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Chapter

Introduction to and Epidemiology of Swallowing Disorders

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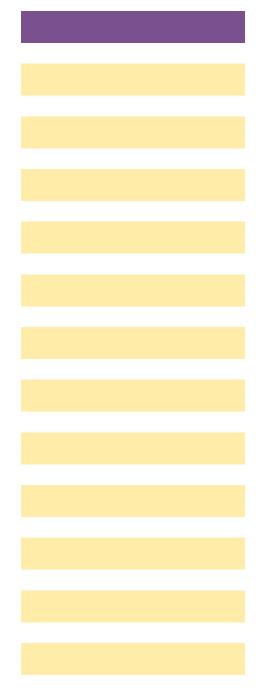
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A Look at the Chapter

In this chapter, normal and disordered swallowing are defined using figures, tables, and video examples. Terminology is reviewed as it relates to normal and abnormal swallowing. The direct and indirect impacts of a swallowing disorder on quality of life are presented, and tools for assessing quality of life are introduced. Those tools are more specifically reviewed in Chapter 5. We also introduce the importance of patient self-assessment as a tool for better understanding the patient's perspective of dysphagia. This is followed by the epidemiology of swallowing disorders. Epidemiology refers to both the prevalence and cause of a disorder. In this chapter, we focus on the prevalence. Specific causes of dysphagia are taken up in later chapters.

INTRODUCTION

Swallowing

What other human activity other than swallowing excites all of the 5 senses: taste—sweet or sour; touch—crusty, chewy or smooth; smell—spicy or tangy; sight—berries and ice cream; and hearing—bubbling or crackling?

And, at many points in the act of swallowing, the senses act in harmony—the sight, smell, and taste of a large fresh orange or the hearing, touch, and crunch of a fresh potato chip, just to name of few.

The allure of a bakery or hot dog stand may entice you to stop and enjoy a croissant or a hot dog smothered in mustard, onions, and ketchup. Or, it may just make you salivate and swallow. All of these sensory stimulations are sent to the brain that then coordinates swallowing activity when you pass by that bakery or hot dog stand. The brain organizes a sequence of actions that lead you to go into the pastry shop, buy that croissant, and enjoy the taste of each flaky bite.

What happens when you bite into that croissant? The body's neuromotor systems go to work. For a normal swallow, the lips, teeth, tongue, pharynx, and esophagus must be coordinated for the food to pass into the stomach. Actions are going on all of the time once the food or liquid is placed near the lips. The integration of the lips opening, the jaw dropping, and the tongue finding its place require fine and rapid activity in the neuromotor control systems. The sensory system joins the motor system that results in an amazing set of actions that take place in a matter of seconds (or faster!). At the same time, the pleasure of that bite is preparing you for the next bite. Almost magic? Not quite. The normal act of swallowing develops in utero and evolves as we are exposed to new tastes, smells, consistencies, and visions of foods and liquids.

Throughout this textbook, the reader is challenged to think of swallowing as a collection of overlapping events; by exploring the details of each of these events, one can appreciate the importance of normal swallowing and understand the conditions and diseases that lead to abnormal swallowing. This textbook explores the sensory and neuromotor actions of normal and disordered swallowing and the clinical management of abnormal swallowing.

Let's begin with a general introduction to normal and abnormal swallowing.

Normal Swallowing

The anatomical structures of the swallowing mechanism can generally be divided into 3 major areas:

(1) nasopharynx, (2) oropharynx, and (3) hypopharynx. The major structures of the swallowing mechanism are shown in Figure 1–1. Interactions within and between each of these divisions takes place to allow the food to move from the mouth to the esophagus and into the stomach.

The normal swallow is a rapid and overlapping sequence of neurologically controlled movements involving the muscles of the oral cavity, pharynx, larynx, esophagus, and stomach. Although most individuals take normal swallowing for granted, everyone experiences an abnormal swallow at some time in life, most likely resulting in an episode of a sudden choking sensation. However, in a normal, healthy person, this is usually resolved quickly by a cough or throat clearing.

When the muscles and nerves that govern the swallowing organs are disordered, disrupted, damaged, or destroyed, swallowing function is altered. However, neuroplasticity allows for adaptations when normal structures are destroyed. The swallowing organs and their ability to develop compensatory strategies in individuals with neurological or muscular damage to the swallowing organs can still swallow certain types of foods and liquids safely. Video 1-1 shows an example of a normal flexible endoscopic evaluation of swallowing (FEES). Video 1-2 presents an example of a normal modified barium swallow (MBS) examination. (MBS is also known as a videofluoroscopic swallow study [VFSS].) Note the fluid movement and the speed of the bolus as it travels to the esophagus.



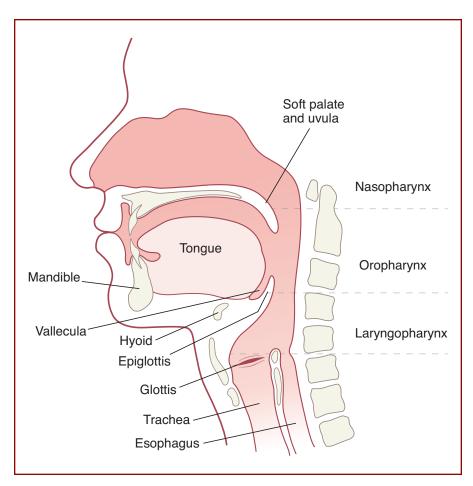


FIGURE 1–1. An overview of the nasopharynx, oropharynx, and laryngopharynx. Below shows the area of the larynx from the epiglottis anteriorly to the esophageal sphincter posteriorly.

A video description of the normal and abnormal swallowing processes can be found at https://swallow.edu.hku/nsns/

Abnormal Swallowing

Abnormal swallowing includes difficulty with swallowing or the total inability to swallow, referred to as dysphagia and aphagia, respectively.

The global definition of **dysphagia** is simply "difficulty in swallowing."

When someone cannot swallow at all, the term *aphagia*, or "inability to swallow anything," is used. The terms *dysphagia* and *aphagia* refer to swallowing saliva, liquids, foods, and medications of all consistencies. Dysphagia may also include such problems as foods or liquids "sticking" in the throat or regurgitation of swallowed liquids or foods. Swallowing difficulties may arise from mechanical problems of the swallowing mechanism, neurological disorders, gastrointestinal disorders, or loss of organs due to surgery or traumatic injury. Dysphagia and aphagia may also involve the disruption of the timing of the events needed to swallow normally. Dysphagia may also include one's perception of difficulty swallowing.



Video 1–3 is a FEES of a patient with a history of dysphagia. Note that the food that is colored green remains in the area above the vocal folds and is not swallowed. It may ultimately be aspirated (fall below the vocal folds) if the patient does not cough it out. Video 1–4 presents an example of an MBS showing a trace of the barium flowing down into the airway after the majority of the bolus is swallowed. In a patient with a weak cough or pulmonary disease, this can lead to aspiration pneumonia.

Impact of Swallowing Disorders on Quality of Life

It is estimated that in the United States alone, 300,000 to 600,000 people with clinically significant

dysphagia are diagnosed annually.^{1,2} Nearly 70% of these patients are older than 60 years of age.² The true incidence of dysphagia may not be known, as it is often a secondary or tertiary diagnosis following a primary diagnosis. Since dysphagia is a symptom, it is often not listed as the principal diagnosis if the physician has only documented the underlying cause. However, according to the International Statistical Classification of Diseases, Tenth Revision (ICD-10), the appropriate code for dysphagia can be listed as a secondary diagnosis following a stroke, esophagitis, and other diseases of the neurological system or gastroesophageal pathway.³ Swallowing disorders, even when subtle, eventually take a toll on the quality of life. Because eating is a natural part of social interactions, daily nutrition, and general health, the importance of normal swallowing cannot be overstated. Swallowing affects quality of life in a number of ways, regardless of the severity of the problem. Table 1-1 summarizes common effects that dysphagia has on the quality of life.

Aspiration

Aspiration is a condition in which foods, liquids, pills, or oropharyngeal secretions pass into the airway below the level of the true vocal folds. This happens occasionally to most people; but in the absence of injuries to the muscles or nerves of swallowing, most people have the ability to sense the food or liquid in the airway and cough it out. When there is an injury or damage to the swallowing mechanism and aspiration is frequent or extensive, there is a higher risk of lung infections, dehydration, and malnutrition, and the enjoyment of eating diminishes; thus, quality of life also diminishes.^{4,5}

Dehydration

Dehydration is the state when there is not enough water in the body to maintain a healthy level of fluids in the body's tissues. Even in an otherwise healthy person, the lack of adequate water intake can lead to dehydration. Water is an essential element for all individuals as it replaces fluid losses from bowel movements, urination, and general physical exercise. A general rule of thumb is to replace body fluids with 3 quarts of water per day or, more specifically,

TABLE 1-1. Effects of Dysphagia on Quality of Life

A. Functional Limitations

- There may be limitations on the types of food that a patient can swallow safely.
- 2. Patients may be limited to a specific diet of foods that they do not like.
- 3. Swallowing and finishing a meal may take longer.
- 4. Oral structures may limit the types of food able to be swallowed.
- 5. Some foods may cause the patient to choke.
- 6. Awareness due to either visual or conscious limitations may restrict eating.
- 7. Gastric structures or functions may limit the amounts or types of foods.

B. Activities and Participation

- Patients on a nonoral diet may be reluctant to attend events where food is served.
- 2. Foods related to culture or religion may not be available to the patient.
- 3. The ability to hold and use a straw or utensils may limit eating/drinking.
- 4. The ability to eat in a group setting may limit activities.
- 5. The ability to prepare meals may reduce food intake.

C. Environmental Factors

- 1. Changes in room lighting or sound may limit eating.
- 2. Proper eating arrangements may be limited due to room spaces.
- 3. Eating in public may present unwanted attention.
- 4. Use of personal care providers may be needed during mealtimes.
- 5. The ability to prepare food may be limited.

with an amount equal to half of the body weight. For patients with neurological impairments who may be at risk for aspiration when swallowing liquids, fluid intake may require constant monitoring. Other factors, such as medications that have dehydrating side effects, as discussed in Chapter 3, and dryness due to treatment with radiation therapy, will also impact one's ability to swallow. For example, when there is not enough natural saliva in the mouth, chewing becomes more difficult, food does not easily form a bolus, and particles may break apart and require multiple swallows. Payne et al reported that patients with dysphagia are at high risk for dehydration, which represents a common cause of morbidity and rehospitalization in this group.⁶ Patients with dysphagia should be evaluated frequently for signs of dehydration, and if present, further evaluation of other nutritional deficiencies may be warranted.

Malnutrition

Malnutrition is the condition that occurs when your body does not get enough nutrients due to the inability to ingest food safely, the reluctance to eat or fear of eating/drinking due to past swallowing problems, or the inability to digest or absorb ingested nutrients. Once a person is unable to ingest food safely, that person's ability to maintain health decreases. This is especially important for patients who are recovering from extensive surgeries, strokes, or other debilitating diseases and will require extensive rehabilitation.⁷ Once malnutrition develops, its treatment may be as important as any other part of the rehabilitation process. Recovery from malnutrition has been shown to help in the rehabilitation process, including in the treatment of dysphagia, leading to improvement in the patient's quality of life. The specifics of nutrition are reviewed in Chapters 8 and 9.

Weight Loss

Weight loss can be tragic: Randy Schmidt wrote a biography of Karen Carpenter, a famous pop singer who died at the age of 33 years due to self-imposed weight loss (anorexia nervosa) followed by a heart attack. His book Little Girl Blue: The Life of Karen Carpenter, tells of the tragedy of weight loss and the causes that bring it about.

There is a great preoccupation with weight loss in our society. Extensive weight loss either induced or without reason requires attention from the dysphagia team. Significant weight loss is associated with the loss of muscle mass, which may produce weakness severe enough to change the daily activities of an individual. Moreover, weight loss may affect coordination of muscles, especially in repeated activities such as swallowing. Weight loss associated with starvation, whether intentional or not, may lead to damage of other vital organs, namely, the heart. When unplanned weight loss develops, a swallowing disorder should be suspected. Weight loss should not be so extensive that it affects quality of life, nor should it continue beyond normal weight ranges. Speechlanguage specialists are often called on to rule in/ out the oral-pharyngeal phase of swallowing, and if normal, the patient is referred to a gastroenterologist.

The impact of weight loss on various medical conditions or postsurgical recovery has been shown to slow or delay recovery.

A survey of studies related to weight loss suggests the importance of monitoring food and liquid intake.⁷ The factors most consistently associated with weight loss were depression, poor oral intake, swallowing issues, and eating/chewing dependency. Staffing factors such as inadequate staffing and lack of professional supervision were associated with weight loss in most studies.

The factors most consistently associated with a low body mass index (BMI) include immobility, poor oral intake, chewing problems, dysphagia, female gender, and older age. The factors most consistently associated with poor nutrition included impaired function, dementia, swallowing/chewing difficulties, poor oral intake, and older age.

Temporary nonoral feeding arrangements are now more commonly used to stabilize weight during recovery from severe diseases and disorders and to speed up such recovery. Dysphagia is a risk factor that impairs an individual's experience of mealtimes. Oropharyngeal dysphagia has been shown to have had a high impact on the quality of life of those with dysphagia living independently.⁸ Focus is needed on **xerostomia**, as well as on the psychological aspects associated with nonoral feeding.^{9,10}

Types of Pneumonia

Not all types of pneumonia are the result of dysphagia or aphagia. Infections, poor health, and lack of proper posthospital care may lead to other types of pneumonia. Clinicians who treat swallowing disorders must be aware of these, as aspiration may play a part in their cause.

Aspiration Pneumonia. When pulmonary infection results from acute or chronic aspiration of fluids, foods, or oral secretions from the mouth or from fluids arising in the stomach and flowing into the airway, aspiration pneumonia develops. This is a potentially life-threatening condition that requires significant medical attention. Aspiration pneumonia can occur in adults or children with medical problems that disrupt a normal swallow. However, not all aspiration leads to pneumonia. Studies report that 28% to 36% of asymptomatic healthy older adults demonstrate trace aspiration on a FEES, and up to 45% of normal adults demonstrate aspiration of oropharyngeal secretions during sleep. 4 In most healthy children and adults, trace aspiration is responded to with awareness and a strong cough to clear the food or liquid. Nonetheless, aspiration pneumonia creates significant morbidity and may account for up to 70% of community-acquired pneumonia in older adult patients.¹¹

Nosocomial Pneumonia. Nosocomial pneumonia, also called hospital-acquired pneumonia, is usually the result of bacterial infections acquired during the first 48 to 72 hours following admission to a hospital. Nosocomial pneumonia is often the cause of death following admission to an intensive care unit. Factors such as older age, aspiration of saliva, fever, gastric contents rising and falling into the airway (gastric reflux), and other medical conditions requiring intensive care are common causes of nosocomial pneumonia.

Community-Acquired Pneumonia. Community-acquired pneumonia (CAP) is an infection of the lungs in people who have not been hospitalized. It is a disease that can affect people of all ages and is often the leading cause of death in countries where vaccination against diseases has not been established. Figure 1–2 shows an x-ray of the lungs. In that figure, evidence of pneumonia can be seen on the right lower lobe of the lung.

In CAP, the patient may appear to be swallowing normally, but due to fever or breathing difficulty, the lungs slowly absorb fluids, resulting in an infection.

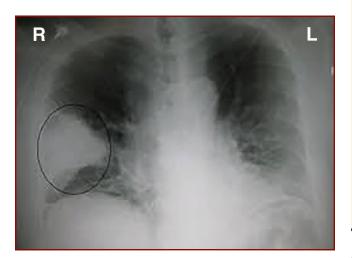


FIGURE 1–2. Standard x-ray shows area of infiltrate in the lower right lobe of the lung. In the figure, evidence of pneumonia can be seen on the right lower lobe of the lung.

CAP is treated with antibiotics and may require rehospitalization. In underdeveloped countries, CAP can occur in patients who have recently been hospitalized and discharged without proper follow-up.¹²

Related Impacts of Swallowing Disorders on Quality of Life

General Health

The inability to swallow correctly may lead to a decline in general health. This may be slow or rapid and is usually, but not always, associated with other diseases. For individuals with systemic diseases such as **Parkinson disease**, diabetes mellitus, or high blood pressure, swallowing may decline slowly. For disorders such as gastroesophageal reflux and autoimmune disorders, dysphagia may initially be sporadic and will increase as the severity of the primary problem increases, for example, in Parkinson disease. With the onset of dysphagia, the body is not able to cope as well with the primary disease. Moreover, the primary disease may be exacerbated by the dysphagia.

Psychological Well-Being

Florence K. had a stroke about 3 months ago. She was recovering nicely but still had trouble with drinking coffee and other liquids. She coughed after each sip. Prior to the stroke, she enjoyed coffee with her friends every Tuesday and Friday morning. Since the stroke, she refused to join them due to the inability to drink coffee without coughing. Therefore, her speechlanguage pathologist had her practice dipping a cookie in the coffee but avoiding drinking the coffee. They practiced it in the session. During the following session, Florence reported an enjoyable visit with her friends, and no one noticed her dipping the cookie in the coffee and not drinking the coffee.

Eating is a social function as well as a nutritional necessity. When an illness or disease is further compounded by dysphagia, the natural social functions in which food plays a role are limited. ¹³ The person with a swallowing disorder can no longer participate seamlessly in the social interactions that surround meals. That person is no longer able to eat in their normal environment (eg, home) or with the same individuals that they have dined with in the past. The meal is now in a clinical setting or in a setting with a caregiver following a prescribed diet that may include foods that are new to the individual and not part of their lifelong diet. In controlled settings such as a hospital or nursing home, the diet to adhere to is one that will allow the patient to regain health rather than a diet that has a primary purpose of enjoyment.

Enjoying a good meal is often taken for granted, but this is not so for anyone with a swallowing disorder. Clinicians should not underestimate the importance of the social aspects of dysphagia.

Financial Well-Being

The financial impact caused by dysphagia can be significant if there is a need for special foods, supplemental feeding, primary **enteral** or **parenteral nutrition**, dysphagia therapy, special gadgets and appliances to aid in the preparation of meals, or for others to assist with feeding. Some or all of these expenses may be paid for by insurance; however, the costs of all dysphagia-related management issues may be substantial and may continue for extended periods of time, straining the financial condition of the patient and the patient's family and the economic welfare of the patient. Limitations brought by insurance capitation or personal financial abilities often compromise ideal rehabilitation strategies.

There are numerous natural ways to treat dysphagia, such as drinkable yogurts, nectars, and smoothies in lieu of commercial products modifying texture. Patients appreciate approaches to swallowing that reflect their normal diets and eating/drinking habits.

The true financial impact of dysphagia remains unknown, as research has not yet determined the total cost of major events such as aspiration pneumonia and hospital readmissions or the cost-benefit ratio for the early identification and management of swallowing disorders.

Conventional wisdom suggests that early intervention may prevent extensive comorbidities that result from the interaction of swallowing disorders with other diseases or disorders. Clinical research ultimately will lead to confirming the efficacy of dysphagia rehabilitation methods.

In 2020, the hospitalized costs are approximately 30% higher for older adult patients with dysphagia than for those without dysphagia.¹⁴

Voice Disorders

Recent evidence suggests that patients with swallowing disorders also have voice changes that impact their quality of life. In a report of patients by Hess et al seen at a voice and swallowing center, 15 18% of patients reported dysphagia as their main complaint, suggesting the need for interdisciplinary management of patients with voice disorders. Conversely, we may detect dysphagia during a voice evaluation. The discipline of a referring provider alone was not a strong enough indicator to reliably predict the type of evaluation needed for the patient. While patients are often seen in a voice and swallowing center for a complaint of hoarseness, a weak voice, or a feeling of the need to clear the phlegm in the throat and are diagnosed with dysphonia, treatment for the dysphonia alone may not improve their ability to swallow liquids and solids normally. Amin and Belafsky¹⁶ also noted that patients with long-term cough often have voice changes related to glottic insufficiency and thus also experience swallowing disorders due to the lack of vocal fold closure. They note that the afferent and efferent pathways of swallowing and cough are the same. 16 In addition, other factors that signal a dysphagia condition, such as laryngopharyngeal reflux, excess mucus, and/or laryngitis, may also contribute to dysphagia. In all of these conditions, the effects on the voice may be significant.

NEED FOR EARLY INTERVENTION

"Not everything that counts can be counted."

Dennis Burket, as quoted in Kitchen
Table Wisdom by R.N. Remen¹⁷

Quality of Life

There is only limited, albeit strong and intuitively correct, evidence that the diagnosis and treatment of dysphagia are efficacious from the standpoint of significantly reducing aspiration pneumonia. Figure 1–3 shows an example of penetration. The food remains just above the vocal folds. If not cleared with a cough, it may fall into the trachea. This example offers ample evidence for the need to provide early intervention to prevent continued penetration of fluids and foods from entering the trachea, leading to aspiration pneumonia.



FIGURE 1–3. An example of penetration. The food remains just above the vocal folds; if not cleared with a cough, it may fall into the trachea.

Most of the evidence that exists is based on studies of stroke patients, although as pointed out in Chapters 6, 7, and 8, there also is evidence derived from research on patients undergoing treatment for cancers of the head and neck that dysphagia treatment improves recovery. The limited evidence suggests that in the acute care setting, dysphagia management is accompanied by reduced pneumonia rates. Furthermore, the use of a complete clinical swallow evaluation (CSE) appears to be cost effective. More recently, specific assessment tools have been devised to examine the swallowing functions in stroke patients. 18 Others have found dysphagia management to be useful in the rehabilitation of swallowing disorders in patients with head or neck cancer. Wasserman et al18 have shown that regardless of the underlying diagnosis, accurate reporting of the CSE information and an early aggressive treatment program are efficacious in reducing the length of hospital stays in patients undergoing major surgery for head and neck cancer. Additionally, development of valid screening procedures, such as the scale created by Foster and colleagues, 19 may offer a further basis for early treatment of patients with dysphagia. They administered a screening instrument for dysphagia to 299 inpatients and found that the scale provided a means for targeting patients for early swallowing assessment and intervention.

Limiting the quality of life: Not all "old friends" can get together for a coffee or tea if they have dysphagia.

McHorney and colleagues^{20,21} presented early versions of 2 quality-of-life assessments to determine the need and value of treating swallowing disorders. The SWAL-QOL is a validated, 44-item tool and is described in detail in Chapter 5. The SWAL-CARE is a 15-item tool that assesses quality of care and patient satisfaction and is also described in Chapter 5. The SWAL-QOL and SWAL-CARE may help clinicians to focus on the patient's treatment and determine treatment effectiveness. The work of McHorney²¹ found that the SWAL-QOL and SWAL-CARE were related primarily to oral transit duration and total swallow duration.

The tangible effects of early dysphagia intervention are ill-defined. In general, the lack of control groups, the undefined effects of diseases, and the lack of long-term follow-up data limit the statements that can be made about the true effects of early dysphagia intervention. Nonetheless, the clinical evidence gathered by those treating patients with dysphagia on a day-to-day basis suggests that intervention improves quality of life. The absence of prospective, controlled, randomized research should not suggest that swallowing programs using the CSE or other programs such as the MBS (see Chapter 6) or the FEES (see Chapter 6) should not be continued. On the contrary, studies such as that by Odderson et al²² and Mahler et al²³ provide strong arguments for continued early intervention in dysphagia. Early on, Odderson et al looked at pneumonia rates before and after initiating a CSE program in a hospital setting.

Aspiration pneumonia rates in patients poststroke were substantially reduced after an early intervention swallowing program was initiated.²³

Mahler and colleagues²³ studied Parkinson disease and found that a program focusing on strengthening laryngeal closure to reduce glottic incompetence and strengthen the ability to cough showed prolonged positive effects on speech and swallowing. Additional research is needed to provide further evidence for programs that focus on dysphagia intervention to include a data acquisition format that offers an opportunity to assess the contributions of the larynx to aid in the reduction of aspiration pneumonia, length of hospital stays, and readmissions to hospitals due to swallowing-related problems.

EPIDEMIOLOGY

Dysphagia can be caused by many different disorders, including natural aging, neurological diseases, head injury, degenerative diseases, systemic diseases, autoimmune disorders, neoplasms, and infections.

Treatment modalities such as surgery, radiation therapy, and medications can also lead to dysphagia. Chronic reflux laryngitis, often overlooked, may also interfere with normal swallowing. Patients with head or neck cancer have a variable presentation. They often have significant dysphagia at the time of initial presentation. Their swallowing function is often altered as a result of treatment, although some deficits improve with time. Patients with Parkinson disease experience dysphagia that becomes more severe as the disease progresses.²³ Because of these varied and often compounded etiologies, it may not be possible to ascertain the true incidence of any particular category of disorder. In addition to these factors, there is no single test that is 100% accurate for diagnosing dysphagia or its primary cause.²⁴

Swallowing disorders may arise as comorbidities of other disorders or as precursors to more significant diseases and disorders. Moreover, the incidence of swallowing disorders may vary depending on the type of diagnostic evaluation. Table 1-2 shows that the incidences of swallowing disorders following a stroke remain high; however, with the advent of improved assessment techniques, the treatment process following evidence of aspiration is now better understood.^{25,26} If all of the tests for examination of swallowing are considered, the true incidence of swallowing disorders may be substantially higher. When the swallowing disorder accompanies other medical conditions, the primary condition may be affected by the swallowing disorder. Conversely, a swallowing disorder may be the symptom of another neurological disease or condition requiring treatment. Thus, the exact incidence of swallowing disorders remains unknown.

Cerebrovascular Accidents and Neurological Diseases

Stroke is the third leading cause of death in the United States. Approximately 500,000 new cases are reported yearly, and as many as 150,000 individuals die of cerebrovascular accidents (CVAs) every year. Prospective studies have demonstrated an incidence of dysphagia as high as 41.7% in the first month after a CVA. The overall rate of aspiration resulting from a CVA is

TABLE 1–2. Incidence of Oropharyngeal Dysphagia in Patients Who Exhibited Aspiration During Videofluoroscopic Examination and Flexible Endoscopic Evaluation of Swallowing

Cause of Dysphagia	Number (%) of Patients		
Head and neck oncological surgery	59 (36)		
Cerebrovascular accident	47 (29)		
Cardiac-related event ^a	294 (22)		
Closed head injury	12 (7)		
Spinal cord injury	10 (6)		
Degenerative neurological diseaseb	9 (6)		
Adductor vocal fold paralysis	7 (4)		
Zenker diverticulum	4 (2)		
Generalized weakness	5 (3)		
Cerebral palsy	3 (2)		
Central nervous system involvement from AIDS	Unknown		
Craniotomy (for aneurysm repair)	2 (1)		
Undetermined	4 (2)		

^aData from Aviv et al.⁴⁸

Adapted from Rasley et al.24

approximately 33.3%. One-half of these patients will aspirate silently (with no obvious clinical symptoms or signs). As many as 20% will die of aspiration pneumonia during the first year after a CVA, and 10% to 15% will die of aspiration pneumonia after the first year following the stroke. In general, the larger the area of ischemia, the more significant is the swallowing disorder. Although the site of the lesion does not always correlate with the type and severity of the swallowing disorder, brainstem strokes produce dysphagia more frequently than cortical strokes. Table 1–3 shows the epidemiological data compiled from the Agency for Healthcare Research and Quality for neurological diseases including stroke.^{1,14}

Specific information concerning stroke suggests that a left cerebral infarction increases the risk

of aspiration pneumonia compared to a right-sided CVA. ²⁶ Flowers et al looked at the co-occurrence of dysphagia, dysarthria, and aphasia. They found estimates of the incidence of dysphagia, dysarthria, and aphasia were 44%, 42%, and 30%, respectively. ²⁷ Brown et al ²⁸ in a previous study found that in patients with CVA, dysphagia and dysarthria were the highest 2 co-occurring impairments. Ten percent of all the 221 patients studied had all 3 impairments (dysphagia, dysarthria, and aphasia). ²⁹ The highest predictors of the impairments were nonalert level of consciousness for dysphagia, symptoms of weakness for dysarthria, and right-sided symptoms for aphasia.

Dementia

Dementia is a diagnostic term that refers to the inability to carry out tasks due to the loss of brain function. For those with dementia, various types of intellectual impairment may exist. These impairments vary according to a past lifestyle as well as education. The loss of function depends on the part or parts of the brain damaged and the severity of the damage. Dysphagia is common in older patients with dementia. According to videofluoroscopic reports, normal swallowing function is found in only 7% of patients with dementia. Patients with dementia are difficult to assess with any type of functional study due to their ability to follow instructions. The effectiveness of therapeutic maneuvers that require patient cooperation is also low. Nonoral nutrition alternatives must be considered in patients with dementia and dysphagia. In patients with dementia, even nonoral feeding may still offer a risk or aspiration. Recurrences of aspiration pneumonia, continued weight loss, and/or refusal to eat are the key indications for implementing nonoral nutrition alternatives.

Since many patients with dementia are also older adults and/or have other medical conditions, the incidence of dysphagia due specifically to dementia remains virtually unknown.

^bIncludes Parkinson disease, motor neuron disease, and multiple sclerosis.

TABLE 1–3. Epidemiological Data From the Published Literature: Neurological Diseases and the Rate of Dysphagia Within Each

Disease	Prevalence (per 100,000)	Incidence (per 100,000)	Study	Source	Diagnosed Occurrence of Dysphagia (%)	Study	Reason
Stroke	NA	145	Brown et al ²⁸	Mayo Clinic	VFSS: 74.6	Daniels et al ³⁸	Median of VFSS studies
		289	Modan and Wagener ²⁹	Mayo Clinic seemed low: this provides an upper estimate	BSE*: 41.7	DePippo et al ³⁹	Median of BSE studies
Parkinson disease	106.9	13	Mayeux et al ³⁰	Only number on general population that included older adults	VFSS: 69.1	Bushmann et al ⁴⁰ ; Fuh et al ⁴¹	Mean of 2 studies in which L-dopa was withheld
Alzheimer disease	259.8	NR	Beard et al ³¹	Only published number	VFSS: 84	Horner et al ⁴²	Only published number
Multiple sclerosis	170.8	NR	Wynn et al ³²	Only number; Mayo Clinic	NR	NA	NA
Motor neuron disease	170.8	6.2	Lilienfeld et al ³³	Only published number	51.2 (method not reported)	Leighton et al ⁴³	Exam, not survey
Amyotrophic lateral sclerosis	NR	1.8	McGuire et al ³⁴	Exam, not survey	29 (method not reported)	Litvan et al ⁴⁴	Only published number
Progressive supranuclear palsy	1.39	1.1	Golbe et al ³⁵ Bower et al ³⁶	Only published number	VFSS: 55.6	Kagel, Leopold ⁴⁵	Only published number
Huntington disease	1.9	0.2	Kokmen et al ³⁷	Only published number	VFSS: 100		

Abbreviations: BSE, bedside swallowing evaluation; NA, not applicable; NR, not reported; VFSS, videofluoroscopic swallowing study (also known as the modified barium swallow [MBS]).

Older Adult Population

Seventy to 90% of older adult patients, even those without known neurological disease, have some

degree of swallowing dysfunction, if not true dysphagia. Objective functional tests are necessary to rule out specific diseases and to assess the risk of aspiration. As many as 50% of older adult patients

^aNow referred to in this text as the clinical swallow evaluation (CSE).

have difficulty eating, leading to nutritional deficiencies with associated weight loss, increased risk of falling, poor healing, and increased susceptibility to other illnesses. Weight loss, increased length of meals, depression, and general complaints of fatigue are often observed in this group prior to the diagnosis of a swallowing disorder. A comprehensive discussion of aging factors is found in Chapter 9.

Cognitive function, dentition, and oral motor function are significant indicators associated with the presence of swallowing in older adults. When assessing frail older adults, case file information can help clinicians identify frail older adults who may be experiencing dysphagia.⁴⁶

Head and Neck Oncology

The presence of a tumor in the upper aerodigestive tract may affect swallowing due to the following:

- 1. Mechanical obstruction due to bulk or extraluminal compression
- **2.** Decreased pliability of the soft tissue due to neoplastic infiltration
- **3.** Direct invasion leading to paralysis of important pharyngeal or laryngeal muscles
- **4.** Loss of sensation (taste, feel) caused by nerve injury
- 5. Pain
- **6.** Factors related to desire for eating (appetite and craving)

Treatments for squamous cell carcinoma, namely, surgery, radiation, or chemotherapy, produce disabilities that are usually proportional to the volume of the resection and/or the radiation field. Surgery produces division and fibrosis of muscles and anesthetic areas due to the transection or extirpation of afferent neural fibers and/or receptors.

Irradiation also produces fibrosis of the oropharyngeal and laryngeal musculature. Chemotherapy may lead to weakness, nausea, or reduced sensory

processes and may add to immediate radiation side effects such as mucositis, the thickening of mucus in the mouth, pharynx, and esophagus. Newer types of radiation treatment known as **intensity modulated radiation therapy** and proton radiation beam therapy to precisely deliver a beam of protons to the tumor have been used recently. The results of these treatments still impact swallowing in both the short and long terms.

Radiation therapy leads to **xerostomia** (dryness of the mouth), which, in many cases, is permanent and a main source of swallowing complaints made by patients.

Swallowing function after radiation treatment appears to be related to both site and stage of disease. In general, patients with so-called anterior tumors, such as those located on the floor of the mouth or on the anterior oral tongue, have better posttreatment outcomes regarding swallowing than do patients with posterior tumors, such as those located in the oropharynx or hypopharynx. Reconstructive methods also influence the swallowing outcome. Patients who are reconstructed with primary closure have fewer problems swallowing than patients who are reconstructed with bulky insensate flaps.

Hospitalized Patients

The incidence of swallowing disorders in patients admitted to critical care units is increased by the need for endotracheal and nasogastric intubation and tracheotomy, the use of sedatives, impaired consciousness, and the debilitated status of many of the patients requiring critical care.

Acute care patients should be assessed for swallowing disorders within the first 24 hours of hospitalization. In many hospitals, a standing order exists for a CSE of the acute patient within 24 hours of admission. Patients requiring mechanical ventilation are at higher risk for aspiration pneumonia. The mortality of nosocomial pneumonia is estimated to be 20% to 50% for hospitalized patients. Hospital

costs due to nosocomial infection may exceed \$22,000 per occurrence.

Nursing Home Residents

Studies carried out in nursing homes have demonstrated that 40% to 60% of the residents have clinical evidence of dysphagia. This number appears to be increasing in recent years. 46,47 The high number of nursing home residents with dysphagia is due, at least in part, to discharging patients with swallowing disorders from acute care settings into institutional care where medical care and nutrition may be less monitored.

The prevalence of all types of pneumonia has been estimated to be 2%, although it is unknown how many of these patients developed pneumonia as a result of aspiration. The death rate for patients diagnosed with pneumonia in a nursing home and admitted to acute care centers may exceed 40% of all readmissions.

Cardiac-Related Conditions

The number of patients seen in major medical centers for cardiac-related conditions is always increasing, due to the life-sustaining procedures available in emergency settings and the types of surgical treatment available to patients following cardiac events. In 2004, a large cohort of patients (1340) with swallowing disorders was examined by Aviv and colleagues⁴⁸ in an effort to identify safety and comfort factors related to assessment of swallowing disorders using the flexible endoscopic examination of swallowing with sensory testing (FEESST) procedure in inpatients and outpatients. The largest patient subgroup, as might be expected, included poststroke patients; however, surprisingly, the second-largest group included patients with cardiac-related events (22.2%). The majority of cardiac-related cases in the acute, inpatient setting had undergone open heart surgery (almost 60% of cases), followed by patients who had had heart attacks and those with congestive heart failure and newly diagnosed arrhythmias. The authors found that a large percentage of these patients had significant vagal nerve sensory dysfunctions when tested with FEESST and thus were at risk for silent aspiration—that is, aspiration without sensing the need to cough.

Gastroesophageal Reflux and Laryngopharyngeal Reflux

Over the past 15 to 20 years, reflux disease has been shown to be a common cause of swallowing disorders. Belafsky reported that the most common cause of dysphagia complaints was related to reflux disease. ⁴⁹ Gastroesophageal and laryngopharyngeal reflux are discussed in detail in Chapter 3. In short, acid from the stomach rises into the esophagus and often to the level of the larynx creating a burning in the chest or a feeling of a lump in the throat leading to a delayed or disrupted normal swallow.

Conditions Leading to Swallowing Disorders

Patients may present to an outpatient facility with numerous problems that include difficulty with swallowing or the inability to swallow. Other swallowing disorders may also be identified when a patient is hospitalized for the care of other conditions. Table 1–4 outlines the most common conditions that may indicate a swallowing disorder is also present. The true incidence of swallowing disorders in patients presenting with these problems is unknown.

In infants and young children, swallowing problems are often overlooked until a nutritional or failure to thrive condition exists.⁵⁰ Infant and childhood dysphagia have evolved into a separate area of study thanks to increased neonatal care, better instrumentation to study the problem, and findings of the importance of nutrition to improve other coexisting problems in young children.⁵⁰ In later chapters (Chapters 10, 11, and 12), the current treatment and feeding of neonatal and infants is discussed. The main causes of sucking, swallowing, and feeding disorders are lesions of the brainstem such as malformations of the posterior fossa, neonatal brainstem tumors, agenesis of cranial nerves, lesions of the posterior brain, craniovertebral anom-

TABLE 1–4. Conditions That May Lead to or Are Directly Related to Swallowing Disorders

Type of Condition	Common Examples
Congenital	Dysphagia lusoria Tracheoesophageal fistula Laryngeal clefts Other foregut abnormalities
Inflammatory	Gastroesophageal reflux disease (GERD) Laryngopharyngeal reflux (LPR)
Infections	Lyme disease Neuropathies/encephalitis Chagas disease HIV
Trauma	Central nervous system trauma Upper aerodigestive tract Blunt traumatic injuries to the oral, laryngeal, and /or esophageal organs Burns
Endocrine	Goiter Hypothyroid Diabetic neuropathy
Neoplasia	Oral cavity and contents Upper aerodigestive tract Thyroid Central nervous system
Systemic	Autoimmune disorders Dermatomyositis Scleroderma Sjögren disease Amyloidosis Sarcoidosis
latrogenic	Surgery Chemotherapy Other medications Radiation

alies, and syndromes that involve rhombencephalon development such as Pierre Robin sequence and CHARGE syndrome, to name just a few. Also, many normal term children have sucking and swallowing problems that are not secondary to these conditions, and they resolve with minor interventions from feeding specialists.

Suprabulbar lesions, neuromuscular disorders, peripheral esophageal, digestive, and laryngeal anomalies and dysfunctions can also be involved. The main principles of the management of congenital sucking, swallowing, and feeding disorders are discussed in Chapters 10, 11, and 12.

Burns

The true incidence of swallowing disorders caused by burns is not well documented. Although burns may occur in the oral cavity, pharynx, or esophagus, unless the burns are extreme in the oral cavity and pharynx, they usually resolve with no significant swallowing disorder. However, burns in the esophagus may lead to esophageal strictures.⁵¹ Examination of the esophagus with endoscopy and ultrasound has improved the morbidity associated with esophageal burn disorders; nonetheless, patients often need recurring dilation and possibly esophageal stents to maintain nutrition. Late reconstructive surgery, mainly using colon transposition, offers the best results in referral centers, in either children or adults, but such a difficult surgical procedure is often unavailable in developing countries.⁵² Continuous long-term monitoring is important as strictures may re-form and esophageal cancer may develop, which is rare but possible.

Muscle Tension Dysphagia

In the past 20 years, a number of specialized centers to treat swallowing disorders have emerged. These centers usually include a multidisciplinary team of voice and swallowing specialists. As a result, careful examination and assessment of the oral-pharyngeal and laryngeal anatomy and physiology are available. These clinicians have long been aware that a condition known as muscle tension dysphonia impacts the clarity and power of the voice without clear evidence of a laryngeal pathology. Often, patients with this condition also complain of dysphagia. Extensive evaluations and instrumental testing often fail to

reveal an underlying abnormality attributable to dysphagia, but noted muscle tension in the examination of the voice on laryngoscopic examination is identified. Following a review of 595 videofluoroscopic swallowing studies, Kang et al⁵³ found signs of laryngeal hyperresponsiveness in 67% of the patients with complaints of dysphagia. They proposed the term muscle tension dysphagia to describe the subset of patients with a functional disorder that resulted in a primary complaint of a swallowing problem. DePietro et al54 reported a subjective improvement in dysphagia symptoms in patients with muscle tension and dysphagia complaints who underwent laryngeal manipulation and meal coaching. The results of these early studies have implications regarding the need for multidisciplinary diagnosis of patients complaining of dysphagia. Treatment modalities remain with little evidence and suggest that further evaluation of both the dysphagia and the dysphonia components of patients' complaints can be addressed despite the lack of an underlying etiology of either.

BIOMEDICAL ETHICS: PRINCIPLES AND PRACTICES

Ethical challenges are not uncommon given the complexity of dysphagia. Professionals should maintain ethical practices and shared decision-making with patient, family, and medical staff to assure ethical principles are not violated. Speech-language pathologists (SLPs) should be aware of the ethical issues when involved with patients with swallowing disorders, whether it be in the assessment, the treatment, or conducting of research. All SLPs involved with swallowing disorders must be aware of issues concerning balancing individuals' preferences, quality of life, and medical consequences.

Ethics is a major branch of philosophy encompassing "the right conduct" and "the good life." It is significantly broader than the common conception of analyzing right and wrong. A central aspect of ethics is "the good life," the life worth living or life that is

satisfying. **Biomedical ethics** is primarily a field of applied ethics, the study of moral values and judgments as they apply to medicine.

Ethical dilemmas may occur in numerous situations as they relate to the patient who has dysphagia. For example, consider whether to recommend nonoral feeding or a specific diet with restrictions to older adult patients or to patients who are at the end-of-life stage. The SLP who observes or finds evidence of a high aspiration risk or inadequate nutritional and hydration intakes should, under normal conditions, recommend the need to modify the oral diet and/or the use of enteral feeding. However, add to the situation when the patient has advance directives or a living will, or when the patient or the surrogate decision-maker does not agree with the recommendations. Here is where medical ethics plays a role for all involved in the patient's care and where the treatment team must make decisions based on ethical considerations.

Beauchamp and Childress⁵⁵ and more recently Leslie and Lisiecka⁵⁶ proposed four ethical principles that could be used to guide ethical decisions:

- Respect for autonomy
- Beneficence
- Nonmaleficence
- Iustice

Respect for autonomy refers to the principle that each competent individual should have the rights to decide how one is medically managed. Beneficence means clinicians should take positive action to do good for patients and act to prevent or remove harm. Nonmaleficence means that clinicians should not cause any deliberate harm to a patient. Finally, justice means patients' needs should be addressed in a fair and equitable manner. A number of clinical settings have published decision-making algorithms or guidelines to aid health care providers to make decisions on diet modifications or tube feeding. ^{57–59}

Beneficence refers to taking positive action to do good and prevent harm. When we assess or treat a patient with a swallowing disorder, the goal may not be to get them to a normal swallow but rather to a safe outcome. This applies to the clinician, the patient, and the caregiver.

Nonmaleficence implies that you deliberately avoid causing harm. Justice refers to providing what

the patient needs and doing it in a fair and equitable way.

A number of common themes to these guidelines are as follows:

- 1. Accurately identify the current progress and prognosis of the patient.
- **2.** Educate the patient and family members of the risks and benefits of the dysphagia management recommendations.
- **3.** Involve the patient and family in the decision-making.
- **4.** Encourage regular follow-up after a decision has been made.

These guidelines can help to ease the burden on health care providers and the patient's family.

Evidence-based practice combined with patient preferences are the core of biomedical ethics. Often, it is important to discuss principles of treatment with a wider team of patient care specialists in order to solve ethical dilemmas that may occur in patient care.⁶⁰



Case Vignette

Mr. Glendon, a 66-year-old retired male history teacher, experienced a CVA 5 months ago. He was advanced to a puree diet and doing well. However, when he came in for a follow-up visit with the SLP and his family physician, his weight dropped 7 pounds in the past 2 months, and he complained of a cough during the day. He was now expressing the request to move to a more regular diet, especially including coffee. The family doctor prescribed a medication for the cough and a return visit in 1 month. The SLP suggested that Mr. Glendon have a repeat VFSS to determine his ability to manage a regular diet with liquids. When discussed with Mr. Glendon's wife, she was afraid to give him coffee since she reported that he often coughed on sipping water. After some discussion with the patient, wife, and SLP, the family physician referred Mr. Glendon for a VFSS. The biomedical ethical principles of autonomy, beneficence, nonmaleficence, and justice were applied in Mr. Glendon's case.

SUMMARY

Swallowing disorders have a significant effect on a patient's quality of life, including the patient's physical, financial, and psychological well-being. These effects are highlighted in this chapter and discussed in depth by Treats within the framework of the World Health Organization's *International Classification of Functioning, Disability, and Health.*¹ Dysphagia leads to a number of complicating factors, whether the patient is generally healthy or is recovering from a neurological event, cancer, or other surgery. The inability to swallow leads to weight loss, weakness, and in severe cases, complicating medical problems.

Although research is somewhat limited, there appears to be a general clinical consensus that early intervention in dysphagia through proper diagnosis and treatment may reduce the comorbidities and thus shorten the length and cost of the hospital stay.

Treatment of swallowing disorders varies according to the underlying pathophysiology and status of the patient. Outpatients with minor problems are generally cooperative and willing to make adjustments in lifestyle and diet to improve their swallowing disorder. Hospitalized patients may be severely deconditioned or their cognitive status may limit their cooperation in the rehabilitation process. The patient with dysphagia presents a unique opportunity for team diagnosis and treatment. The remainder of this text explores the methods and approaches to treating swallowing disorders.

DISCUSSION QUESTIONS

- 1. With which groups of patients might the SWAL-QOL and SWAL-CARE be most useful? In what groups might its use be limited?
- **2.** What are some of the significant negative effects of a swallowing disorder on an otherwise healthy person?
- 3. There is a rising awareness of reflux disease reported among otolaryngologists and SLPs. What evidence exists to suggest the need for SLP involvement?