A RESOURCE FOR HEALTHCARE PROFESSIONALS SWALLOWING DISORDERS AND THEIR MANAGEMENT IN PATIENTS WITH MS

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Introduction

Permanent and transitory swallowing disorders (dysphagia) occur with high frequency in patients with multiple sclerosis (MS) (Restivo et al., 2006; Prosiegel et al., 2004; Abrahams & Yun, 2002; Calcagno et al., 2002; De Pauw et al., 2002; Wiesner et al., 2002;). In fact, swallowing disorders may be present long before the person with MS experiences any related symptoms.

In 1987, Dr. Angie Fabiszak studied three groups of individuals: healthy controls with no diagnosis of multiple sclerosis or other medical problems; patients with MS but no complaints of swallowing problems; and patients with multiple sclerosis who were complaining of a swallowing disorder. Results of x-ray studies (modified barium swallow) on these patients revealed that both of the groups of patients with multiple sclerosis exhibited similar abnormalities in swallowing, whereas the normal control group exhibited no swallowing disorders. In recent years, several other investigators have corroborated the fact patients with multiple sclerosis frequently exhibit swallowing disorders, even if they have no such complaints.

It is, therefore, important for the MS patient's primary care physician to refer the patient with multiple sclerosis—with or without a complaint of swallowing problems—for a full workup of his or her oropharyngeal and esophageal swallowing function as soon as the patient has a diagnosis of multiple sclerosis, in order to establish a baseline swallow physiology against which to compare any future changes. Dysphagia can result in several serious medical complications, including malnutrition, dehydration, respiratory illness, and choking which could exacerbate other MS-related symptoms or even be fatal if left untreated.

Normal swallowing

Normal swallowing involves neural control of the facial muscles and tongue in placing food in the mouth, manipulating and tasting the food, chewing it, and forming it into a ball or bolus to be swallowed. Once the bolus is formed, the tongue begins to propel the food, or part of it, into the throat (pharynx). The movements of the tongue and bolus stimulate sensory nerve endings which, in turn, trigger contractions in the pharynx, initiating the pharyngeal stage of the swallow. When the pharyngeal swallow is triggered, several motor components are initiated:

- The soft palate lifts and closes to prevent food or liquid from going into the nose.
- The larynx lifts and closes to prevent food or liquid from entering the trachea.
- The base of the tongue and walls of the throat converge to create pressure at the back of the bolus, propelling it throughout the pharynx into the esophagus.
- The upper esophageal sphincter (located at the top of the esophagus) opens to enable the food to enter the esophagus.
- The airway closes to prevent accidental aspiration of food or liquid into the lungs.

Once in the esophagus, sequential esophageal motor contraction (peristalsis) propels the bolus through the esophagus to the stomach. The lower esophageal sphincter opens to allow the bolus to enter the stomach. The entire swallow, from placement of food in the mouth through entrance to the stomach, occurs *rapidly* (1 second in the oral cavity, 1 second in the pharynx, and 8-10 seconds in the esophagus), *safely* (with no aspiration), and *efficiently* (with minimal residue).

The normal swallow depends upon a well-functioning central nervous system, including cortical and subcortical areas, the brainstem, and peripheral nerves—particularly cranial nerves. If the patient's MS lesions affect any of these areas, swallowing may be challenged. Many patients with MS will cough if food enters their airway or will require multiple swallows to clear food that has been left behind in the pharynx. Keep in mind, however, that patients who are experiencing reduced sensation may be unaware that food particles have entered the airway or that residual food particles have been left in the pharynx; they will not cough or repeat their swallows in spite of the need to do so – a phenomenon called silent aspiration.

Baseline swallow assessment: clinical and instrumental evaluation tools

The patient with multiple sclerosis who is experiencing symptoms of dysphagia should be evaluated with one of several clinical assessment options to determine the nature, etiology, and severity of swallowing dysfunction. In most clinical settings, the first formal assessment is the *clinical or bedside swallowing evaluation* (Carnaby-Mann & Lenius, 2008), which is conducted by a speech-language pathologist (SLP). This assessment consists of a careful case history of swallowing problems, evaluation of the strength and sensory responses of the structures and muscles of the head and neck, and structured trials of different food and liquid textures and possibly postural modifications to determine which consistencies and compensatory strategies might improve swallowing assessment to examine more specific sources of potential aspiration or other swallowing dysfunction not readily evident on the clinical evaluation.

Two common instrumental assessments for dysphagia are accessible in most medical settings: a *modified barium swallow study (MBS)* to examine oral and pharyngeal swallow physiology, followed by an esophagram to examine esophageal function; or a *fiberoptic endoscopic evaluation of swallowing (FEES)*. The MBS is designed with modified procedures because the patient with MS may aspirate when given the usual large-volume swallows, including cup drinking, which are used for a standard barium swallow. In contrast to the standard barium swallow, one common protocol for the MBS is designed to introduce calibrated, measured volumes of thin liquids first, beginning with 1 ml, which is similar to a saliva swallow, and building to 3 ml, 5 ml, and 10 ml as tolerated by the patient without aspiration. Then, the patient is given a cup to drink from, followed by several swallows of 3 ml of pudding, and then 2 pieces of shortbread cookie (1/4 of a cookie) coated with barium pudding (Logemann, 1993). This procedure, which involves a total of 14 swallows, allows the clinician to identify any abnormalities in the swallow as it progresses from small to large volumes of thin liquids, and thin to thicker viscosities. In healthy individuals, both volume and viscosity sequentially change the physiology of the swallow; it is important to determine whether the person with MS exhibits a similar systematic change in his or her swallow physiology in response to changing volume and viscosity (Logemann, 1998).

The fiberoptic endoscopic evaluation of swallowing (FEES) involves passing a thin fiberoptic camera through the nose and into the throat to record live video images of a patient swallowing food and liquid mixed with a bright dye (Langmore et al, 1988). The general procedure for quantities and textures assessed is similar to the protocol for performing an MBS. This assessment is occasionally implemented in acute care settings with medically fragile individuals or rural clinics where access to a radiology suite to perform the MBS study can be difficult or unsafe for the patient. While a FEES study can be administered across the entire duration of a meal and in more flexible environments than the MBS, there are elements of swallowing physiology that are not as directly observable during FEES examination as compared with MBS (notably esophageal phase function). When a person with MS is referred for an instrumental examination of swallowing, he or she should have a discussion regarding testing procedures and limitations with the referring clinician to determine the most appropriate option available.

In addition to demonstrating the individual patient's swallow physiology, instrumental swallowing assessments make it possible to introduce and evaluate management strategies should they be needed. Strategies for management are introduced and evaluated when the patient aspirates or has significant residual food left in the pharynx after the swallow. By the time the patient has completed an instrumental swallowing assessment, the clinician should have an outline of recommendations for: 1) effective management strategies, including any swallowing therapy procedures that are needed; and 2) optimal, safe diet consistencies. Interpretation of data from an MBS or FEES study should involve an SLP who is familiar with the various management strategies and can introduce and evaluate the immediate effectiveness of the therapies during the study.

Common swallowing disorders in MS

The most common MS-related swallowing disorders in the oral and pharyngeal areas are:

• Xerostomia (dry mouth): Reduction in the production of saliva makes the process of breaking down solid material into a cohesive bolus for swallowing more laborious, inefficient, and potentially uncomfortable in the mouth. This can also lead to difficulty swallowing whole medication tablets and capsules. In addition, it can result in impaired transport of solid material through the throat and esophagus, bad breath, and increased presence of anaerobic bacteria in the mouth and throat which, if aspirated into the airway, could lead to infection. Xerostomia can present as a side effect of many different

classes of medication (both disease-modifying therapies and symptomatic management medications). Some research also suggests a possible – but as yet unproved – link between MS and other autoimmune disorders such as Sjögren syndrome, which can also exacerbate the presence of xerostomia (de Seze et al, 2001).

- Slower and less coordinated processing of material in mouth: The reduction in facial muscle strength and coordination as well as impaired sensation (either reduction or heightened sensitivity to temperature or pain from conditions such as trigeminal neuralgia) results in a longer amount of time to chew food or create a single cohesive bolus of liquid. This can lead to increased fatigue later in meals, pocketing of food residue between the gumline and cheek or lips, accidental spillage of material into the throat prior to the initiation of a swallow, or loss of material from the lips while food or liquid is being chewed or manipulated. Besides interfering with swallowing safety, this is perhaps the most visible swallowing change in a person with MS, which can negatively impact the social aspects of dining with other people.
- Delay in triggering the pharyngeal swallow: The delay in triggering the pharyngeal swallow, which is the most common swallowing problem seen in MS patients, can cause particular difficulties with liquid swallowing, including aspiration (Logemann, 2000). When the pharyngeal swallow is delayed, liquid may splash from the mouth into the pharynx. Because motor control of the pharynx has not been activated by the brainstem, the airway remains open and the upper esophageal sphincter remains closed, causing liquid that enters the pharynx to splash into the open airway and be aspirated.
- **Reduction in laryngeal excursion:** Reduced laryngeal excursion (the brisk, coordinated upward and forward movement of the voice box (larynx) during the swallow response to move the entrance to the airway out of the path of the bolus and facilitate opening of the top of the esophagus) can contribute to weakened closure of the airway during the swallow and to reduced clearance of material from the pharynx, thereby causing residue after the swallow and possible aspiration.
- **Reduction in tongue base retraction:** Reduction in tongue base activity reduces the pressure generated during the swallow, allowing residual food to remain in the pharynx and be aspirated when the patient resumes breathing.

These disorders can be mild, without causing any significant difficulties such as aspiration or inefficient swallow; or, they can be more severe and require therapeutic (behavioral) management.

Barium swallow evaluation

Esophageal disorders require a standard barium swallow evaluation in which the patient is given a cup of barium and asked to swallow sequentially. A typical swallow from a cup or glass includes approximately 15 to 20 ml per swallow, a large volume that can cause difficulty if the patient has any significant abnormality. For this reason, the modified barium swallow should always precede the barium swallow to identify the locus of oropharyngeal swallow difficulty prior to giving the patient a large volume of liquid in a barium swallow or esophagram. The assessment of esophageal disorders will often include referral to a gastrointestinal specialist, who may perform an esophagogastroduodenoscopy (EGD) study to obtain color imaging of the structure and function of the esophagus and stomach, which might be interfering with normal swallowing function.

Dysphagia management

The goal of dysphagia management is to maintain the patient on a normal diet as much as possible. Generally, two management plans are devised for each patient based on outcomes from swallowing assessments and after discussion of options and personal preferences with the patient—one to promote safe and efficient swallowing for oral intake and one focused on exercise/therapy (Logemann, 2006).

Techniques to promote safe and efficient swallowing

There are various kinds of strategies that can be introduced, including:

- **Postural change**—which helps to redirect food along the correct pathway (i.e., away from the airway) and improves overall body positioning and alignment to allow for better control and coordination of swallowing.
- Heightened oral sensation prior to the swallow—which enables the patient to get a faster pharyngeal swallow.
- Voluntary control over swallows, such as holding one's breath to protect the airway, or increasing effort, if possible, to clear a greater amount of bolus through the pharynx and into the esophagus with each swallow.
- Patient /caregiver education of swallowing function and safety—which increases awareness of what is normal and what is abnormal about a patient's swallowing function and provides a starting point for implementing swallowing strategies. In some cases, simply increasing a patient's self-awareness of swallow function improves safety and efficiency because the act of swallowing is such an automatic and overlearned bodily function that most people are minimally cognizant of how they perform it.
- Diet texture modifications—which promote decreased effort required to enhance swallow safety. This can involve making solids softer or more cohesive (e.g., chopping or pureeing foods; adding additional sauce or gravy, straining/blending stews) so that they stick together as a bolus when chewed, or thickening liquids to increase viscosity and slow them down during each phase of swallowing. Commercial products are available that provide modified food and liquid textures or that people with dysphagia and their caregivers can use to thicken beverages, soups, or other liquids. Although this strategy has the most immediate impact on improving safety, it can be resisted by patients because of the reduced sensory enjoyment of their favorite foods and liquids. This resistance can ultimately lead to malnutrition, dehydration, and impaired quality of life if oral intake becomes reduced on a long-term basis.

Complicating factors that can play a role in the selection of strategies for swallowing therapy include the patient's level of fatigue (one of the most universal symptoms among people with

MS) and cognitive dysfunction. If the patient is extremely fatigued or presents with significant impairments of memory or even awareness of the presence of dysphagia, some swallow therapy strategies might not be appropriate.

Exercises and other therapy interventions for swallowing

Other options for rehabilitation of swallowing function include:

- **Resistance exercises** to improve range of motion or coordination of the movement in the oral and pharyngeal structures, as well as techniques to improve strength in the tongue-- w the most important muscle for swallowing.
- Electrical stimulation (common formats include NMES or PENS) of the front of the neck, which is used in conjunction with resistance exercises and swallowing trials to facilitate increased muscle contractions in certain groups around the larynx and the base of the tongue in order to promote stronger pressure on the bolus with each swallow attempt. While the overall efficacy of this intervention remains unclear at this time, specific research among patients with MS has been positive with no adverse side effects (Bogaardt et al, 2009).

If the patient experiences significant exacerbations and/or the disease progresses, the nature or severity of his or her swallowing disorder could be expected to change as well. A reassessment of the person's swallowing problems and a revised treatment plan are appropriate whenever a major change in disease status occurs.

Recommendations for non-oral versus oral feeding

After the video fluoroscopic clinical or instrumental study of oropharyngeal swallow, the clinician will recommend continued oral feeding, or partial or complete non-oral feeding-depending upon the patient's safety, efficiency of swallow, and prognosis for potential rehabilitation of the dysphagia. If the patient is regularly aspirating on all foods, no matter what food viscosity is presented, or therapy is used, non-oral feeding may be recommended for two reasons: First, regular aspiration can cause pneumonia; second, whatever the patient aspirates will not provide nutrition or hydration. Several studies have shown that patients who aspirate during the x-ray study have a significantly greater risk of pneumonia in the next 6 months than patients who do not aspirate during the study (Pikus et al., 2003; Schmidt et al., 1994). Non-oral supplements to ensure adequate nutrition and hydration may also be recommended for patients who have been exhibiting weight loss and fatigue when taking food orally. Whether or not the patient exhibits chronic aspiration or fatigue, partial non-oral feeding may be helpful. For example, the patient who aspirates may do so only on certain foods and be able to eat other foods orally. Similarly, the patient who fatigues easily may eat some foods orally and initiate non-oral nutrition when fatigue sets in. This person is receiving "pleasure intake" for sensory stimulation, improved quality of life, and to continue exercising the function of oral swallowing as long as possible.

The three basic types of non-oral feeding that allow food and liquids to be taken into the body without being swallowed are the nasogastric tube that goes through the nose and throat into the esophagus and stomach (generally used for no longer than 2 weeks because of the irritation it can cause to the nose and throat), total or partial parenteral nutrition (TPN/PPN) to provide nutrition and hydration via specialized intravenous delivery, and the percutaneous endoscopic gastrostomy (PEG or sometimes G-tube) that involves inserting a feeding tube through the abdominal wall directly into the stomach (or, in some cases, directly into the jejunum of the small intestine, which is commonly referred to as a J-tube). Of these, the PEG or J-tubleare the only options indicated for long-term non-oral feeding. All these options for non-oral feeding can be removed or not used when desired. Often patients and their significant others think that a decision to introduce partial or full non-oral feeding means that the patient will never eat by mouth again. However, non-oral feeding can serve as a temporary bridge while the patient improves and returns to oral feeding.

On the other hand, there is a common misperception that non-oral feeding has minimal risks or eliminates the person's risk for aspiration. This is not the case, since providing nutrition via IV or a surgical tube comes with an increased risk for infection. In addition, the presence of a feeding tube has been associated with an elevated risk for aspiration pneumonia as compared to the presence of dysphagia itself without a feeding tube (Langmore et al, 2002). Therefore, the recommendation for continued oral feeding, partial non-oral, or full non-oral feeding will be made following the clinical or instrumental swallow study. This is a recommendation to be carefully considered by the patient's physician, the patient, and his or her significant others.

Patient and family counseling regarding swallowing management

The SLP can also provide counseling to the patient and family regarding the importance of completing the recommended exercises and the ways in which the family can facilitate the patient's exercises and use of techniques for improved swallowing during mealtime. This is critical information for people who will serve as primary caregivers for patients with dysphagia in the community, since feeding and swallowing are integrated into so many cultural, family, and social events and occur multiple times every day of the person's life. This presents a challenge to implement safer swallowing strategies or modify food/liquid consistencies on a reliable basis, especially if the patient has significant weakness, fatigue, or cognitive disabilities that limit his or her capacity to apply these techniques every time there is something to swallow or assistance is required with feeding.

Follow up

It is important for patients with MS and their family members to contact both their physician and their SLP if swallowing function appears to worsen. It is common for dysphagia in patients with multiple sclerosis to wax and wane. This does not mean that swallowing management cannot be done, but rather that the therapy procedures used may need to be changed. The goal of swallowing management is to keep the patient with MS from getting pneumonia, losing weight because of a swallowing difficulty, and missing out on the many opportunities to eat and drink safely each day.

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Patient resources

Speech and Swallowing Problems: The Basic Facts: <u>nationalmssociety.org/brochures</u> Swallowing Difficulties in MS (video): <u>nationalmssociety.org/videos</u>

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