory aid, paired with SR can be applied to reach clinical goals for participant-specific clinical problems.

The effects of training the use of external memory aids with SR or another learning strategy, cuing hierarchies (CH), was compared in Bourgeois et al., (2003). Research staff identified four problem behaviors for each participant (N=25) and wrote goals for these behaviors, two of which were trained with SR and two with CH. Most of the SR goals incorporated an external memory aid (e.g., written steps, activity reminder card) in the training. The SR session followed the standard SR protocol and utilized an external memory aid, with pleasant and unrelated conversation held between intervals or the time was used for treatment of other goals unrelated to the experiment. The goal was considered mastered when the stimulus question was answered correctly at the beginning of each of three sessions with a minimum of 24-hours between each session. The cuing hierarchy sessions utilized the same introduction and expected response as in SR, however; if the participant did not respond correctly or did not respond at all a hierarchy of cues (from semantic, phonemic, visual, tactile, to imitative) was provided until the participant was able to recall the response. One-week and 4-month maintenance sessions were administered to assess retention of the learned information. Results indicated significantly more goals were attained using the SR procedure than the cuing hierarchy procedure. Additionally, SR goals were maintained longer than cued hierarchy goals at 1-week and 4-months post training.

A second controversy that has been dismissed is the assumption that new information taught would not be maintained by persons with dementia due to the

regressive nature of the disease. Abrahams and Camp (1993) trained two participants with memory impairments to name common objects via the standard SR protocol. Training proved to be successful and generalization from line drawing to actual objects was shown. Two weeks after final testing one participant was reevaluated for a change in cognitive status. The participant's *Mini Mental State Examination* (MMSE; Folstein, Folstein, & McHugh, 1975) score declined from 16 points to 10 points out of 30. Despite the decline in cognitive testing, the participant was able to recall one of the two trained items. Cherry, Hawley, Jackson and Boudreaux (2009) trained six participants with AD to recall a name-face association with the standard SR protocol. Half of the participants were provided with; 6- 12-, and 18-week booster sessions after training sessions were ended. In a 6-month follow up program a benefit was shown with the inclusion of booster sessions implying that the additional sessions helped participants to maintain the trained information. Those who did not receive booster sessions had a notable drop, but memory for trained associations was able to be reestablished through additional training in a few days. These days appear to have acted as booster sessions since at day three their performance was comparable to those who had received booster sessions at 6-, 12-, and 18-weeks. The authors noted that despite the regressive nature associated with AD, all participants demonstrated the same success at the 6-month retest as they did during the original training. These studies support that the use of SR is still useful to teach important information or strategies even though the person with dementia will regress. Efforts to improve functioning through SR training may require follow up, or booster sessions, long term, however; the new learning can be maintained.

Conceptually, there are several reasons why SR is hypothesized to be effective for persons with dementia. First, presenting learning intervals over expanding periods of time, opposed to mass practice, has proven to increase the likelihood of learning (Baddeley, 1999; Wilson, 2009). Second, opportunities for recall occur over time can be incorporated into social conversation or other therapeutic activities, allowing the practice to be more pleasant in nature (Camp, Foss, Stevens and O’Hanlon, 1996). Next, high rates of successful recalls are due to the shaping procedure that facilitates an association between the exact question and response (Camp, Foss, Stevens & O’Hanlon, 1996). Moreover, the incorporation of errorless learning contributes to the likelihood of increased long-term retention when errors are not made during practice. By eliminating the incorrect response or behavior and the opportunity to repeat it, the individual is less likely to accidentally learn it (Fridriksson, Holland, Beeson & Morrow, 2005; Turkstra & Bourgeois, 2005). Finally, SR requires very little cognitive effort on behalf of the person by utilizing the spared implicit memory, described as an unconscious form of retention (Camp, Foss, Stevens & O’Hanlon, 1996; Camp & Stevens, 1990).

Application of Spaced Retrieval to Dysphagia

Researchers from a variety of fields have effectively applied the use of SR to a wide range of skills including; face/name associations (Backman, Mantyla, & Herlitz, 1990), ability to implement an intention for future action (McKittrick, Camp & Black, 1992), object/location associations (Kotler-Cope & Camp, 1990), performance of a future action (Camp, Foss, Stevens & O’Hanlon, 1996), object naming (Abrahams & Camp, 1993), use of a strategy (Camp, Foss, O’Hanlon, & Stevens, 1996), and achievement of

speech-language therapy goals (Brush & Camp, 1998a, 1998b). One application that continues to have little support in the literature is the use of SR in persons with dementia with a coexisting dysphagia. To date, only Lin et al. (2010) and Brush and Camp (1998b) have addressed this concern.

Brush and Camp's (1998b) retrospective case study reviewed the results of one male resident of a long-term care facility who was trained to use the compensatory strategy of alternating bites of food and sips of liquid, which was recommended following a modified barium swallow study. The participant received three weekly training sessions during mealtime. An external aid of brightly colored paper, on which was written, "after you swallow your food, take a sip of liquid" was placed in front of the place setting. The participant was instructed to use the card if he could not remember, and the standard SR protocol was followed to teach the behavior. After session three the external aid was changed to say "chew, sip, swallow" and by session five, the participant no longer utilized the external aid. After 13 sessions, the participant was admitted to the hospital for one week and did not receive SR training. Upon his return, the participant remembered the need for his strategy and used it 83% of the time. At the completion of training, the resident required instruction only once during meals to use his strategy and in an 8-week follow-up he was remembering to use his strategy 95% of the time. Given the level of evidence and quality of this case study provides level III evidence. Brush and Camp (1998b) provided a more thorough explanation of the procedures utilized and examined maintenance of the learned behavior, but the study only included one participant and was retrospective.

The idea of using SR and Montessori-based activities to improve eating ability was explored by Lin et al. (2010). Baseline data addressing eating difficulty, nutritional status and intake amounts for residents with dementia in a long-term care setting (N=85) were collected through meal observation in three baseline sessions. Additionally, researchers measured intake time and assistance levels offered during meal times. Spaced Retrieval training was provided for self-feeding and swallowing behaviors, but specific methods were not described. The only trained eating behaviors mentioned and addressed were teaching the participant to recognize mealtime when Mozart music was played and to prompt the mastication of food during eating. Montessori-based activities addressed hand-eye coordination for self-feeding, scooping, pouring and squeezing. A third group (control) received no SR training or activities and followed their normal daily routine. The two treatment groups participated in three 30-40 minute weekly sessions over eight weeks. Results reported that both groups showed decreased eating difficulty and eating dependency. A significant improvement in eating ability was obtained after the SR training. Self-eating time increased in both groups when compared to the control group and eating amount showed no significant differences. Given quality of the study's design and of the reported outcomes, this case study provided only level II evidence. Lin et al. (2010) reported promising results, yet; the design and behaviors trained were very vague which does not lend itself to replication of the study. Additionally, maintenance of the trained behaviors was not addressed.

Spaced Retrieval has been shown to be an effective therapeutic technique, but more still needs to be known in its application to dementia and dysphagia. The existing

studies have provided the underpinnings for additional exploration. Therefore, a prospective study with rigorous methods and procedures is needed to evaluate the potential effects of using SR to train specific eating and swallowing behaviors.

Statement of the Problem

In previous research two treatment approaches, SR and the use of external memory aids assisted persons with dementia to learn and recall important pieces of information, but the concepts have never been combined into one treatment to address eating and swallowing in a methodical and rigorous format. In the present research, SR and the use of external memory aids were combined to teach persons with dementia new information related to eating and swallowing behaviors. These approaches help to compensate for impaired sensory, motor and cognitive functions that are characteristic of persons with dementia. The aim of this study was to determine if SR, when paired with an external memory aid, is an effective technique to teach persons with dementia to use compensatory swallowing strategies. Examples of these strategies may include alternating bites of food with sips of liquid, small bites and sips, tucking the chin or turning the head when swallowing. It is not known to extent to which persons with dementia would learn compensatory swallowing strategies using SR and an external memory aid. It is predicted, however, that given previous success of these approaches, that persons who are provided with SR training to use an external memory aid will demonstrate the trained compensatory swallowing strategies after training in comparison to baseline sessions when they will not have used the strategies. This study also sought to learn if SLPs naïve to the study aims would judge post-training sessions as improved,

or safer, in comparison to baseline sessions; thereby validating the changes due to SR training to use external aids during meals.

Chapter 2: Methods

Participants

Nine participants diagnosed with dementia with a suspected coexisting oral or oral-pharyngeal dysphagia were recruited from area nursing homes. Staff nurses were asked to identify those who were diagnosed with dementia and who had perceived or known eating and swallowing impairments. Additionally, the nursing home's speech therapy caseloads were reviewed to find participants who may qualify for the study. Once recruitment began, the investigator reviewed any resident with a dementia diagnosis who was referred for speech therapy (such as new admissions) within the building for potential recruitment. No persons who were recruited declined to enroll in the study. Eight participants were included in the study having met the following criteria (a) diagnosis of dementia, confirmed by a medical chart review and through a score of two or more standard deviations below the norm for age and education (Crum, Anthony, Bassett, & Folstein, 1993) on the *Mini-Mental State Examination* (MMSE; Folstein, Folstein, & McHugh, 1975); (b) suspected dysphagia at referral with physician willingness to order, and participant's power of attorney (POA) agreement to undergo a videofluoroscopy study for confirmation of dysphagia and recommendation for treatment including 1-3 compensatory strategies or; (c) confirmed dysphagia through a videofluoroscopy study completed no longer than 4-weeks prior to referral with recommendation for

effectiveness of 1-3 compensatory strategies; (d) willingness to participate in a meal analysis to determine additional compensatory strategies not found in the videofluoroscopy study (for a total of 2-3 compensatory strategies); (e) no prior training for the recommended strategies and consent from the participant's POA to forego any additional treatment while enrolled in the study; (f) between 65-99 years of age; (g) 6th grade or higher level of education; (h) ability to sit at 90-degrees during the sessions; (i) participant agreement to eat in a quiet environment when working with the investigator instead of the dining room; (j) be a verbal communicator; (k) ability to complete a reading screening with at least 90% accuracy; and (l) passing score on the SR screening (Brush & Camp, 1998a). Exclusion criteria included diagnosis of psychiatric illness.

One participant was excluded due to scoring within normal range on the MMSE.

Approval was obtained from the Biomedical Sciences Institutional Review Board of The Ohio State University.

Screening

Upon receiving a referral from the nursing home nursing staff, the investigator obtained signed informed consent (see Appendix A), HIPAA research authorization (see Appendix B), and Personal Health Information (see Appendix C) from the potential participant's POA in person or through the mail. When completed through the mail, a telephone conference was held to explain the procedures and the forthcoming paperwork to the participant's POA. Biographical information, medical history and confirmation of dementia diagnosis were obtained through a review of the medical chart.

Figure 2. Swallowing Screening Cues Cards Replicated in 18-, 24- and 36-point Times New Roman font.

Participants participated in one screening session, which was one-hour in length or less, to evaluate for inclusion and exclusion criteria. Participants' dementia diagnosis was documented by a medical chart review and cognitive status was documented with the MMSE. The participant's oral reading ability was confirmed with the swallowing screening cue cards (see Figure 2) and a score of 90% or higher was required for eligibility. The cue cards were presented in three font sizes (18-, 24- and 32-point) in Times New Roman to determine appropriate font size for visual aids during treatment. Finally, the SR screening (Brush & Camp, 1998a) was administered using the first name of the investigator with recall expected up to 30-seconds (See Appendix D). Three participants were withdrawn from the study after enrollment. One participant expired due to congestive heart failure following enrollment and screening, but before the

experiment began, one participant expired due to an unknown cause in the first week of data collection, and one participant was discharged home with hospice following the first baseline session. Pertinent descriptive data on the five participants who completed the study are presented in Table 1 and on the three participants who were withdrawn in Table 2. The mean age and MMSE scores for those who completed the study were 71.2 (SD = 7.26) and 19.2 (SD = 1.3) and 91.67 (SD = 10.21) and 14.33 (SD = 3.06) for those who were withdrawn from the study. The difference between these means was statistically significant for both age ($p < 0.01$) and MMSE scores ($p < 0.01$). Four males and one female were included in data collection. All five participants scored between 3.5 - 10 standard deviations below the norm for age and education (Crum, Anthony, Bassett, & Folstein, 1993) ($M = 19.2$ $SD = 1.3$) on the MMSE. Participants' oral reading performance on the reading screening was measured by dividing the total number of words read correctly by the total number of words and ranged from 93% to 100% ($M = 98\%$; $SD = .03$).

Subjects	Sex	Age	MMSE ¹	SD Below the Mean ²	Oral Reading Screening	Education
1	M	66	19	10	100%	BA
2	M	77	21	4	100%	High School
3	M	66	18	4.5	93%	6 th grade
4	F	66	20	5.5	100%	11 th grade
5	M	81	18	3.5	96%	High School
Mean		71.2	19.2		98%	
SD		7.26	1.3		0.03	

Table 1. Subject Characteristics, Completed

Note 1. Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975)

Note 2. Population-Based Norms for the Mini-Mental State Examination by Age and Educational Level (Crum, Anthony, Bassett, & Folstein, 1993)

Subjects	Sex	Age	MMSE ¹	SD Below the Mean ²	Oral Reading Screening	Education	Reason for Withdrawn status
1	F	96	11	3.5	96%	8th grade	Death
2	F	99	15	2.5	100%	8th grade	Death
3	F	80	17	11	100%	BA	Discharged with hospice
Mean		91.67	14.33		99%		
SD		10.21	3.06		0.02		

Table 2. Subject Characteristics, Withdrawn

Note. 1. Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975)

Note. 2. Population-Based Norms for the Mini-Mental State Examination by Age and Educational Level (Crum, Anthony, Bassett, & Folstein, 1993)

The investigator confirmed the diagnosis of oral or oral-pharyngeal dysphagia through a review of the videofluoroscopy study report completed by a local SLP following referral for enrollment in the study. Verification of no intervening disease that would change the videofluoroscopy results in the time between diagnosis and initiation of the experiment was obtained from the medical chart during the screening. A meal

analysis was performed to determine any additional strategies to be implemented that were not examined under videofluoroscopy. The investigator watched the person eat and drink a typical meal prepared by the facility and coded the relevant behaviors (see Appendix D). The investigator confirmed that that participant was able to physically perform the target compensatory strategies (e.g., chin-down posture) through visual observation of their cued performance.

Setting, Apparatus and Design

All components of this study took place in a quiet environment such as a bedroom, activity room or living room within the participant's home or skilled nursing facility to limit noise and distractions. If in a skilled nursing facility, participants must have been willing to eat outside of the dining room for eligibility. Televisions and radios were turned off and doors and windows were closed to limit as many distractions as possible in the setting. Whenever possible, the session was held during the same meal each day. Participants were sitting up at 90 degrees in a chair, with a table in front of them and materials clearly visible. All interactions were audio recorded (Olympus DS-40 digital voice recorder) and video recorded (Sony HDR-CX260V Handycam). A timer with an alarm (Apple iPhone 4s) was used to time SR intervals. Relevant data were tracked on a baseline data collection form (see Appendix E) or training data collection form (see Appendix F). Family members and facility staff were not present during baseline and treatment sessions.

A single subject multiple baseline design with repeated measures across participants was used to evaluate the effects of the training of compensatory swallowing

behaviors. This design allowed the replication of the treatment effects only when the treatment was applied, showing no effect for behaviors not treated, and then replicated across participants. The initiation of the treatment conditions was staggered across the participants and the behaviors being taught were monitored as the control. Additionally, the multiple baseline design was utilized because the participants were not expected to return to baseline after the treatment was applied.

Stimuli

Prior to the start of SR training, participant-specific questions and corresponding target responses were written based on the compensatory recommendations found on the videofluoroscopy report (e.g. chin-down posture) and meal analysis (see Table 3). In the event that multiple participants had recommendations for the same compensatory strategies, if possible, strategies were counterbalanced to control for a sequencing effect (see Table 3). The experimental stimuli consisted of an 8x11 inch yellow card with the target responses printed in appropriate font size determined during the screening in Times New Roman font in black ink. The card was printed on one half of an 8.5x11 vertical sheet, tented and placed facing the participant. The phrase “I eat and drink safely” was printed at the top and target responses were printed in sequential order below (see Figure 3). The untrained responses were covered and then revealed during the relevant portion of the SR training.

Subjects	Questions	Target Responses
1	What do you do after you take a bite?	I take a drink.
	What do you after you take a drink?	I clean my mouth out with my finger.
2	What do you do after you take a bite?	I take a drink.
	What do you after you take a drink?	I tuck my chin and swallow.
	What do you do after you tuck your chin and swallow?	I cough and swallow again.
3	What do you do after you take one bite?	I take a drink.
	What do you after you take a drink?	I clean my mouth out with my tongue.
	What do you do after you wash your mouth out with your tongue?	I swallow two more times.
4	What do you do before you take a drink?	I inhale and hold my breath.
	What do you do after inhale and hold your breath?	I swallow and then cough.
	What do you do after you swallow and then cough?	I swallow again and then breathe.
5	What do you do after you take a bite and swallow?	I swallow again.
	What do you do after you swallow twice?	I take a drink.
	What do you do after you take a drink?	I clean my mouth out with my finger.

Table 3. Participant-Specific Questions and Target Responses.

Figure 3. Example Visual Aids for Participant 1 and Participant 5

Baseline

Prior to the initial baseline session, the investigator provided the participant with education on the individualized compensatory strategies and behaviors by verbally explaining how to perform the strategies and demonstrating how to execute them

appropriately. The participant was asked to perform the compensatory strategies and behaviors to demonstrate understanding by first imitating the investigator's example (e.g., taking a drink, tucking the chin and then swallowing) and then by performing the strategies independently. The participant was asked to perform the strategies independently three times before baseline was initiated. Baseline began with the experimenter stating, "Show me how you eat and/or drink safely." The participant was given approximately 1-minute to perform the target behaviors. The intervals were timed and if the participant was taking a bite or sip; the interval was not stopped until the behavior was completed. The observed behaviors were recorded on the baseline data sheet and scored as correct, incorrect or no response (see Appendix E). No additional cuing was provided during each baseline session. After a 1-minute interval, the investigator repeated the trial, by stating, "Show me how you eat and/or drink safely" and recorded the responses five times for one session. In each visit, the investigator conducted sessions of five trials each with a 10-minute break between sessions until there was a pattern of stable performance of at least eight data points. During the breaks, the participant engaged in a pleasurable activity of his or her choice such as a puzzle, looking at a magazine or conversation with the investigator. If the breaks lasted longer than 10-minutes, it was noted and the session continued as planned. Results for each session (i.e. performance of behaviors) were graphed and baseline continued until there was a pattern of stable and low performance of the target behaviors of at least eight data points. After each visit, the experimenter transferred the data from the baseline data sheet to a graph

for monitoring patient performance of the target behaviors and determination of stable performance by visual analysis of the graphed data.

Treatment

Once a stable baseline was established for the first target behavior, treatment began for the first target response. The second and third (if applicable) target behaviors continued in baseline, being probed daily. Each session began with the probe “Show me how you eat and/or drink safely” in order to collect data on the remaining behaviors. Treatment was provided in 30-45 minute treatment sessions five times weekly and responses were recorded on the data sheet (see Appendix F). The visual aid showing only the phrase “I eat and drink safely” and the target response reflecting the compensatory strategy to be trained was placed in front of the participant above the plate of food or glass of liquid. The standard SR protocol was followed and a timer was used to time each interval:

1. The participant was told that he/she would be given practice remembering a technique that would need to be done every time he/she swallows liquid and/or food (e.g., “Today we are going to practice remembering to take a drink after you take a bite. This card tells you what to do. What do you do every time after you take a bite?” Expected participant response: “I take a drink.” Investigator replies: “Good. Now take a bite and then take a drink.”).
2. There was a brief pause filled by saying: “Now let’s practice again. What do you do after you take a bite?”

3. If the participant remembered the expected response, the investigator proceeded to step four below. If the response was incorrect, the investigator pointed to the memory aid and repeated the question prompt. Each time an incorrect response was given, the investigator pointed to the memory aid and said: “Actually you can look at your reminder card and read what it says. What do you do after you take a bite?” This gave the participant the opportunity to finish the trial with a successful recall.
4. The investigator filled the third interval, lasting 10 seconds, by saying: “Good. I will give you more chances to practice this as I am working with you today. Let’s try again. What do you do after you take a bite?”
5. If the correct answer was given, the investigator proceeded to step six below. If an incorrect response was given, the investigator immediately pointed to the memory aid, said the correct information and repeated step two.
6. The investigator filled the fourth interval, lasting 30 seconds, by saying, “Good. You are doing very well at remembering to take a drink after you take a bite and you are remembering for a longer period of time. That is the idea, for you to remember for longer and longer times so you will always be able to remember it. I will be asking you the same question every once in a while just to give you practice. What do you do after you take a bite?”
7. If participant gave the correct answer the investigator proceeded to step eight below. If an incorrect response was given the investigator immediately pointed to the memory aid, said the correct information and repeated step four.

8. The investigator continued to ask the participant to recall and perform the response after increasingly longer intervals of time by doubling the time interval after each successful recall and demonstration. After an unsuccessful recall, the investigator returned to the last successful trial by cutting the time in half.

The treatment continued until the participant attained goal mastery: the correct response was given to the first prompt of three consecutive sessions with no fewer than 24 hours between sessions.

After the first target behavior was mastered, training began on the next behavior. A new patient-specific question and target response was introduced (e.g., “What do you when you take a drink?” Target response: “I tuck my chin and then swallow.”). Additionally, the visual aid was changed to include the addition of the new behavior. Maintenance of the previously learned strategies was tested throughout training of the new behavior through the probe “Show me how you eat and/or drink safely”.

Training continued until the participant demonstrated mastery of goal two; then goal three was introduced and trained until mastery. Treatment ended when mastery for all goals was achieved, or discontinuation of treatment as necessary (e.g., participant discharge to hospital).

Maintenance

One-week and 4-weeks post-goal mastery, participants were given the probe “Show me how you eat and/or drink safely” to assess goal maintenance of each trained compensatory strategy. The investigator ensured ahead of time that the relevant external aid was available and in place prior to providing the verbal prompt. The participant was

expected to recall and perform the targeted behaviors taught in the treatment phase. If they did not do so upon first attempt, the participant was directed to the external aid and probed again. If the participant did not respond correctly, a verbal cue was provided with the correct response and a final probe was provided. During the maintenance period no related dysphagia treatment was provided. At the end of the four-week maintenance period for Participants 1, 2 and 5 the family or nursing home staff was provided with the external aid and were educated on behaviors for reinforcement during mealtime.

Reliability

One trained student volunteer removed all identifiable information from the data sheets, assigned each data set a code and randomly selected data for reliability assessment. A second student volunteer, trained to a 90% agreement criterion with video samples, reviewed 21% of baseline, treatment and maintenance video recordings of the data collected that were not used in training (23 of 108 total sessions) and coded the independent and dependent variables using the data sheet (see Appendix G). The student volunteer watched the video sessions and tracked timing of training intervals, recall of target responses during baseline, first probe and training, and coded the behaviors of the participant during training. Primary data of the investigator was compared to the secondary data of the student volunteer and agreement was scored (i.e., number of items in agreement over total scored). As shown in Tables 4 and 5, the overall inter-observer percent agreement for all independent variable observations coded was 96.9% (range 73.8% to 100%). The inter-observer percent agreement for timing of training intervals was 99% (range 95.3% to 100%), recall of target responses during training was 100%,

and the behaviors of the participant during training was 91.7% (range 73.8% to 100%).

The overall inter-observer percent agreement for all dependent variable observations coded was 100%. The inter-observer percent agreement for recall of target responses at baseline was 100% and recall of target responses at first probe was 100%.

	Timing of Training Intervals	Recall of Target Response During Training	Participant Behaviors During Training
1	100%	100%	98%
2	100%	100%	73.8%
3	100%	100%	86.7%
4	95.3%	100%	100%
5	100%	100%	100%
Mean	99%	100%	91.7%
Overall Mean	96.9%		

Table 4. Independent Variables Reliability

	Recall of Target Response at Baseline	Recall of Target Response at First Probe
1	100%	100%
2	100%	100%
3	100%	100%
4	100%	100%
5	100%	100%
Mean	100%	100%
Overall Mean	100%	

Table 5. Dependent Variable Reliability

Social Validation

A video recording of the first baseline and one post treatment session of each participant was randomly ordered on a digital recording and presented to a panel of 10

SLPs. The target responses were superimposed on the bottom of the video clips for reference. The clips were labeled A-J and a random letter generator was used to assign the order of review for each SLP. Using a 7-point Likert scale (see Appendix H), the SLPs were asked to rate the effectiveness of the following; (1) participant performs target strategy; and (2) was this an episode of use of a safe strategy to improve eating safety or quality of life (see Appendix G).

Chapter 3: Results

To provide a visual representation of the results of training 2-3 target responses for each participant, one graph and one table will be presented for each participant. The graphs (see Figures 4, 5, 6, 7 and 8) display the correct or incorrect responses to the probe “Show me how to eat and/or drink safely” at the beginning of each session. In baseline, all participants showed stable rate of inability to recall the target responses. The response was only considered correct if all of the target responses were performed, in the correct order. None of the participants ever demonstrated the entire set of compensatory swallowing behaviors that were verbally and physically rehearsed with the investigator during the initial therapy sessions

The investigator initiated the training protocol for the training phase at the next scheduled treatment session following the discontinuation of the baseline phase for the first target response. The investigator continued to measure the other untrained behaviors during training through provision of the first probe. Tables 9, 10, 11, 12 and 13 summarize the target responses trained, the total number of trials with the number of successful and unsuccessful responses and the highest retention interval achieved for each participant. The mean number of sessions to meet criterion for each target response was 6.73 sessions ($SD = 3.32$) with a range of 4-25 sessions (see Table 6).

Participants	Behaviors	Total Sessions	Mean Sessions	Overall Mean (SD)
1	Drink	6	10.67	
	Finger Sweep	25		
2	Drink	11	10	
	Chin Down	9		
	Cough & Swallow again	DNM		
3	Drink	4	4	
	Lingual Sweep	4		
	Double Swallow	4		
4	Inhale & Hold	4	4	
	Breath	4		
	Swallow & Cough	4		
5	Swallow & Breathe	DNM	5	
	Double Swallow	6		
	Drink	4		
	Finger Sweep	5		
				6.73 (3.32)

Table 6. Summary of Number of Sessions to Meet Training Criterion

Note. DNM = did not meet criterion

The number of training sessions to meet criterion for a target response varied across behaviors and across participants. For example, Participant 1 demonstrated the first target response in six training sessions, but demonstrated the second target response in 25 training sessions and did not demonstrate this behavior without the use of the visual aid. On the other hand, Participant 3 demonstrated the first target response in four training sessions and demonstrated both the second and third target responses in four training sessions for each response. As shown in the training phase of the graphs (see Figures 4, 5, 6, 7 and 8), all participants demonstrated mastery of up to two of the target responses. Participant 1 was trained on only two behaviors; Participant 2 never performed the third behavior, so it was discontinued; and Participant 4 was withdrawn from the study prior to reaching criterion for the third behavior.

The investigator tested maintenance of each mastered target response during the first prompt at the beginning of each training session. Maintenance was recorded as “yes” the behavior was performed or “no” it was not performed. Training was not provided if the participant did not demonstrate the target responses in the maintenance phase. Overall, the mean of correct demonstrations during the maintenance phase was 93% (SD = 0.08%) for all participants (see Table 7).

Participants	Behaviors	# of Correct Trials	# of Incorrect Trials	Total Trials	Total % Correct
1	Drink	22	3	25	88%
	Finger Sweep	N/A	N/A		
2	Drink	11	2	13	82.35%
	Chin Down	3	1	4	
	Cough & Swallow again	N/A	N/A		
3	Drink	8	0	8	100%
	Lingual Sweep	4	0	4	
	Double Swallow	N/A	N/A		
4	Inhale & Hold Breath	10	0	10	93.75%
	Swallow & Cough	5	1	6	
	Swallow & Breathe	N/A	N/A		
5	Double Swallow	9	0	9	100%
	Drink	5	0	5	
	Finger Sweep	N/A	N/A		
Mean					93%
SD					0.08

Table 7. Maintenance Summary for Participants

Follow-up sessions were held at 1-week and 4-weeks post goal mastery. Follow-up sessions began with the visual aid in place and the prompt “Show me how to eat and/or drink safely” was stated by the investigator. After the participant performed the

target responses, the session was ended. All participants demonstrated the mastered target responses with the use of the visual aid representing the intervention in which they participated. Participants 1, 2 and 5 participated in both the 1-week and 4-week follow-up sessions. The Investigator could not locate Participant 3 for the 4-week follow-up. Follow-up sessions were not conducted for Participant 4 due to being withdrawn early from the study.

As an outcome of successful demonstration of behaviors, four of the five participants (80%) (Participants 1, 2, 3 and 5) were able to tolerate upgraded diet levels (see Table 8) with the use of the visual aid. The investigator recommended upgraded diet levels for Participants 1, 2 and 5 at the conclusion of the study and for Participant 4 following the training phase.

Subject	Pre-Training Diet Level		Post-Training Diet Level	
	Solid	Liquid	Solid	Liquid
1	Mechanical-Soft	Thin	Regular	Thin
2	Puree	Honey	Mechanical-Soft	Nectar
3	Regular	Nectar	Regular	Thin
4	Regular	Nectar	N/A	N/A
5	Mechanical-Soft	Nectar	Regular	Thin

Table 8. Diet Summary Pre and Post training for Participants

Statistical analysis was not completed for the current study due to lack of variability in the baseline and follow-up phases. The method in which the behaviors

were measured was clinically relevant for this treatment modality; however, an effect size could not be obtained due to lack of variability in the standard deviations.

Participant 1

Participant 1 presented with a mild oral dysphagia. The participant was edentulous, but chose to forgo wearing dentures. The modified barium swallow study reported a mild oral dysphagia and recommended alternation of solids and liquids. The participant's family had previously chosen not to restrict the diet at home to maintain quality of life, but a diet of mechanical soft was ordered upon admission to the facility. The family planned to bring the participant home following a short rehabilitation stay due to recent falls within their home. During the meal analysis, three pieces of raw vegetables were found in the participant's left buccal cavity. When asked about what was in the mouth, the participant indicated it was chewing gum. The main objective was to teach behaviors to clear the oral cavity by taking a drink and completing a finger sweep following each bite of food. At pre-baseline instruction the participant did not demonstrate the ability to take a drink and perform a finger sweep following one bite of food. During baseline, the participant took 2-3 bites of food in a row before taking a drink and never demonstrated the use of a finger sweep. The following target responses were printed on the visual aid below the words "I eat and drink safely:"

1. "I take a drink."
2. "I clean my mouth out with my finger."

As seen in Figure 4, the first target response trained was the use of a drink following each bite of food. The only acceptable response was that a drink followed one bite of food. Participant 1 demonstrated the use of a drink for 41 of 41 trials and achieved criterion in six sessions. The longest retention interval was 960 seconds, which occurred in therapy session one, (data point nine, see Table 9). During the maintenance phase, Participant 1 demonstrated the target response in 22 out of 25 opportunities.

Figure 4. Correct Response on First Probe at the Initiation of Each Session for Participant 1

The second target response trained for Participant 1 was the use of a finger sweep following the drink (see Figure 4). The participant did not recall the target response at the first probe, without the visual aid, for 13 training sessions. The investigator noted that once the visual aid was introduced, there was a stable pattern of successful recalls and demonstrations of the target response. At treatment session 20 (data point 28), the investigator introduced the visual aid prior to the first probe for the participant's use. As seen in Figure 4, Participant 1 performed the target response at first probe for 5 of 6 opportunities. Once stable for three sessions, the investigator removed the visual aid during the first probe. Participant 1 was never performed the target response at first probe for three sessions without the visual aid. At treatment session 29 (data point 37) the investigator reintroduced the visual aid prior to the first probe for use and Participant 1 demonstrated the target response for 3 of 3 opportunities. Training was terminated following treatment session 31 (data point 39) because it was determined that Participant 1 recalled and demonstrated both target responses with the use of a visual aid. The longest retention interval was 960 seconds, which occurred in treatment session 10 (data point 18, see Table 9).

Following treatment session nine (data point 17), Participant 1 was discharged from the skilled nursing facility to home. Data collection resumed at the normal time the following day at home. The change in location did not appear to impact Participant 1's performance. At the one-week and four-week follow up sessions, Participant 1 demonstrated both strategies at the first probe with the use of the visual aid and it was reported to the participant's family that regular consistencies could be served with

continued use of the strategies and they were provided with the visual aid for use during all oral intake.

Treatment Session	Behavior	# of Correct Responses	# of Incorrect Responses	Total # of Trials	Highest Interval Achieved (seconds)
1	drink	7	0	7	960
2	drink	7	0	7	960
3	drink	7	0	7	960
4	drink	7	0	7	960
5	drink	7	0	7	960
6	drink	6	0	6	480
7	finger sweep	7	2	9	240
8	finger sweep	7	1	8	480
9	finger sweep	6	0	6	480
10	finger sweep	7	0	7	960
11	finger sweep	7	0	7	960
12	finger sweep	7	0	7	960
13	finger sweep	7	0	7	960
14	finger sweep	7	0	7	960
15	finger sweep	7	0	7	960
16	finger sweep	7	0	7	960
17	finger sweep	7	0	7	960
18	finger sweep	7	0	7	960
19	finger sweep	6	0	6	480
20	finger sweep	6	0	6	480
21	finger sweep	6	0	6	480
22	finger sweep	6	0	6	480
23	finger sweep	6	0	6	480
24	finger sweep	6	0	6	480
25	finger sweep	6	0	6	480
26	finger sweep	6	0	6	480
27	finger sweep	6	0	6	480
28	finger sweep	6	0	6	480
29	finger sweep	6	0	6	480
30	finger sweep	6	0	6	480
31	finger sweep	6	0	6	480

Table 9. Treatment Session Summary for Participant 1

Participant 2

Participant 2 presented with a mild-moderate oropharyngeal dysphagia. The participant had been consuming puree and honey-thickened liquids for an unknown amount of time as a result of previous speech treatment, however; the nursing staff reported frequent refusal of the liquids and occasional physical behaviors directed at the staff (e.g. hitting) related to refusal of thickened liquids. No record was found for implementation of any strategies with prior treatment. The modified barium swallow study determined that the chin-down posture was effective at elimination of penetration and aspiration of thin liquids. During the meal analysis, Participant 2 presented with a wet vocal quality following intake of thin liquids. The use of a throat clear with a second swallow was assessed and added. Finally, the staff reported that the participant often ate at a rapid rate, which resulted in a large amount of food within the oral cavity causing him to cough and/or choke. To slow the intake rate, alternating bites of solids with liquids was assessed in the meal analysis and was shown to be effective. The main objectives were to teach behaviors for tolerance of a thinner consistency by teaching the use of a chin-down posture with a throat clear and second swallow and to slow the rate of intake to reduce the risk of choking by alternating food and liquid. At pre-baseline instruction the participant demonstrated the ability to perform the chin-down posture, throat clear and second swallow after each bite of food. During baseline, the participant took 3-7 bites of food in a row before taking a drink, often not taking a drink at all and never demonstrated the use of the chin-down posture or throat clear with a second

swallow. The following target responses were printed on the visual aid below the words “I eat and drink safely:”

1. “I take a drink.”
2. “I tuck my chin and swallow.”
3. “I cough and swallow again.”

Figure 5. Correct Response on First Probe at the Initiation of Each Session for Participant 2

As seen in Figure 5, the first target response trained was the use of a drink following each bite of food. Participant 2 demonstrated the use of a drink for 77 of 78 trials and achieved criterion in 11 sessions. The longest retention interval was 960 seconds, which occurred in treatment session one (data point nine, see Table 10). The only acceptable response was that a drink followed one bite of food. During the maintenance phase, Participant 2 demonstrated the target response in 11 out of 13 opportunities.

The second target response trained for Participant 2 was the use of a chin-down posture when swallowing the drink (see Figure 5). Participant 2 demonstrated the use of a chin-down posture prior to swallowing the drink for 19 of 22 trials and achieved criterion in nine sessions. The longest retention interval was 960 seconds, which occurred in treatment session 13 (data point 21, see Table 10). The only acceptable response was that the chin was tucked and held down while the swallow occurred. During the maintenance phase, Participant 2 demonstrated the target response 3 out of 4 opportunities.

The third target response trained for Participant 2 was the use of a throat clear followed by a second swallow. The participant could physically complete this target response during the meal analysis and physical exam with and without a model. During the first training session, the participant did not perform a throat clear, replacing the behavior with a sigh followed by a second swallow. The behavior was modified to a cough, which the participant achieved when verbally prompted by the Investigator. The Investigator modified the words “clear my throat” to “cough” on the visual aid and the

treatment continued as normal. The longest retention interval was 960 seconds, which occurred in treatment session 21 (data point 29, see Table 10). During the same session, the participant demonstrated the use of a cough and swallow for 7 out of 7 trials. In the second training session for this target response (treatment session 22, data point 30), the participant did not perform the cough, which was successfully demonstrated throughout the previous training session. The participant replaced this behavior with a sigh followed by a second swallow. Verbal prompting and demonstration from the Investigator was unsuccessful. The Investigator probed the original behavior of a throat clear, but was also unsuccessful at eliciting demonstration from the participant. The Investigator did not change the target response of a cough and continued the session normally. In treatment session 22 (data point 30) the participant verbally recalled the target response for 7 out of 7 trials, but demonstrated a sigh instead of a cough. This procedure was replicated in treatment sessions 23 and 24 (data points 31 and 32). In treatment session 24 (data point 32) the participant became increasingly agitated, so the Investigator terminated the session. Following treatment session 24 (data point 32), the Investigator discontinued training the third target response, as it was not required in the modified barium swallow study for tolerance of a thinner consistency. Additionally, while verbal recall was accurate, Participant 2 was not performing the desired target response and the Investigator wanted to avoid training an ineffective behavior. The third target response was removed from the visual aid for the follow-up sessions. At the one-week and four-week follow up sessions, Participant 2 was demonstrated target response one and target response two at the first probe with the use of the visual aid. The participant was not

prompted for target response three. The participant's liquid was changed from honey-thickened liquid to nectar-thickened liquid and he was upgraded to a mechanical soft consistency. The Investigator provided the staff with the visual aid for use during all oral intake.

Treatment Session	Behavior	# of Correct Responses	# of Incorrect Response	Total # of Trials	Highest Interval Achieved (seconds)
1	drink	7	0	7	960
2	drink	7	0	7	960
3	drink	7	0	7	960
4	drink	7	1	8	480
5	drink	7	0	7	960
6	drink	7	0	7	960
7	drink	7	0	7	960
8	drink	7	0	7	960
9	drink	7	0	7	960
10	drink	7	0	7	960
11	drink	7	0	7	960
12	chin-down	7	2	9	240
13	chin-down	7	0	7	960
14	chin-down	7	0	7	960
15	chin-down	7	0	7	960
16	chin-down	7	0	7	960
17	chin-down	7	0	7	960
18	chin-down	7	1	8	480
19	chin-down	7	0	7	960
20	chin-down	7	0	7	960
21	cough & swallow	7	0	7	960
22	cough & swallow	7	0	7	960
23	cough & swallow	7	0	7	960
24	cough & swallow	6	0	6	480

Table 10. Treatment Session Summary for Participant 2

Participant 3

Participant 3 presented with a mild oropharyngeal dysphagia. The participant was admitted to the facility for a short rehabilitation stay with an order for nectar-thickened liquids, but would be found sneaking thin liquids from the bathroom and coffee pot in the lobby area by the staff. The modified barium swallow study determined that a second swallow was effective at clearing pharyngeal residue. The participant was edentulous and did not have dentures, but preferred a regular diet. The meal analysis revealed mild pocketing in the buccal cavities. The main objectives were to improve tolerance of thin liquids by teaching a double swallow and to clear oral residue found during the meal analysis through the use of a lingual sweep and alternation of food and liquids. At pre-baseline instruction the participant demonstrated the ability swallow twice and perform a lingual sweep after each bite of food. During baseline, the participant took an average of two or more bites of food in a row, often not taking a drink at all. A lingual sweep was performed in one trial, but out of order and a second swallow was omitted. A second swallow was performed at the end of two trials, but one or more of the behaviors expected to precede the second swallow were omitted. The following target responses were printed on the visual aid below the words “I eat and drink safely:”

1. “I take a drink.”
2. “I clean my mouth out with my tongue.”
3. “I swallow two times.”

As seen in Figure 6, the first target response trained was the use of a drink following each bite of food. Participant 3 demonstrated the use of a drink for 28 of 29 trials and

achieved criterion in four sessions. The longest retention interval was 960 seconds, which occurred in treatment session two (data point 10, see Table 11). The only acceptable response was that a drink followed one bite of food. During the maintenance phase, Participant 3 demonstrated the target response in 8 out of 8 opportunities.

Figure 6. Correct Response on First Probe at the Initiation of Each Session for Participant 3

The second target response trained for Participant 3 was the use of a lingual sweep following the drink (see Figure 6). The participant demonstrated the use of a lingual sweep for 27 of 28 trials and achieved criterion in four sessions. The longest retention interval was 960 seconds, which occurred in treatment session six (data point 14, see Table 11). The only acceptable response was that the participant performed a lingual sweep to clear the oral cavity following a drink. During the maintenance phase, Participant 3 demonstrated the target response 4 out of 4 opportunities.

The third target response trained for Participant 3 was the use of a second swallow following the drink (see Figure 6). Participant 3 demonstrated the use of a second swallow for 27 of 27 trials and criterion was achieved in four sessions. The longest retention interval was 960 seconds, which occurred in treatment session nine (data point 17, see Table 11). The only acceptable response was that the participant swallowed a second time following the lingual sweep and prior to taking another bite or drink. At the one-week follow up session, Participant 3 demonstrated the target response for all three strategies at the first probe with the use of the visual aid. At this time the participant's liquids were changed from nectar-thickened to thin, but the visual aid was not provided to the staff because one more follow-up session was planned. Participant 3 was discharged from the facility prior to the four-week follow-up session. Because Participant 3 was determined to be homeless and without transportation, the investigator made a calendar stating the date, time and location (of Participant 3's choosing) for the four-week follow up. The Investigator arrived at the location and stayed for 30-minutes, but Participant 3 did not come, so a four-week follow-up session was not conducted.

Treatment Session	Behavior	# of Correct Responses	# of Incorrect Responses	Total # of Trials	Highest Interval Achieved (seconds)
1	drink	7	1	8	480
2	drink	7	0	7	960
3	drink	7	0	7	960
4	drink	7	0	7	960
5	lingual sweep	7	1	8	480
6	lingual sweep	7	0	7	960
7	lingual sweep	7	0	7	960
8	lingual sweep	6	0	6	480
9	double swallow	7	0	7	960
10	double swallow	7	0	7	960
11	double swallow	7	0	7	960
12	double swallow	6	0	6	480

Table 11. Treatment Session Summary for Participant 3

Participant 4

Participant 4 presented with a moderate pharyngeal dysphagia. The modified barium swallow study reported that Participant 4 silently aspirated thin liquids and the supraglottic swallow was recommended for increased airway protection. Participant 4 refused to drink thickened liquids, which was supported by the family and primary care physician. The main objective was to improve the participant's safety by improving airway protection with the intake of thin liquids through the use of a supraglottic swallow. At pre-baseline instruction the participant demonstrated the ability to perform all six behaviors in the supraglottic swallow, but had some confusion regarding when to resume breathing. The investigator added a prompt to breathe at the end of the six-supraglottic swallow steps to help clarify when breathing was permitted. During baseline, the participant took a drink and then performed a chin-down posture during all

trials. It was later learned that a previous SLP had trained the participant to perform the chin-down posture without the recommendation of an instrumental exam. The modified barium swallow study conducted for participation in the current study reported that the chin-down posture was ineffective for airway protection. The six steps of the supraglottic swallow and the prompt to resume breathing were divided up into the following three target responses and printed on the visual aid below the words “I eat and drink safely:”

1. “Inhale and hold my breath”
2. “I swallow and then cough”
3. “I swallow and then breathe”

Participant 4 had a visual impairment, so the visual aid was printed in a 72-point Times New Roman font and at Participant 4’s request the visual aid was elevated to direct line of sight.

As seen in Figure 7, the first target response trained was a deep inhalation and breath hold prior to liquid intake. Participant 4 demonstrated a deep inhalation and breath hold for 28 of 28 trials and achieved criterion in four sessions. The longest retention interval was 960 seconds, which occurred in treatment session one (data point nine, see Table 12). The only acceptable response was that the participant inhaled deeply and then demonstrated a breath hold. During the maintenance phase, Participant 4 demonstrated the target response in 10 out of 10 opportunities.

Figure 7. Correct response on first probe at the initiation of each session for Participant 4

The second target response trained for Participant 4 was to take a drink and then cough, while continuing to hold the breath (see Figure 7). Participant 4 demonstrated taking a drink and then coughing, while continuing to hold the breath in 28 of 28 trials and criterion was achieved in four sessions. The longest retention interval was 960

seconds, which occurred in treatment session five (data point 13, see Table 12). The only acceptable response was that the participant drank and then coughed, while holding the breath following the inhalation. During the maintenance phase, Participant 4 demonstrated the target response 5 out of 6 opportunities.

The third target response trained for Participant 4 was the use of a second swallow followed by the resumption of breathing (see Figure 7). Participant 4 demonstrated the use of a second swallow followed by resumption of breathing for 21 of 21 trials, but criterion was not achieved because she became ill and was discharged to the hospital. The longest retention interval was 960 seconds, which occurred in treatment session 12 (data point 20, see Table 12). The only acceptable response was that the participant swallowed a second time, following the inhalation and cough while holding the breath and prior to resumption of breathing. At approximately treatment session nine (data point 17), Participant 4 became increasingly weak and ill. Pneumonia was suspected, reported to the nursing staff and the participant was monitored over the next few days by the medical staff. Participant 4 was sent to the hospital the morning of treatment session 14 (data point 22) and was diagnosed with aspiration pneumonia at the hospital. Subsequently, an Ear Nose and Throat physician diagnosed vocal cord paralysis and Participant 4 was not reinstated back into the study as the supraglottic swallow was determined to be ineffective since her vocal cords were paralyzed and could not be held together during the maneuver. Follow-up sessions were not conducted. Participant 4's last successful recall, treatment session 14 (data point 22), was used for the social validation study.

Treatment Session	Behavior	# of Correct Responses	# of Incorrect Responses	Total # of Trials	Highest Interval Achieved (seconds)
1	inhale & hold breath	7	0	7	960
2	inhale & hold breath	7	0	7	960
3	inhale & hold breath	7	0	7	960
4	inhale & hold breath	7	0	7	960
5	swallow & cough	7	0	7	960
6	swallow & cough	7	0	7	960
7	swallow & cough	7	0	7	960
8	swallow & cough	7	0	7	960
9	swallow again & breathe	7	0	7	960
10	swallow again & breathe	7	0	7	960
11	no treatment administered. Participant became ill following first probe.				
12	swallow again & breathe	7	0	7	960
13	swallow again & breathe	7	0	7	960
14	swallow again & breathe	7	0	7	960

Table 12. Treatment Session Summary for Participant 4

Participant 5

Participant 5 presented with a moderate oropharyngeal dysphagia. The participant was being served nectar-thickened liquids and a mechanical soft diet for an unknown amount of time as a result of previous speech treatment. No record was found for implementation of any strategies with prior treatment. The modified barium swallow study determined that a second swallow following solids was the most effective target response to clear pharyngeal residue. The meal analysis found that a finger sweep helped to clear oral residue from solids. The main objectives were to improve tolerance of thin liquids and to clear oral residue found during the meal analysis through alternation of food and liquid, a second swallow and finger sweep. At pre-baseline instruction the

participant demonstrated the ability to swallow twice and perform a finger sweep after each bite of food. During baseline, the participant took 1-2 bites of food before taking a drink, but omitted the use of a double swallow prior to taking a drink. The use of a finger sweep was demonstrated once at the beginning of the trial and a second swallow was demonstrated twice at the end of the trials. In all three instances, the behaviors were out of order with additional behaviors omitted. The following target responses were printed on the visual aid below the words “I eat and drink safely:”

1. “I swallow twice.”
2. “I take a drink.”
3. “I clean my mouth out with my finger.”

As seen in Figure 8, the first target response trained was to swallow twice following each bite of food. Participant 5 demonstrated the use of a second swallow for 42 of 44 trials and criterion was achieved in six sessions. The longest retention interval was 960 seconds, which occurred in treatment session two (data point 10, see Table 13). The only acceptable response was that two swallows followed one bite of food and criterion was achieved in six sessions. During the maintenance phase, Participant 5 demonstrated the target response in 9 out of 9 opportunities.

The second target response trained for Participant 5 was the use of a drink following the second swallow (see Figure 8). The participant demonstrated the use of a drink following the second swallow for 28 of 28 trials and criterion was achieved in four sessions. The longest retention interval was 960 seconds, which occurred in treatment session seven (data point 15, see Table 13). The only acceptable response was that the

participant drank following the second swallow. During the maintenance phase, Participant 5 demonstrated the target response 5 out of 5 opportunities.

Figure 8. Correct Response on First Probe at the Initiation of Each Session for Participant 5

The third target response trained for Participant 5 was the use of a finger sweep following the drink (see Figure 8). The participant demonstrated the use of a finger sweep for 34 of 41 trials and criterion was achieved in five sessions. The longest retention interval was 960 seconds, which occurred in treatment session 13 (data point 21, see Table 13). The only acceptable response was that the participant used a finger sweep following the drink. At the one-week and four-week follow up sessions, Participant 5 demonstrated all three target responses at the first probe with the use of the visual aid. The investigator changed the participant's liquid from nectar-thickened to thin and solids were changed from mechanical soft consistency to regular consistency. The investigator provided the staff with the visual aid for use during all oral intake.

Treatment Session	Behavior	# of Correct Responses	# of Incorrect Responses	Total # of Trials	Highest Interval Achieved (seconds)
1	double swallow	7	2	9	480
2	double swallow	7	0	7	960
3	double swallow	7	0	7	960
4	double swallow	7	0	7	960
5	double swallow	7	0	7	960
6	double swallow	7	0	7	960
7	drink	7	0	7	960
8	drink	7	0	7	960
9	drink	7	0	7	960
10	drink	7	0	7	960
11	finger sweep	7	2	9	240
12	finger sweep	6	4	10	240
13	finger sweep	7	0	7	960
14	finger sweep	7	0	7	960
15	finger sweep	7	1	8	480

Table 13. Treatment Session Summary for Participant 5

Social Validation

The video recordings of one baseline and one post-treatment session of each participant were randomly ordered on a DVD and presented to 10 SLPs working with this population who were naïve to the study aims. The last successful session for Participant 4 was used because the participant was withdrawn prior to the follow-up phase. The target responses were superimposed on the bottom of the video clips for reference. Using a 7-point visual Likert scale (see Appendix H), the SLPs rated the effectiveness of the following (a) did the participant perform target strategy; and (b) was this an episode of use of a safe strategy to improve eating safety or quality of life. As seen in Table 14, a paired samples t-test using ratings from SLPs revealed that the naïve judges scoring of participants' performance of the target behaviors increased significantly from baseline with a mean of 1.58 (SD = 0.76) to post-treatment with a mean of 6.90 (SD = 0.10) ($p < 0.001$). Additionally, social validation ratings showed that raters saw a significant difference between baseline and treatment behaviors and that the strategies improved eating safety significantly from baseline with a mean of 1.34 (SD = 0.50) to post-treatment with a mean of 6.9 (SD = 0.12) ($p < 0.001$).

	Participant performs the target behavior		Was this an episode of use of a safe strategy to improve eating safety or quality of life?	
Subjects	Pre	Post	Pre	Post
1	1	7	1	7
2	1	7	1	7
3	2.6	6.8	2.1	6.9
4	1.1	6.9	1	6.7
5	2.2	6.8	1.6	6.9
Mean	1.58	6.90	1.34	6.90
SD	0.76	0.10	0.50	0.12
T-test (p)		<.0001		<.0001

Table 14. Summary of Social Validation Ratings for Participants

Chapter 4: Discussion

The purpose of this study was to (a) determine whether SR, paired with an external memory aid is effective to teach mealtime compensatory strategies to persons with dementia; and (b) to investigate if SLPs naïve to the study aims, who treat persons with dementia, would judge post-training mealtime sessions as improved, or safer, in comparison to baseline sessions, thereby validating the changes due to the training. Studies examining teaching and implementation of compensatory strategies for safer swallowing are few in number because memory and cognition impairments of persons with dementia interfere with learning such treatments. Evidence for effective treatment options that avoid modification of liquid and food is lacking for persons with dementia and a coexisting dysphagia in all settings.

Effects of Spaced Retrieval

The results of the current study revealed that the application of SR when paired with a visual aid was a successful intervention technique for teaching five persons with dementia to use compensatory strategies during oral intake. Visual analysis of the baseline and treatment phases of all five participants' graphs documented training effects for two or three compensatory strategies during oral intake with the use of a visual aid for each participant. The training effects for one of five participants lasted through the completion of the 1-week follow-up phase and three of the five participants lasted through the completion of the 4-week follow-up phase. All four participants completed

the trained strategies with the use of the visual aid during the follow-up phase at the first prompt.

The current study trained multiple target behaviors that were taught one at a time until all steps were completed in sequence for each swallowing episode. Participants recalled and demonstrated at least two behaviors with the use of a visual aid at the conclusion of the training phase. The standard protocol for SR has a long-standing and successful history of teaching behaviors using only verbal cues (Abrahams & Camp, 1993; Brush & Camp, 1998a; Camp, 1989; Lin et al., 2010; Schacter, Rich & Stamp, 1985). Some researchers have paired a visual aid with the standard SR protocol to enhance the learning effect (Bourgeois et al., 2003; Brush & Camp, 1998b). The current study utilized the standard SR protocol at first probe to determine criterion and maintenance, but included the use of a visual aid during training and for additional support at follow-up as use of visual aids has proven to be supportive for persons with dementia when there is difficulty learning with verbal cues only. Practical support of a visual aid was made apparent in the training phase of Participant 1. Participant 1 did not recall the second target response at first probe with the absence the visual aid, but consistently recalled the second target response once the visual aid was available during the first treatment13 sessions. The visual aid was introduced at first probe for the next six treatment sessions and Participant 1 performed the second target response in 5 of 6 first probes. The visual aid was then removed at first probe for the following three treatment sessions and Participant 1 performed the target response at first probe.

Subsequently, the visual aid was reintroduced at first probe and Participant 1 performed to criterion with the use of the visual aid.

Participants 2, 3, 4 and 5 easily increased performance accuracy using SR and the visual aid during the training phase. All four performed the target responses at first probe without the use of the visual aid. Participants 3 and 5 consistently performed three target responses. Participant 4 met criterion for two target responses, and was demonstrating progress toward the third target response prior to being discharged to the hospital and withdrawn from the study.

Some difficulty was noted during training for the third behavior for Participant 2. This participant did not meet criterion on the third behavior due to the inability to consistently perform the behavior during the training phase, not the inability to verbally recall it with the use of the visual aid during the training phase. Participant 2 physically demonstrated the use of a cough and a throat clear during the screening and teaching prior to baseline, but did not perform either of these behaviors during training. Instead, the participant substituted both with a loud sigh, which is a logical physiologic substitution for the target behavior, but was not the effective behavior being targeted for an upgrade to thin liquids. Surprisingly, this participant had the highest MMSE score, so the inability to demonstrate the target response appeared to be unrelated to the severity of dementia. This outcome may indicate that the choice to carry out such mealtime behaviors could be related to the person's ability to understand the importance of carrying out the behavior, not solely the ability to recall it. Perhaps, if thin liquids had been used during the training the relationship between the trained strategy and thin

liquids would have been clearer to the participant. Alternatively, the participant may have understood the behavior but did not want to cough or clear his throat in front of other people when eating, so chose to do something similar, such as a loud sigh. When compensatory strategies for swallowing are taught to persons without memory loss, they typically understand the need for the strategies, and make the educated decision to either comply or not comply during oral intake. In the case of Participant 2, education was provided on several occasions regarding why the strategies were necessary to enjoy desired liquids; however, maintenance of understanding for why the strategy was needed was lacking. Perhaps this was related to the degree of cognitive impairment, but it does not explain why other participants with a lower MMSE score demonstrated their behaviors. Participant 2 had the highest MMSE score, so this outcome could also imply that the training may be more effective for those with more cognitive impairment because the participant with less cognitive impairment could have been making a choice not to perform the strategy. Dementia severity, as measured by the MMSE, did not appear to be a factor for teaching and learning any behaviors. Alternatively, Participant 2 was the only subject who was being taught the behavior of performing a cough or throat clear followed by a dry swallow and maybe the combination was too complicated to learn and perform. The verbal recall was intact, but the ability to carry out the techniques was impaired.

The overall results of the current study are similar to those of Brush and Camp (1998a) in which six participants learned information such as their room number, the name of the facility, a loved one's birthday or the year, or to use a compensatory strategy

such as writing in or accessing a daily schedule using SR techniques. The mean number of sessions their participants required to meet criterion for each target response was 7.94 sessions (SD = 4.76) with a range of 3-20 sessions. In the current study, the mean number of sessions to meet criterion for each target response was 6.73 sessions (SD = 3.32) with a range of 4-25 sessions. It is important to note that mastery criterion in Brush and Camp (1998a) was achieved when the correct response was given to the first probe of two consecutive sessions with no fewer than 24-hours between sessions and treatment did not include a visual aid. The current study required correct recall for three consecutive sessions to achieve mastery. Interestingly, all participants in the present study who participated in the 4-week follow-up performed the target responses with 100% accuracy with the use of a visual aid. Brush and Camp (1998a) reported that at the 4-week follow-up only 65% of information was recalled; however, their participants did not have access to a visual aid. The current outcomes suggest that the use of a visual aid may shorten the training time needed to teach a behavior and may assist in maintaining the learned information. Additionally, extended time to reach criterion may contribute to more accurate performance in maintenance phases.

The current study helps to extend the results of Brush and Camp (1998b), which initiated the idea of applying SR to dysphagia treatments, by training a wider variety of specific eating and swallowing behaviors with rigorous methods and procedures, replicating the procedures across subjects, and replicating more training effects. In addition, the successful use of these compensatory strategies reduced the need for altered viscosities and consistencies in 4 of 5 participants, allowing for liquid and food

preferences that would have otherwise been withheld, and reducing the risk of dehydration and malnutrition. The liquid viscosity recommendations for Participant 4 were not modified due to the medical complications that arose following enrollment in the study and due to the post-study diagnosis of vocal cord paralysis.

Furthermore, the social validation ratings revealed that other SLPs were able to tell that participants' ability to perform the target strategies increased significantly from baseline to post-treatment ($p < .001$) and that the post-treatment episodes were judged to reflect significantly improved eating safety when compared to baseline episodes ($p < .001$).

Effect of Visual Aid versus No Visual Aid

The use of the visual aid appeared to influence a participant's performance within and across sessions and the ability to recall during the follow-up period. The visual aid was not used at baseline, or the first probe during the training and maintenance phases, but it was always present during the training phase after the first probe data were collected and during the follow-up phase. All of the target responses for each participant were novel behaviors that had not been trained previously. All five participants met criterion, except when training was discontinued due to individual factors reported, and demonstrated the target responses at all follow-up sessions conducted. In fact, the initial protocol for follow-up sessions initially stated: "The participant will be expected to perform the targeted behaviors taught in the treatment phase. If they do not do so upon first attempt, the participant will be directed to the external aid and probed again. If the participant does not respond correctly, a verbal cue will be provided with the correct

response and a final probe will be provided.” The investigator observed all five participants immediately refer to the visual aid at first probe in both the one-week and four-week follow-up sessions with no additional cues provided because they referred to the visual aid without investigator assistance at the first probe.

Limitations and Future Research

There were several limitations within the current study. The first limitation is related to the number and type of subjects included. This was a relatively small study investigating the performance of five participants. All of the subjects were judged to be mildly to moderately impaired on the MMSE based on standard cutoff scores (Perneczky et al., 2005), and to exhibit a mild or mild to moderate dysphagia. To generalize the findings of this study to a larger population of people with dementia, more participants with a wider range of severity of dementia need to be investigated. As the severity of the dementia increases, decreasing the number of behaviors and extending the time to meet criterion may be required to demonstrate similar treatment effects. Recruitment of subjects with different lengths of stay in the nursing home, which may indicate different levels of comorbidities, will also contribute to increased generalization.

Additionally, several threats to internal validity existed, which should be considered for future research. First, the participants who completed the study compared to the participants who withdrew due to death were an average of 20-years younger; age of participants may be an important variable to investigate. Gender might also be a factor related to treatment success; four males were the only participants who completed to follow-up phase. It is difficult to predict if similar outcomes would be observed if the

older population survived, or more women survived to the completion of the study. The mortality rate of the total group of participants in this study was 37.5%; participant frailty and related medical conditions should be considered for future research with a population that has a shortened life expectancy. Next, while it was confirmed that the subjects had not previously been trained to do the compensatory strategies utilized during data collection, the complete history of dysphagia treatment for the participants in the study was unknown. Some were already on modified diets prior to enrollment; however, nurses have the authority to downgrade diets for nursing home residents, so this is not an indication that treatment had occurred. If previous treatment had occurred (e.g., in the home, outpatient, in the hospital, at a different facility) the treatment could have impacted the attitudes of those included in the study either positively or negatively. Finally, the modified barium swallow studies were not completed by the investigator and were not confirmed visually by the investigator. While the modified barium swallow study reports were reviewed by the investigator, future studies should aim for visual confirmation by the investigator that the recommended compensatory strategies are effective on the imaging.

This study was focused on investigating the potential training effects of SR and a visual aid for multi-step compensatory swallowing behaviors and determining if the trained behaviors would be maintained for up to four weeks post training. While this study documented persons' ability to learn and demonstrate behaviors for presumed safer eating, a second limitation was that generalization of the behaviors to actual mealtimes in the typical dining environment was not measured. Future research should include

observation of behaviors in the natural environment during regular mealtimes and during other instances of oral intake such as, snacks and medication administration. The trained compensatory strategies are presumed to be needed for safe oral intake at all times, so if the person is using the strategies in instances other than scheduled mealtimes then modifications would not need to be made for oral intake. Future researchers may also benefit by observing a transition from individual mealtimes to observations of participants in small groups of three or four people at one table who are all using visual aids. Restorative nurses who provide specific follow-up with residents who have completed in-house therapy sessions could manage this type of group for additional practice before transitioning into independent mealtime without direct supervision.

A third limitation is that generalization was only measured for four weeks. It is imperative that the generalization of the trained behaviors be maintained beyond four weeks to consider the behavior maintained. Therefore, observations should be made to measure how long the person maintains the trained behaviors. It is possible that booster sessions to assist in maintenance beyond four weeks would be appropriate (Cherry et al., 2009). Another possible strategy to assure maintenance would be to examine effectiveness of training provided to staff and families for follow up support, as verbal cues could help to maintain the behaviors (Abbott et al., 2013; Bird, 2001; Brush & Camp, 1998b).

A fourth limitation is that physiologic measures of dysphagia were not assessed after treatment, which would have validated the presumed inference that patients are swallowing more safely. Future studies should utilize a post-treatment instrumental

evaluation to ensure the trained behaviors are actually resulting in the safety that was presumed when they were prescribed.

Swallowing problems and mechanically altered diets have been cited as two of the significant predictors that increase the probability of aspiration and pneumonia in nursing home residents, including those with AD (Langmore et al., 2002). Optimization of nutrition, hydration and reduction of the risk for respiratory infection can be measured in future studies to strengthen the support of the current outcomes. A clinical protocol can be designed to measure such variables in addition to safety during oral intake. Additional behaviors such as taking small bites, taking small drinks, and self-feeding can also be addressed. Other studies may extend beyond the post-training to measure if intake of more desired liquid viscosities and solid consistencies improve with the use of the trained compensatory strategies and how long the postponement in change of diet lasts. Development of respiratory infections and development of dehydration and/or malnutrition in relation to a delayed diet change with use of safety strategies could be examined in future studies. Outcome measures, such as respiratory infection, dehydration and malnutrition are typically examined long-term, such as months or years and were not measured in the current study.

Finally, consideration should be given to the participant's quality of life in terms of diet modifications. Extensions of the current study could collect pre- and post-study data using an outcome-tracking tool such as the SWAL-QOL and SWAL-CARE (McHorney, Martin-Harris, Robbins, & Rosenbek, 2006), which objectively measures a

patient's perspective of swallowing. Such data could strengthen the outcomes when viscosities and consistencies are changed from pre- to post-treatment.

Conclusion

Spaced Retrieval training and a visual aid were used to teach five subjects compensatory swallowing strategies for use during oral intake. Participants ranged in age from 66 to 81 years with MMSE scores ranging from 18-21. The purpose of this study was to (a) determine if SR, when paired with an external memory aid, is an effective technique to teach persons with dementia to use compensatory swallowing strategies; and (b) to learn if SLPs naïve to the study aims would judge post-training mealtime sessions as improved, or safer, in comparison to baseline sessions, thereby validating the changes due to SR training to use external aids during meals. Following the standard SR protocol with the addition of a visual aid in the training and follow-up phases, results demonstrated the effectiveness of teaching compensatory swallowing strategies using SR and a visual aid. The results furthered the previous work of Brush and Camp (1998b) by replicating the effects of the training with five participants learning up to three safe swallowing strategies each. A variety of behaviors were trained and each participant who completed the study demonstrated use of the strategies during follow-up sessions with access to the visual aid.

In conclusion, there was a treatment effect of SR training with the use of a visual aid for at least two behaviors for each participant. These study outcomes paired with social validation ratings demonstrated that persons with dementia can learn compensatory

swallowing behaviors for safety during oral intake, but further research is needed to validate the outcomes in this study. Therefore, SR, with the use of a visual aid, may prove to be an effective treatment option for persons with dementia and a coexisting dysphagia.

References

- Abbott, R. A., Whear, R., Thompson-Coon, J., Ukoumunne, O. C., Rogers, M., Bethel, A., ... & Stein, K. (in press). Effectiveness of mealtime interventions on nutritional outcomes for the elderly living in residential care: A systematic review and meta-analysis. *Ageing Research Reviews*.
- Abrahams, J. P., & Camp, C. J. (1993). Maintenance and generalization of object naming training in anomia associated with degenerative dementia. *Clinical Gerontologist*, 12(3), 57-72.
- Allen-Burge, R., Burgio, L., Bourgeois, M., Sims, R., & Nunnikhoven, J. (2001). Increasing communication among nursing home residents. *Journal of Clinical Geropsychology*, 7, 213-230.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed., revised). Washington, DC: American Psychiatric Association.
- Aggarwal, N. T., Wilson, R. S., Beck, T. L., Bienias, J. L., & Bennett, D. A. (2005). Mild cognitive impairment in different functional domains and incident Alzheimer's disease. *Journal of Neurology, Neurosurgery & Psychiatry*, 76(11), 1479-1484.
- Backman, L., Mantyla, T., & Herlitz, A. (1990). The optimization of episodic remembering in old age. In P. B. Baltes, and M. M. Baltes (Eds.), *Successful*

- Aging: Perspectives from the Behavioral Sciences* (pp. 188-163). New York: Cambridge University Press.
- Baddeley, A. (1992). Working memory. *Science*, 255, 556-569.
- Baddeley, A. D. (1995). The psychology of memory. In A. D. Baddeley, B. A. Wilson, & F. N. Watts (Eds.), *Handbook of memory disorders* (pg. 3-26). New York: John Wiley.
- Baddeley, A. D. (1999). *Essentials of human memory* (Vol. 1). Hove: Psychology Press.
- Baddeley, A. D. (2000). The episodic buffer: A new component of working memory? *Trends in Cognitive Science*, 4(11), 417-423.
- Balota, D. A., Duchek, J. M. & Logan, J. M. (2007). Is expanded retrieval practice a superior form of spaced retrieval? A critical review of the extant literature. In J. S. Narine (Ed.), *The Foundations of Remembering. Essays in Honor of Henry L. Roediger, III* (pp. 83-105). New York, NY: Psychological Press.
- Balota, D. A., Duchek, J. M., Paullin, R. (1989). Age-related differences in the impact of spacing, lag, and retention interval. *Psychology and Aging*, 4(1), 3-9.
- Bird, M. (2001). Behavioural difficulties and cued recall of adaptive behaviour in dementia: Experimental and clinical evidence. *Neuropsychological Rehabilitation*, 11(3/4), 357-375.
- Bisch, E. M., Logemann, J. A., Rademaker, A. W., Kahrilas, P. J. & Lazarus, C. L. (1994). Pharyngeal effects of bolus volume, viscosity and temperature in patients with dysphagia resulting from neurologic impairment and in normal subjects. *Journal of Speech and Hearing Research*, 37, 1041-1049.

- Bourgeois, M. S. (1990). Enhancing conversation skills in residents with Alzheimer's disease using a prosthetic memory aid. *Journal of Applied Behavior Analysis*, 23, 29-4
- Bourgeois, M. S. (1992a). *Enhancing the conversations of memory-impaired persons: A memory aid workbook*. Gaylord, MI: Northern Speech Services, Inc.
- Bourgeois, M. S. (1992b). Evaluating memory wallets in conversations with persons with dementia. *Journal of Speech and Hearing Research*, 35, 1344-1357.
- Bourgeois, M. S. (1993). Effects of memory aids on the didactic conversations of individuals with dementia. *Journal of Applied Behavior Analysis*, 26, 77-87.
- Bourgeois, M. S. (2007). *Memory Books and Other Graphic Cuing Systems: Practical Communication and Memory Aids for Adults with Dementia*. Baltimore: Health Professions Press.
- Bourgeois, M., Burgio, L., Schultz, R., Beach, S., & Palmer, B. (1997). Modifying repetitive verbalization of community dwelling patients with AD. *The Gerontologist*, 37, 30-39.
- Bourgeois, M. S., Camp, C., Rose, M., White, B., Malone, M., Carr, J., & Rovine, M. (2003). A comparison of training strategies to enhance use of external aids by persons with dementia. *Journal of Communication Disorders*, 36(5), 361-378.
- Bourgeois, M., Dijkstra, K., Burgio, L., & Allen-Burge, R. (2001). Memory aids as an AAC strategy for nursing home residents with dementia. *Augmentative and Alternative Communication*, 17, 196-210.

- Bourgeois, M. S., & Hickey, E. M. (2009). *Dementia: From diagnosis to management: A functional approach*. New York, NY: Psychological Press.
- Bourgeois, M. S., Lenius, K., Turkstra, L., & Camp, C. (2007). The effects of cognitive teletherapy on reported everyday memory behaviours of persons with chronic traumatic brain injury. *Brain Injury*, 21(12), 1245-1257.
- Bourgeois, M. S., & Mason, L. A. (1996). Memory wallet intervention in adult day care setting. *Behavior Interventions: Theory and Practice in Residential and Community-Based Clinical Programs*, 11, 3-18.
- Brookshire, R. H. (2003). *Introduction to neurogenic communication disorders* (6th ed.). St. Louis, MO: Mosby.
- Brush, J., & Camp, C. (1998a). Using spaced-retrieval training as an intervention during speech-language therapy. *Clinical Gerontologist*, 19(1), 51-64.
- Brush, J., & Camp, C. (1998b). Spaced retrieval during dysphagia therapy: a case study. *Clinical Gerontologist*, 19(2), 77-99.
- Brush, J., Fleder, H., & Calkins, M. (2012). *Using the Environment to Support Communication and Foster Independence in People with Dementia: A review of case studies in long term care settings*. Kirtland, Ohio: I.D.E.A.S., Inc.
- Brush, J. A., Meehan, R. A., & Calkins, M. (2002). Using the environment to improve intake for people with dementia. *Alzheimer's Care Quarterly*, 3(4), 330-338.
- Burgio, L., Allen-Burge, R., Roth, D., Bourgeois, M., Dijkstra, K., Gerstle, J., et al. (2001). Come talk with me: Improving communication between nursing

- assistants and nursing home residents during care routines. *The Gerontologist*, 41, 449-460.
- Burton, E., & Torrington, J. (2007). Designing environments suitable for older people. *CME Journal Geriatric Medicine*, 9(2), 39.
- Calkins, M. P., & Brush, J. A. (2003). Designing for dining. *Alzheimer's Care Quarterly*, 4(1), 73-76.
- Camp, C. J. (1989). Facilitation of new learning in Alzheimer's disease. In G. Gilmore, P. Whitehouse, & M. Wykle (Eds.) *Memory and dementia: Research, theory, and practice* (pp. 212-225). New York: Springer.
- Camp, C. J. (2001). From efficacy to effectiveness to diffusion: Making the transitions in dementia intervention research. *Neuropsychological Rehabilitation*, 11(3-4), 495-517.
- Camp, C. J., Foss, J. W., O'Hanlon, A. M., & Stevens, A. B. (1996). Memory interventions for persons with dementia. *Applied Cognitive Psychology*, 10, 193-210.
- Camp, C. J., Foss, J. W., Stevens, A. B., & O'Hanlon, A. M. (1996). Improving prospective memory task performance in persons with Alzheimer's disease. In M. A. Brandimonte, G. Einstein, & M. McDaniel (Eds.) *Prospective Memory: Theory and Applications* (pp. 351-367). Hillsdale, NJ: Lawrence Erlbaum.
- Camp, C. J., & Schaller, J. R. (1989). Epilouge: Spaced-retrieval memory training in an adult day-care center. *Educational Gerontology: An International Quarterly*, 15(6), 641-648.

- Camp, C. J., & Stevens, A. B. (1990). Spaced-retrieval: A memory intervention for dementia of the Alzheimer's type. *Clinical Gerontologist: The Journal of Aging and Mental Health*.
- Carroll, W. R., Locher, J. L., Canon, C. L., Bohannon, I. A., McColloch, N. L., & Magnuson, J. S. (2008). Pretreatment swallowing exercises improve swallow function after chemoradiation. *The Laryngoscope*, 118(1), 39-43.
- Castellanos, V. H., Butler, E., Gluch, L., & Burke, B. (2004). Use of thickened liquids in skilled nursing facilities. *Journal of the American Dietetic Association*, 104(8), 1222-1226.
- Chaudhuri, G., Hildner, C. D., Brady, S., Hutchins, B., Aliga, N., & Abadilla, E. (2002). Cardiovascular effects of the supraglottic and super-supraglottic swallowing maneuvers in stroke patients with dysphagia. *Dysphagia*, 17(1), 19-23.
- Cherney, L. R. (1994). *Clinical management of dysphagia in adults and children*. Aspen Publishers.
- Cherry, K. E., Hawley, K. S., Jackson, E. M., & Boudreaux, E. O. (2009). Booster sessions enhance the long-term effectiveness of spaced retrieval in older adults with probable Alzheimer's disease. *Behavior Modification*, 33(3), 295-313.
- Clark, H., Lazarus, C., Arvedson, J., Schooling, T., & Frymark, T. (2009). Evidence-based systematic review: Effects of neuromuscular electrical stimulation on swallowing and neural activation. *American Journal of Speech-Language Pathology*, 18(4), 361-375.

- Crum, R. M., Anthony, J. C., Bassett, S. S., & Folstein, M. F. (1993). Population-based norms for the Mini-Mental State Examination by age and educational level. *The Journal of the American Medical Association*, 269(18), 2386-2391.
- Dejaeger, E., Pelemans, W., Ponette, E., & Vantrappen, G. (1994). Effect of body position on deglutition. *Digestive diseases and sciences*, 39(4), 762-765.
- Dunne, T. E., Nearing, S. A., Cipolloni, P. B., & Cronin-Golomb, A. (2004). Visual contrast enhances food and liquid intake in advanced Alzheimer's disease. *Clinical Nutrition*, 23(4), 533-538.
- Easterling, C. S. & Robbins, E. (2008). Dementia and dysphagia. *Geriatric Nursing* 29(4), 275-285.
- Folstein, M., Folstein, S., & McHugh, P. (1975). Mini-mental state. *Journal of Psychiatric Research*, 12, 189-198.
- Fridriksson, J., Holland, A., Beeson, P., & Morrow, L. (2005). Spaced retrieval treatment of anomia. *Aphasiology*, 19(2), 99-109.
- Fujiu, M., & Logemann, J. A. (1996). Effect of a tongue-holding maneuver on posterior pharyngeal wall movement during deglutition. *American Journal of Speech-Language Pathology*, 5(1), 23.
- Furia C.L., Carrara-de Angelis E., Martins N.M., Barros A.P., Carneiro B., Kowalski L.P. (2000). Video fluoroscopic evaluation after glossectomy. *Archives of Otolaryngology- Head & Neck Surgery*. 126(3), 378-83.
- Gillick, M. R., & Mitchell, S. L. (2002). Facing eating difficulties in end-stage dementia. *Alzheimer's Care Quarterly* 3(3), 227-232.

- Glenberg, A. M. (1977). Influences of retrieval processes on the spacing effect in free recall. *Journal of Experimental Psychology: Human Learning and Memory*, 3, 282-294.
- Groher, M. E., & McKaig, N. (1995). Dysphagia and dietary levels in skilled nursing facilities. *Journal of the American Geriatrics Society*, 43(5), 528-532.
- Hellen, C. R., (2002). Doing lunch: A proposal for functional well-being assessment. *Alzheimer's Care Quarterly* 3(4), 302-315.
- Hind, J. A., Nicosia, M. A., Roecker, E. B., Carnes, M. L., & Robbins, J. (2001). Comparison of effortful and noneffortful swallows in healthy middle-aged and older adults. *Archives of Physical Medicine and Rehabilitation*, 82(12), 1661.
- Hopper, T., Mahendra, N., Kim, E., Azuma, T., Bayles, K. A., Cleary, S. J., & Tomoeda, C. K. (2005). Evidence-based practice recommendations for working with individuals with dementia: spaced-retrieval training. *Journal of Medical Speech-Language Pathology*, 13(4), xxvii-xxxiv.
- Hoerster, L., Hickey, E. M., & Bourgeois, M.S. (2001). Effects of memory aids on conversations between nursing home residents with dementia and nursing assistants. *Neuropsychological Rehabilitation*, 11 (3/4), 399-427.
- Jacob, P., Kahrilas, P. J., Logemann, J. A., Shah, V., & Ha, T. (1989). Upper esophageal sphincter opening and modulation during swallowing. *Gastroenterology*, 97, 1469-1478.
- Jean, L. A., (1997). Finger-food menu restores independence in dining. *Health Care Food Nutrition Focus*, 14(1), 4-6.

- Kahrilas, P. J., Logemann, J. A., Krugler, C., & Flanagan, E. (1991). Volitional augmentation of upper esophageal sphincter opening during swallowing. *American Journal of Physiology-Gastrointestinal and Liver Physiology*, 260(3), G450-G456.
- Kotler-Cope, S., & Camp, C. J. (1990). Memory interventions in aging populations. In E. A. Lovelace (Eds.), *Aging and cognition: Mental processes, self-awareness and interventions* (pp. 231-261). North Holland: Elsevier.
- Landauer, T. K., & Bjork, R. A. (1978). Optimum rehearsal patterns and name learning. In M. M. Gruneberg, P. E. Morns, & R. N. Skeyes (Eds.), *Practical aspects of memory* (pp. 625-632). London: Academic Press
- Langmore, S. E., Skarupski, K. A., Park, P. S., & Fries, B. E. (2002). Predictors of aspiration pneumonia in nursing home residents. *Dysphagia*, 17(4), 298-307.
- Langmore, S. E., Terpenning, M. S., Schork, A., Chen, Y., Murray, J. T., Lopatin, D., Loesche, W. J. (1998). Predictors of aspiration pneumonia: How important is dysphagia? *Dysphagia*, 13, 69-81.
- Lazarus, C., Logemann, J. A., & Gibbons, P. (1993). Effects of maneuvers on swallowing function in a dysphagic oral cancer patient. *Head & Neck*, 15(5), 419-424.
- Lazarus, C., Logemann, J. A., Huang, C. F., & Rademaker, A. W. (2003). Effects of two types of tongue strengthening exercises in young normals. *Folia phoniatrica et logopaedica*, 55(4), 199-205.

- Lin, L-C., Huang, Y-J., Su, S-G., Watson, R., Tsai, B., & Wu, S-C. (2010). Using spaced retrieval and Montessori-based activities in improving eating ability for residents with dementia. *International Journal of Geriatric Psychiatry*, 25(10), 953-959.
- Links, K. A., Merims, D., Binns, M. A., Freedman, M., & Chow, T. W. (2010). Prevalence of primitive reflexes and parkinsonian signs in dementia. *The Canadian Journal of Neurological Sciences*, 37(5), 601-607.
- Logemann, J. A. (1998). *Evaluation and treatment of swallowing disorders (2nd Edition)*. Austin, TX: Pro-Ed.
- Logemann, J.A., Gensler, G., Robbins, J.A., Lindblad, A.S., Brandt, D.K., Hind, J.A., Kosek, S., Dikeman, K., Kazandjian, M., Gramigna, G. D., Lundy, D., McGarvey-Toler, S., Miller Gardner, P. J. (2008). A randomized study of three interventions for aspiration of thin liquids in patients with dementia or Parkinson's disease. *Journal of Speech, Language and Hearing Research*; 51: 173-183.
- Logemann, J. A., Kahrilas, P. J., Cheng, J., Pulaski, B. R., Gibbons, P.J., Rademaker, A.W., Un, S. (1992). Closure mechanisms of the laryngeal vestibule during swallowing. *American Journal of Physiology*, 262, G338-G344.
- Logemann, J. A., Pauloski, B. R., Colangelo, L., Lazarus, C., Fujii, M., Kahrilas, P. J. (1995). Effects of a sour bolus on oropharyngeal swallowing measures in patients with neurogenic dysphagia. *Journal of Speech and Hearing Research*, 38, 556-563.
- Logemann, J. A., Rademaker, A., Pauloski, B. R., Kelly, A., Stangl-McBreen, C.,

- Antinoja, J., Grande, B., Farquharson, J., Kern, M., Easterling, C., Shaker, R. (2009). A randomized study comparing the shaker exercise with traditional therapy: A preliminary study. *Dysphagia*, 24(4), 403-411.
- Martin, B. J., Logemann, J. A., Shaker, R., & Dodds, W. J. (1993). Normal laryngeal valving patterns during three breath-hold maneuvers: a pilot investigation. *Dysphagia*, 8(1), 11-20.
- Medicare National Coverage Determinations Manual (2011). *Coverage determinations* (Rev. 131, 02-23-11). Retrieved from http://www.cms.gov/manuals/downloads/ncd103c1_Part3.pdf
- McHorney, C. A., Martin-Harris, B., Robbins, J., & Rosenbek, J. (2006). Clinical validity of the SWAL-QOL and SWAL-CARE outcome tools with respect to bolus flow measures. *Dysphagia*, 21(3), 141-148.
- McKittrick, L. A., Camp, C. J., & Black, F. W. (1992). Prospective memory intervention in Alzheimer's disease. *Journal of Gerontology*, 47(5), 337-343.
- Morris, R. G. (1994). Working memory in Alzheimer-type dementia. *Neuropsychology*, 8(4), 544-554.
- Morris, J., & Volicer, L. (2001). Nutritional management of individuals with Alzheimer's disease and other progressive dementias. *Nutrition in Clinical Care*, 4, 148-155.
- Neath, I., & Surprenant, A. M. (2003). *Human Memory* (2nd ed.). Belmont, CA: Wadsworth/Thompson Learning.

- Peterson, L. R., Wampler, R., Kirkpatrick, M., Saltzman, D. (1963). Effect of spacing presentations on retention of a paired associate over short intervals. *Journal of Experimental Psychology*, 66(2), 206-209.
- Poertner, L. C., & Coleman, R. F. (1998). Swallowing therapy in adults. *Otolaryngologic Clinics of North America*, 31(3), 561-579.
- Priefer, B. A., & Robbins, J. (1997). Eating changes in mild-stage Alzheimer's disease: A pilot study. *Dysphagia*, 12(4), 212-221.
- Rasley, A., Logemann, J. A., Kahrilas, P. J., Rademaker, A. W., Pauloski, B. R., & Dodds, W. J. (1993). Prevention of barium aspiration during videofluoroscopic swallowing studies: value of change in posture. *American Journal of Roentgenology*, 160(5), 1005-1009.
- Robbins J., Butler, S. G., Daniels, S. K., Gross, R.D., Langmore, S., Lazarus, C.L., Martin-Harris, B., McCabe, D., Musson, N., Rosenbek, J.C. (2008). Swallowing and dysphagia rehabilitation: Translating principles of neural plasticity into clinically oriented evidence. *Journal of Speech, Language, and Hearing Research*, 51(1), S276–S300.
- Robbins, J., Gangnon, R. E., Theis, S. M., Kays, S. A., Hewitt, A. L., & Hind, J. A. (2005). The effects of lingual exercise on swallowing in older adults. *Journal of the American Geriatrics Society*, 53(9), 1483-1489.
- Robbins, J., Gensler, G., Hind, J., Logemann, J. A., Linblad, A. S., Brandt, D., Baum, H., Lilienfeld, D., Kosek, S., Lundy, D., Dikeman, K., Kazandjian, M., Gramigna, G. D., McGarvey-Toler, S., & Miller Gardner, P. J. (2008). Comparison of two

- interventions for liquid aspiration on pneumonia incidence. *Annals of Internal Medicine*, 148(7), 509-518.
- Robbins, J., Hamilton, J. W., Lof, G. L., & Kempster, G. B. (1992). Oropharyngeal swallowing in normal adults of different ages. *Gastroenterology*, 103(3), 823-829.
- Robbins, J., Kays, S. A., Gangnon, R. E., Hind, J. A., Hewitt, A. L., Gentry, L. R., & Taylor, A. J. (2007). The effects of lingual exercise in stroke patients with dysphagia. *Archives of Physical Medicine and Rehabilitation*, 88, 150-158.
- Roberts, S., & Durnbaugh, T. (2002). Enhancing nutrition and eating skills in long term care. *Alzheimer's Care Quarterly*, 3(4), 316-329.
- Sapienza, C. M., & Wheeler, K. (2006). Respiratory muscle strength training: Functional outcomes versus plasticity. *Seminars in Speech and Language*, 27, 236-244.
- Schacter, D. L., Rich, S. A., & Stamp, M. S. (1985). Remediation of memory disorders: Experimental evaluation of the spaced-retrieval technique. *Journal of Clinical Experimental Neuropsychology*, 7(1), 79-96.
- Shaker, R., Easterling, C., Kern, M., Nitschke, T., Massey, B., Daniels, S., Grande, B., Kazandjian, M. & Dikeman, K. (2002). Rehabilitation of swallowing by exercise in tube-fed patients with pharyngeal dysphagia secondary to abnormal UES opening. *Gastroenterology*, 122(5), 1314-1321.
- Sharkawi, A. E., Ramig, L., Logemann, J. A., Pauloski, B. R., Rademaker, A.W., Smith, C. H., et al. (2002). Swallowing and voice effects of Lee Silverman Voice Treatment (LSVT): A pilot study. *Journal of Neurology, Neurosurgery and Psychiatry*, 72, 31-36.

- Simmons, S. F., & Schnelle, J. F. (2003). Implementation of nutritional interventions in long-term care. *Alzheimer's Care Quarterly*, 4(4), 286-296.
- Sohlberg, M. M., (2005). External aids for management if memory impairment. In W. High, A. Sander, K. M. Struchen, & K. A. Hart (Eds.), *Rehabilitation for traumatic brain injury*. New York: Oxford University Press.
- Spitzer, H. F. (1939). Studies in retention. *Journal of Educational Psychology*, 30(9), 641-657.
- Turkstra, L. S., & Bourgeois, M. (2005). Intervention for a modern day HM: Errorless learning of practical goals. *Journal of Medical Speech Language Pathology*, 13(3), 205.
- Turley, R., & Cohen, S. (2009). Impact of voice and swallowing problems in the elderly. *Otolaryngology--Head and Neck Surgery*, 140(1), 33-36.
- Veis, S., Logemann, J. A., & Colangelo, L. (2000). Effects of three techniques on maximum posterior movement of the tongue base. *Dysphagia*, 15(3), 142-145.
- Walsh, J.C., & Unwin, B., K. (2011). Recognition and management of autonomic dysfunction in patients with a Lewy body disorder: part I. *Clinical Geriatrics*, 19(10), 33-38.
- Welch, M. V., Logemann, J. A., Rademaker, A.W., Kahnilas, P. J. (1993). Changes in pharyngeal dimensions effected by chin tuck. *Archives of Physical Medicine and Rehabilitation*, 74(2), 178-181.
- Wijting, Y., & Freed, M. (2010). *Training manual for the use of neuromuscular electrical stimulation in the treatment of dysphagia*. Gulf Breeze, FL: Authors.

Wilson, B. A. (2009). *Memory rehabilitation: Integrating theory and practice*. New York, NY: Guilford Press.

Wilson, B. A., Baddeley, A., Evans, J. & Shiel, A. (1994). Errorless learning in the rehabilitation of memory impaired people. *Neuropsychological Rehabilitation*, 4(3), 307-326.

Zgola, J. M., & Bordillon, G. (2002). Four guys at the table. *Alzheimer's Care Quarterly* 3(4), 279-288.

Appendix A: Consent to Participate in Research Form

■

■ **The Ohio State University Consent to Participate in Research**

Study Title: Using Spaced Retrieval with External Aids to Improve Use of Compensatory Strategies during Eating for Persons with Dementia

Principal Investigator: Michelle S. Bourgeois, PhD

Sponsor: None

- **This is a consent form for research participation.** It contains important information about this study and what to expect if you decide to enroll the participant. Please consider the information carefully. Feel free to discuss the study with your friends and family and to ask questions before making your decision whether or not to enroll the participant.
- **The participant's participation is voluntary.** You may refuse to enroll the participant in this study. If you decide to enroll the participant in the study, he/she may leave the study at any time. No matter what decision you make, there will be no penalty to the participant and the participant will not lose any of his/her usual benefits. Your decision will not affect the participant's future relationship with The Ohio State University. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.
- **The participant may or may not benefit as a result of participating in this study.** Also, as explained below, participation may result in unintended or harmful effects that may be minor or may be serious depending on the nature of the research.
- **The participant will be provided with any new information that develops during the study that may affect your decision whether or not to continue to keep the participant enrolled.** If you decide to enroll the participant, you will be asked to sign this form and will receive a copy of the form. You are being asked to consider enrolling the participant in this study for the reasons explained below.

1. Why is this study being done?

The purpose of this research is to determine the effects of a memory training technique, called spaced retrieval, on safe mealtime behaviors and strategies for persons with memory impairments (dementia) and difficulty swallowing (dysphagia).

2. How many people will take part in this study?

Ten people (male and female ages 65-95) will be enrolled in the study.

3. What will happen if I take part in this study?

The investigators will meet with the participant to administer four measures: 1) the *Mini Mental Status Examination* (Folstein, Folstein, & McHugh, 1978), 2) informal reading measure utilizing stimuli similar to that in the research, 3) the spaced retrieval screening, and 4) an observation on the participant eating during a normal meal. A swallowing study will be obtained and behaviors and strategies will be determined for a safer mealtime. The investigator will then write 2-3 questions and target responses based on the meal analysis and swallow study finding. During each session, the participant will be asked their question and will practice answering the questions in expanding time intervals. Each session will include a pleasurable and engaging activity during the timed intervals (e.g., taking a walk, reading a book, making a puzzle, etc.).

4. How long will I be in the study?

Each session will last 30-40 minutes. The initial screening protocol should take no longer than 60 minutes to administer. At any time if the participant expresses fatigue or disinterest in the procedures, the session will be discontinued. Each participant will be visited for two maintenance sessions (1-week and 4-week post). All sessions will be audio and video recorded for analysis.

5. Can I stop being in the study?

The participant may leave the study at any time. If the participant decides to stop participating in the study, there will be no penalty to him/her, and the participant will not lose any benefits to which he/she is otherwise entitled. The decision to leave the study will not affect the participant's future relationship with The Ohio State University.

6. What risks, side effects or discomforts can I expect from being in the study?

The aim of this study is to determine if a cognitive training technique (spaced retrieval), when paired with an external memory aid, such as a written reminder card, is an effective technique to teach persons with memory impairments (dementia) behaviors that elicit a safer swallow. Examples of these behaviors may include alternating bites of food with sips of liquid, small bites and sips, tucking the chin or turning the head when swallowing. Participants will be trained in timed intervals and therefore, some participants may feel embarrassed at their inability to recall the target response. If a participant expresses, either verbally or nonverbally, that they are confused, suspicious, reluctant, or unwilling to engage in training with the PI, the session will be terminated immediately. It is the experience of the PI that these expressions of discomfort are rare and easily resolved by terminating the session. The PI will notify the staff or family member immediately after terminating a session, in order that the appropriate support measures are implemented to resolve any negative ramifications of the session.

7. What benefits can I expect from being in the study?

The direct benefit to participants is that they will receive individualized attention, including opportunities to converse with the investigator, and that may be pleasurable for them. Additionally, the participant will be trained on mealtime behaviors and strategies that could provide a safer swallow for the reduced risk of respiratory infections and avoidance of food and liquid modifications. The benefit to others includes providing health care professionals with insight into the best way to train persons with memory impairments (dementia) to remember these helpful behaviors and strategies.

8. What other choices do I have if I do not take part in the study?

The participant may choose not to participate without penalty or loss of benefits to which he/she is otherwise entitled.

9. Will my study-related information be kept confidential?

Efforts will be made to keep the participant's study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding participation in this study may be disclosed if required by state law.

Also, records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- U.S. Food and Drug Administration;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;
- The sponsor supporting the study, their agents or study monitors; and
- The participant's insurance company (if charges are billed to insurance).

If this study is related to the participant's medical care, the study-related information may be placed in the participant's permanent hospital, clinic, or physician's office records. Authorized Ohio State University staff not involved in the study may be aware of the participant's inclusion in a research study and have access to your information.

A description of this clinical trial will be available on <http://www.ClinicalTrials.gov>, as required by U.S. law. This website will not include information that can identify the participant. At most, the website will include a summary of the results. You can search the website at any time.

You may also be asked to sign a separate Health Insurance Portability and Accountability Act (HIPAA) research authorization form if the study involves the use of the participant's protected health information.

10. What are the costs of taking part in this study?

There are no costs to take part in this study.

11. Will I be paid for taking part in this study?

No, the participant will not be paid for taking part in this study. Law considers payments to subjects considered taxable income.

12. What happens if I am injured because I took part in this study?

If the participant suffers an injury from participating in this study, you should notify the researcher or study doctor immediately, who will determine if he/she should obtain medical treatment at The Ohio State University Medical Center.

The cost for this treatment will be billed to the participant or his/her medical or hospital insurance. The Ohio State University has no funds set aside for the payment of health care expenses for this study.

13. What are my rights if I take part in this study?

If you choose to enroll the participant in the study, you may discontinue his/her participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights the participant may have as a participant in this study.

You will be provided with any new information that develops during the course of the research that may affect your decision whether or not to continue enrollment of the participant in the study.

You may refuse to enroll the participant in this study without penalty or loss of benefits to which he/she is otherwise entitled.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

14. Who can answer my questions about the study?

For questions, concerns, or complaints about the study you may contact Michelle S. Bourgeois, Ph.D., CCC-SLP, (614) 292-1742.

For questions about the rights as the participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

If the participant is injured as a result of participating in this study or for questions about a study-related injury, you may contact Michelle S. Bourgeois, Ph.D., CCC-SLP, (614) 292-1742.

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

_____ Printed name of subject	_____ Signature of subject _____ Date and time AM/ PM
_____ Printed name of person authorized to consent for subject (when applicable)	_____ Signature of person authorized to consent for subject (when applicable) _____ Date and time AM/ PM
_____ Relationship to the subject	_____ Date and time

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

_____ Printed name of person obtaining consent	_____ Signature of person obtaining consent _____ Date and time AM/PM
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Witness(es) - May be left blank if not required by the IRB

_____ Printed name of witness	_____ Signature of witness _____ Date and time AM/PM
_____ Printed name of witness	_____ Signature of witness _____ Date and time AM/PM

Appendix B: HIPPA Research Authorization Form

THE OHIO STATE UNIVERSITY HIPAA RESEARCH AUTHORIZATION FORM

Beginning April 14, 2003, the new HIPAA Privacy Rule requires that Ohio State University Principal Investigators (PIs) provide research subjects with greater detail than what is currently included in the IRB-approved consent form concerning how a subject's past, present and future health-related information (collectively, Protected Health Information or PHI) will be used, shared and protected during the research. Specifically, the Privacy Rule now requires that PIs inform subjects of the following: 1) what specific kinds of information will be used or disclosed to others during the course of the research; 2) the specific identities of collaborating investigators, sponsor companies or sponsor agencies that will potentially receive copies of subjects' PHI during the research; 3) that subjects have a right to review their research-related PHI; and 4) that subjects have the express right to revoke their authorizations for the release of PHI at any time.

To meet these new requirements, PIs using PHI obtained from medical or research records from the Ohio State University Hospitals, The Arthur G. James Cancer Hospital and Richard J. Solove Research Institute, OSU & Harding Behavioral Health Care & Medicine, the Ohio State University Hospitals East and the Primary Care Network (the University Health System), or other University operated health centers or clinics, must now complete and receive a signed copy of the University's "Authorization to Use Personal Health Information in Research" form (the Authorization) below from subjects enrolling in research studies on or after April 14th (or be granted a waiver by a HIPAA Privacy Board) in addition to obtaining a signed IRB-approved consent form. The form will need to be carefully prepared by PIs to ensure that the Authorization covers ALL of the necessary uses and disclosures of personal health information used in clinical research. Failure to do so may violate the Privacy Rule and result in penalties against the University as well as individual civil and criminal penalties against the Principal Investigator.

INSTRUCTIONS TO RESEARCHERS FOR PREPARING THE RESEARCH AUTHORIZATION FORM

1. Complete the first section of the Authorization form with title of the study, the OSU IRB protocol number, and PI name. Add subject name at the time of authorization. Do not include these instructions as part of the completed Authorization form.
2. "Uses and Disclosures Covered by this Authorization" – List every known non-OSU person, class of persons, or organizations (including the sponsor agency or company, known subsidiaries of the sponsor, cooperative data groups, etc.) that may create, disclose, receive, and/or use the information in connection with the study. Fill in the blanks on the form (and delete the instructions in italics as well as inapplicable bulleted sections) as appropriate. If information will not be disclosed outside of The Ohio State University, delete all bullets and insert "None". Note: if a person(s) or organization is not listed on the form, they may not create, disclose, receive or use PHI in connection with the study.
- 3a. "HIPAA Privacy Contact" – If the research involves the use of medical records from the University Health System, where applicable, insert the contact and address: HIPAA Privacy

Manager, the Ohio State University Medical Center, 140 Doan Hall, 410 W. Tenth Avenue, Columbus, Ohio 43210.

- 3b. If the research solely involves the use of personal health records at non-University Health System clinics or health care facilities (for example, the Dental School, Optometry School, Nisonger Center, Younkin Center, Psychological Services Center, Anxiety and Stress Disorder Clinic, Marriage & Family Therapy Clinic, Camera Center or faculty practice group such as OSU-P) insert the name and address of the appropriate Privacy Contact for the center, school, clinic or practice group. If unknown, contact the director of the health center, school, clinic or practice group or the Office of Legal Affairs at (614) 292-0611 for the contact and address of the applicable Privacy Contact.
- 4. The Authorization must be presented to all newly enrolled or “re-consented” subjects in IRB-approved research beginning April 14, 2003 at the time the IRB-approved consent form is signed. The subject or his/her legally authorized representative must be provided with a copy of this form after it has been signed. The original, signed copy must be retained in the research file for a period of six years from the date the Authorization was signed (or longer, according to sponsor requirements). Prior IRB approval of the Authorization is not required; however, the Privacy Contact and/or HIPAA Privacy Board may conduct audits of the Authorization to ensure completeness.
- 5a. “Notice of Privacy Practices” – Each subject who receives health care services at the University on or after April 14, 2003 should receive a copy of a Notice of Privacy Practices (NPP) and sign an acknowledgement (NPP Acknowledgement form) that (s)he obtained the NPP.
- 5b. If the research involves the use of health and/or medical records from the University Health System and the subject has not received a copy of the University Health System’s NPP, provide the subject with a copy of the NPP. The subject should sign a copy of the University Health System’s NPP Acknowledgement form. The original, signed copy of the NPP Acknowledgement form must be retained in the research file for a period of six years from the date the NPP Acknowledgement was signed (or longer, according to sponsor requirements). The University Health System’s NPP and NPP Acknowledgement form are available in electronic format on the Office of Responsible Research Practices (ORRP) website at <http://www.orrp.ohio-state.edu> as well as the Medical Center’s website at <http://www.osumedcenter.edu>.
- 5c. If the research involves the use of health records at other non-University Health System clinics or facilities (including the sites listed above in item 3b.) and the subject have not received a copy of the facility or clinic’s individual NPP; provide the subject with a copy of the NPP. Contact the director of the applicable health center, school, clinic or practice group to obtain a copy of the NPP and the NPP Acknowledgement form. The original, signed copy of the NPP Acknowledgement form must be retained in the research file for a period of six years from the date the NPP Acknowledgement was signed (or longer, according to sponsor requirements)

Appendix C: Personal Health Information in Research Form

**THE OHIO STATE UNIVERSITY
AUTHORIZATION TO USE
PERSONAL HEALTH INFORMATION IN RESEARCH**

Title of the Study:

**Using Spaced Retrieval with External Aids to Improve Use of
Compensatory Strategies during Eating for Persons with Dementia**

OSU Protocol Number: 2012H0201

Principal Investigator: Michelle Bourgeois, Ph.D.

Subject Name _____

Before researchers use or share any health information about you as part of this study, The Ohio State University is required to obtain your authorization. This helps explain to you how this information will be used or shared with others involved in the study.

- The Ohio State University and its hospitals, clinics, health-care providers and researchers are required to protect the privacy of your health information.
- You should have received a Notice of Privacy Practices when you received health care services here. If not, let us know and a copy will be given to you. Please carefully review this information. Ask if you have any questions or do not understand any parts of this notice.
- If you agree to take part in this study your health information will be used and shared with others involved in this study. Also, any new health information about you that comes from tests or other parts of this study will be shared with those involved in this study.
- Health information about you that will be used or shared with others involved in this study may include your research record and any health care records at the Ohio State University. For example, this may include your medical records, x-ray or laboratory results. Psychotherapy notes in your health records (if any) will not, however, be shared or used. Use of these notes requires a separate, signed authorization.

Please read the information carefully before signing this form. Please ask if you have any questions about this authorization, the University's Notice of Privacy Practices or the study before signing this form.

Initials/Date: _____

Those Who May Use, Share And Receive Your Information As Part Of This Study

- Researchers and staff at The Ohio State University will use, share and receive your personal health information for this research study. Authorized Ohio State University staff not involved in the study may be aware that you are participating in a research study and have access to your information. If this study is related to your medical care, your study-related information may be placed in your permanent hospital, clinic or physician's office records.
- Those who oversee the study will have access to your information, including:
 - Members and staff of the Ohio State University's Institutional Review Boards, including the Western Institutional Review Board
 - The Office for Responsible Research Practices
 - University data safety monitoring committees
 - The Ohio State University Research Foundation
- Your health information may also be shared with federal and state agencies that have oversight of the study or to whom access is required under the law. These may include:
 - The Food and Drug Administration
 - The Office for Human Research Protections
 - The National Institutes of Health
 - The Ohio Department of Human Services

These researchers, companies and/or organization(s) outside of The Ohio State University may also use, share and receive your health information in connection with this study: None

Authorization Period

This authorization will not expire unless you change your mind and revoke it in writing. There is no set date at which your information will be destroyed or no longer used. This is because the information used and created during the study may be analyzed for many years, and it is not possible to know when this will be complete.

Signing the Authorization

- You have the right to refuse to sign this authorization. Your health care outside of the study, payment for your health care, and your health care benefits will not be affected if you choose not to sign this form.
- You will not be able to take part in this study and will not receive any study treatments if you do not sign this form.

Initials/Date _____

- If you sign this authorization, you may change your mind at any time. Researchers may continue to use information collected up until the time that you formally changed your mind. If you change your mind, your authorization must be revoked in writing. To revoke your authorization, please write to:

Michelle Bourgeois, Ph.D., Principal Investigator, The Ohio State University, Dept. of Speech & Hearing Science, 1070 Carmack Road, Columbus, OH 43210

- Signing this authorization also means that you will not be able to see or copy your study-related information until the study is completed. This includes any portion of your medical records that describes study treatment.

Contacts for Questions

- If you have any questions relating to your privacy rights, please contact:

Gail Whitelaw, Clinic Director, OSU Speech-Language-Hearing Clinic, 110 Pressey, 1070 Carmack Road, Columbus, OH 43210, 292-6251

- If you have any questions relating to the research, please contact:
- **Michelle Bourgeois, Ph.D., Principal Investigator, The Ohio State University, Dept. of Speech & Hearing Science, 1070 Carmack Road, Columbus, OH 43210**

Signature

I have read (or someone has read to me) this form and have been able to ask questions. All of my questions about this form have been answered to my satisfaction. By signing below, I permit *[insert name of Principal Investigator]* and the others listed on this form to use and share my personal health information for this study. I will be given a copy of this signed form.

Signature _____
(Subject or Legally Authorized Representative)

Name _____
(Print name above)
(If legal representative, also print relationship to subject.)

Date _____ Time _____ AM / PM

Appendix D: Screening Form

Subject Name: _____
Address: _____
Caregiver Name: _____
Relationship: _____
Caregiver Address: _____
Caregiver Phone: _____

Subject Demographic Information:

Date of Birth: _____
Race: _____
Gender: _____
Education: _____

I. Medical Record Review

1. Diagnoses: _____

2. Was a videofluoroscopy study performed?
() Yes Date: _____ () No

II. Mini Mental State Examination (Folstein, Folstein, & McHugh, 1975)

Score: _____

III. Oral Reading Screening

18-point font
Words read correctly:
card 1: _____ card 2: _____ card 3: _____ card 4: _____

24-point font
Words read correctly:
card 1: _____ card 2: _____ card 3: _____ card 4: _____

36-point font
Words read correctly:
card 1: _____ card 2: _____ card 3: _____ card 4: _____

IV. Meal Analysis

Can the participant self feed and drink? + -

If the strategy is recommended, can the participant perform it with or without cues?

Recommended Strategy	Performance		Cues needed	
_____ Small bite	+	-	+	-
_____ Small sip	+	-	+	-
_____ Chin down posture	+	-	+	-
_____ Take a drink after you take a bite	+	-	+	-
_____ Swallow twice after you take a bite	+	-	+	-
_____ Wipe mouth with napkin	+	-	+	-
_____ Finger sweep of residue	+	-	+	-
_____ Lingual sweep of residue	+	-	+	-
_____ Ability to stop verbalization	+	-	+	-
_____ Other: _____	+	-	+	-
_____ Other: _____	+	-	+	-
_____ Other: _____	+	-	+	-

Notes:

IV. Spaced Retrieval Screening

Question: What's my name?

Target Response: Jeanette

Goal: 30 seconds

Trial	Number of seconds	Response		
1		+	-	NR
2		+	-	NR
3		+	-	NR
4		+	-	NR
5		+	-	NR
6		+	-	NR
7		+	-	NR
8		+	-	NR
9		+	-	NR
10		+	-	NR
11		+	-	NR
12		+	-	NR
13		+	-	NR

Appendix E: Baseline Data Collection Form

Participant Code: _____ Baseline Session #: _____ Date: _____

Prompt: Show me how you eat and drink safely.

Targeted Response: _____

Verbal Prompt

Trial	Number of seconds	Observed behaviors	Response
1			+ - NR
2			+ - NR
3			+ - NR
4			+ - NR
5			+ - NR

10-minute break

Trial	Number of seconds	Observed behaviors	Response
6			+ - NR
7			+ - NR
8			+ - NR
9			+ - NR
10			+ - NR

10-minute break

Trial	Number of seconds	Observed behaviors	Response
11			+ - NR
12			+ - NR
13			+ - NR
14			+ - NR
15			+ - NR

Comments: -

Appendix F: Data Collection Form

Participant Code: _____ Baseline Session #: _____ Date: _____

Question: _____

Targeted Response: _____

Was the compensatory strategy performed? Yes No

Trial	Number of seconds	Use of card	Response	Latency to response
1		+ -	+ - NR	
2		+ -	+ - NR	
3		+ -	+ - NR	
4		+ -	+ - NR	
5		+ -	+ - NR	
6		+ -	+ - NR	
7		+ -	+ - NR	
8		+ -	+ - NR	
9		+ -	+ - NR	
10		+ -	+ - NR	
11		+ -	+ - NR	
12		+ -	+ - NR	
13		+ -	+ - NR	
14		+ -	+ - NR	
15		+ -	+ - NR	
16		+ -	+ - NR	
17		+ -	+ - NR	
18		+ -	+ - NR	
19		+ -	+ - NR	
20		+ -	+ - NR	

Comments:

Appendix G: Reliability Form

Participant Code: _____ Baseline Session #: _____ Date: _____

Question:

Targeted Response:

Was the compensatory strategy performed? Yes No

Trial	Number of seconds	Use of card	Response	Did the Investigator Prompt Correctly?
1		+ -	+ - NR	+ -
2		+ -	+ - NR	+ -
3		+ -	+ - NR	+ -
4		+ -	+ - NR	+ -
5		+ -	+ - NR	+ -
6		+ -	+ - NR	+ -
7		+ -	+ - NR	+ -
8		+ -	+ - NR	+ -
9		+ -	+ - NR	+ -
10		+ -	+ - NR	+ -
11		+ -	+ - NR	+ -
12		+ -	+ - NR	+ -
13		+ -	+ - NR	+ -
14		+ -	+ - NR	+ -
15		+ -	+ - NR	+ -
16		+ -	+ - NR	+ -
17		+ -	+ - NR	+ -
18		+ -	+ - NR	+ -
19		+ -	+ - NR	+ -
20		+ -	+ - NR	+ -

Appendix H: Example of Social Validity Form

You will view 10 clips of randomly ordered research sessions that teach compensatory strategies for safe oral intake of food and/or liquid. The clips have been coded for future analysis. Please observe each clip carefully, in the order they are listed, and mark one box for each of the three questions.

Clip #: _____

Participant performs the target behavior

NO |-----| YES

1 2 3 4 5 6 7

Was this an episode of use of a safe strategy to improve eating safety or quality of life?

NO |-----| YES

1 2 3 4 5 6 7

Clip #: _____

Participant performs the target behavior

NO |-----| YES

1 2 3 4 5 6 7

Was this an episode of use of a safe strategy to improve eating safety or quality of life?

NO |-----| YES

1 2 3 4 5 6 7