

EBP Edge—Dysphagia and Dementia: What Evidence Tells Us About This At-Risk Population



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Introduction

The role of the speech-language pathologist (SLP) is critical in making recommendations for dysphagia intervention for patients with dementia. Over time, evidence for best practice in dysphagia management for this population has changed. There is a growing concern for the pervasiveness of dysphagia in patients with dementia as the number of elderly people in the population continues to grow (Rogus-Pulia, Malandraki, Johnson, & Robbins, 2015). As new research emerges and clinical practice evolves, clinicians should implement effective and compassionate services for those suffering from this progressive disease. While there is no cure for dementia, there is a significant push in the medical community to focus on quality of life and dignity for these patients. This article will examine research regarding dysphagia in the dementia population, aspiration pneumonia and how it relates to dementia, the role of tube-feeding in advanced dementia, and approaches to oral feeding as dementia progresses.

In order to understand dysphagia and the special risks associated with aspiration in the population with dementia, it is important to define aspiration and aspiration pneumonia. Aspiration, according to Son, Shin, & Ryu (2017), is simply “to draw in or out by means of suction.” When we refer to aspiration in terms of patient care related to dysphagia, we are talking about material that is being drawn into the lungs via the airway. Aspiration can occur both prandially, which is a term used to describe during a meal, and post-prandially, which describes after a meal. Aspirated material is not always food or liquid. It also may include saliva, secretions, bacteria, toxic substances, gastric contents, or any combination of these. Research has shown that aspiration is a normal part of physiology, and even normal adults aspirate on a daily basis, especially during sleep (Huxley, 1978). When aspiration occurs frequently or in large amounts, the risk for pneumonia increases. Son et al. (2017) define aspiration pneumonia as an acute infectious process secondary to an aspiration event, which may be witnessed or unwitnessed. The infection causes an acute decline in respiratory status and is usually treated with antimicrobial therapy.

Risk Factors

Understanding that all normal adults aspirate, aspiration alone does not place one at particularly high risk for developing aspiration pneumonia. Pneumonia is the second most common cause of death for people with Alzheimer’s disease (Rogus-Pulia et al., 2015). We must question what it is about patients with dementia that makes them particularly susceptible to this infection. Dr. John Ashford’s published work outlines what he considers to be the risk factors for pneumonia (Ashford, 2005). He states that the three pillars of pneumonia are dysphagia, poor oral care, and overall health status or debilitation. Let’s examine each of these pillars specifically in the population with dementia.

In 2009, Mitchell et al. reported that 85 percent of people with advanced dementia had eating difficulty. As the disease progresses, patients lose their ability to self-feed, experience decreased oral awareness when food or liquid is placed in their mouths, demonstrate lack of control of food or liquid, and experience decreases in the coordination required for airway protection during swallowing.

According to a literature review by Chalmers and Pearson (2005), oral care for people with dementia presents its own set of challenges. Salivary gland function declines, and accumulation of plaque and tartar is higher in people with dementia. Individuals with dementia present with an increased risk for dental caries and a need for dental treatments. However, people with dementia, especially in later stages, are less likely to utilize dental services. Oral hygiene for people with dementia may be

difficult due to dependency on others to assist with oral care, poor participation or cooperation to complete oral care, and higher levels of care burden on those caring for people with dementia. Cleaning someone's mouth when he or she does not understand what is happening or why it is important is not easy. Therefore, oral care may easily be neglected for this population, and a stronger push for education and advocacy for this issue is needed.

The third pillar of pneumonia is overall debilitation. As dementia progresses, mobility declines. Patients become bedbound and dependent on others for activities of daily living, including ambulation, bed mobility, and feeding (Mitchell et al., 2009). A study published in 2002 by Langmore, Skarupski, Park, & Friessuggested that these factors are predictors of pneumonia in relation to impaired pulmonary clearance. As patients lose their ability to expel or even sense their own secretions, the ability to protect the airway decreases. Debilitation in combination with poor oral care and progressive dysphagia places individuals with dementia at high risk for the development of pneumonia.

PEG as an Intervention

Because patients with dementia are particularly susceptible to the development of pneumonia, a variety of treatments have been implemented to combat and eliminate the risk factors previously mentioned. One such treatment was the frequent use of the percutaneous endoscopic gastrostomy (PEG) tube as an alternative to oral feeding. The PEG is used to route tube-feeding directly into the stomach through the abdominal wall. It was originally thought that by inserting a PEG tube we could bypass the shared opening between the digestive and the respiratory systems (the oropharynx) that allowed prandial aspiration to occur in patients with oropharyngeal dysphagia, thus eliminating the risk of aspiration (Mitchell et al., 2016). The rate of PEG tube insertion rose in the 1990s, and by 2000, roughly 12 percent of patients with dementia in nursing homes were receiving nutrition via PEG (Mitchell et al., 2016). Unfortunately, this treatment did not result in decreased pneumonia rates for patients with dementia. As research on this topic continued to be published, it became clear that a PEG could not prevent aspiration in advanced dementia. Patients can still aspirate their own secretions or contents of reflux. Guedón et al. (1996) found that gastroesophageal reflux events increased in patients with dementia and co-occurring PEG placement. Finucane found in 1996 that a PEG was ineffective in preventing aspiration pneumonia. In 2000, Sootin, Caushaj, Hathaway, & Gagneconcluded, "The role of aspiration in the mortality of chronically ill patients following PEG tube placement is significant with gastric feeding being an important risk factor in the development of aspiration pneumonia."

Use of a PEG was previously thought to help improve a person with dementia's nutritional status and thus decrease their risk of mortality; however, the literature now tells us this was a misconception. In fact, research has shown that PEG insertion results in decreased life expectancy when compared to people with dementia who continue PO intake, or oral intake, with known risk of aspiration (Goldberg and Altman, 2014). A critical review published by Goldberg and Altman in 2014 concluded that there is no evidence to support improved long-term survival rates for people with advanced dementia who undergo PEG placement.

While the research tells us that tube-feeding will not prevent aspiration or prolong life for people with advanced dementia, it may be difficult for family members to make decisions regarding PEG placement because they see their loved one slowly develop difficulties with eating or stop eating over time. Family members may ask a member of the multi-disciplinary team if the patient will "just slowly starve to death." This, to many family members, is a cruel and uncomfortable way for the disease to progress at the end of life. The speech-language pathologist can play an important role in educating the patient and their family (early in the disease, if possible) on the progression of dysphagia and what the research actually tells us about comfort at the end of life. Pasma et al. (2015) found that patients who continued oral (PO) intake in lieu of PEG insertion did not experience any greater levels of discomfort than those with PEG tubes. When considering quality of life, careful consideration should be implemented when employing treatments that may contribute to confusion, fear, or agitation. Patients with PEG tubes frequently must be transported to the emergency

department or admitted to the hospital due to tube complications such as dislodgement or blockages (Givens, Selby, Goldfeld, & Mitchell, 2012). This is likely a scary or disconcerting experience for people with dementia, and it often leads to agitation, which may then require the use of chemical or physical restraints to prevent them from pulling at tubes and lines. When considering comfort and quality of life, most family members do not wish to restrain their loved one.

The American Geriatrics Society (AGS) revised its position statement regarding feeding tubes in advanced dementia in 2013, stating that feeding tubes are not recommended for this population. Multiple factors contribute to this position statement, including the knowledge that a PEG does not prevent aspiration, does not improve quality of life, and does not prolong life, as previously discussed. The AGS points out that eating and drinking may be one of the few remaining pleasurable activities in which a person with advanced dementia can participate, and it recommends that “efforts to enhance oral feeding by altering the environment and creating individual-centered approaches to feeding should be part of usual care for older adults with advanced dementia.” The position statement then goes on to highlight the importance of honoring the patient’s wishes and the importance of shared and well-informed decision making on a case-by-case basis.

Thickened Liquids, Postural Changes, and Modified Diets

One common form of intervention is the use of thickened liquids or postural changes to decrease or prevent aspiration. In 2008, a study by Logemann et al. compared three different interventions for aspiration of thin liquids in patients with dementia or Parkinson’s disease. Patients were evaluated via videofluorographic swallow study using thin liquids with a chin-down posture, nectar-thick liquids with a chin-neutral posture, and honey-thick liquids using a chin-neutral posture. While the study did not find any uniform effectiveness of one particular intervention, it did suggest that the use of nectar- or honey-thick liquids has a higher success rate in preventing aspiration in the short term than chin-down posture. Logemann et al. concluded that a need for additional research remains on this topic. They also concluded that each patient should be individually evaluated using instrumental assessment rather than using a generalized approach for multiple patients. Of note, many patients in this study had been placed on thickened liquids prior to instrumental evaluation by clinicians using only a clinical bedside swallow evaluation only to find they did not aspirate with thin liquids during the instrumental assessment. This finding highlights the importance of using instrumental assessments to make recommendations involving thickened liquids as a clinical bedside swallow evaluation is not reliable in determining whether thickened liquids are beneficial for a person with dysphagia.

Robbins et al. conducted a separate study in 2008 that looked at subjects with dementia or Parkinson’s disease who did equally well (aspiration was eliminated) or poorly (aspiration was not eliminated) with the same three interventions (chin-down with thin liquids, nectar-thick liquids in chin-neutral, or honey-thick liquids in chin-neutral) during an instrumental assessment. Each subject was assigned one intervention, and at a follow-up after three months, the incidence of pneumonia in the chin-down group was 9.8%. The incidence of pneumonia in the nectar-thick group was slightly lower at 8.4%. Interestingly, the incidence of pneumonia was 15% for subjects on honey-thick liquids. The study suggested that the previously accepted idea that “the thicker the better” was not always true as more viscous fluids may be more difficult to clear from the airway. The authors of this study suggested that further investigation using a combination of these interventions may prove useful.

Other options to consider as a multi-disciplinary team include modified diets, high-calorie nutritional supplements, appetite stimulants, and physical feeding assistance. Hansen, Ersek, Gilliam, & Carey completed a systematic review in 2011 examining oral feeding options for people with dementia and found that nutritional supplements were most effective in helping people with dementia gain weight. The author examined weight gain as the only outcome and did not consider outcomes such as pneumonia or dehydration. To date, there have been no randomized control trials (RCTs) examining the prevention of aspiration using modified diets, and the studies described above by Logemann and Robbins are considered the best RCTs examining the use of thickened liquids. While many argue that the use of modified diets for patients with dementia is a logical one, others criticize this practice due to lack of evidence. In 2018, O’Keefe pointed out that modified diets may result in

poor nutrition and hydration, increased caregiver burden, and a negative impact to quality of life. He did go on to state that modified diets have a rational pathophysiological basis in dysphagia; however, the lack of evidence warrants further investigation to support the use of modified diets and thickened liquids in any dysphagia population.

Careful Hand-Feeding

We also should consider the option of careful hand-feeding for people with dementia. Careful hand-feeding, or the practice of giving someone small amounts of food and drink when they are comfortable and want to be fed, is endorsed by the American Geriatrics Society and the Alzheimer's Association as an alternative to tube-feeding. Careful hand-feeding can involve the use of thickened liquids or modified diets and should take into consideration the patient's food preferences, ethnic food preferences, and the aesthetic appeal or presentation of the food (DiBartolo, 2006). The technique should be individually tailored to consider patient positioning. Additionally, the strategy should allow the patient to set the pace for feeding, meaning that a person may need to be fed at a slower rate than adults without dementia. There are currently no randomized control trials that have ever compared outcomes of tube-feeding versus careful hand-feeding, and this type of study will likely never be completed given the ethical issues involved in designing such a study. Continuing oral intake seems to be the more reasonable option for this population since research has not demonstrated any benefits from tube-feeding, and oral intake allows the patient to continue to participate in a pleasurable and sociable activity (Fischberg et al., 2013).

Palecek et al. (2010) propose the idea of reframing the discussion with patients and families regarding tube-feeding versus hand-feeding. He suggests that clarifying the language by using the order "comfort feeding only" helps emphasize the goal of the least invasive, most comfortable approach to maintain nutrition rather than the more harsh language used in the past that made some family members feel as though they were withholding care for a loved one. He explains that an important piece of this discussion is education for the family in weighing the risks and benefits of continued PO intake, including the risk of aspiration. Pros and cons of feeding tubes also should be discussed, allowing the family to make an informed decision with the input of the multidisciplinary team. Previously discussed wishes and advanced care planning that the patient expressed prior to their current stage of dementia should be heavily considered and honored. Overall, this approach has become widely accepted in healthcare and is considered the most compassionate and comprehensive way of making decisions for this population (American Geriatrics Society, 2014). Nevertheless, it is not an easy decision or conversation, and as research continues in this area, clinicians should stay up-to-date on the evidence in order to make knowledgeable recommendations and do what is best for our patients.

Conclusion

There is currently no cure for dementia, and dysphagia in this ever-growing population is inevitable. The population with dementia is at increased risk for pneumonia as the disease progresses, and we must consider the available evidence we have in order to evaluate and treat these patients. While current research does not support one definitive dysphagia intervention for the population with dementia, an instrumental assessment is important to evaluate each patient on an individual basis. Further research involving other possible interventions continues to be warranted. Using our knowledge of research on tube-feeding, modified diets, thickened liquids, and careful hand-feeding in this population, we can more competently participate in difficult conversations as a multidisciplinary team to help educate patients and families to empower them to make the best choices for each person's individual plan of care.

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