PEDIATRIC DYSPHAGIA

Etiologies, Diagnosis, and Management

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FOREWORD

It is indeed an honor to write this foreword and to have personally been at the forefront of the conceptual and clinical change that transformed the model of care for children with airway and swallowing issues. The traditional fragmented approach became one in which all involved clinical specialists evaluated the patient and together developed an integrated management plan-an interdisciplinary team approach. The interdisciplinary feeding team at Cincinnati Children's Hospital Medical Center exemplifies this holistic, cohesive model of care. The team began as a pilot project in 1987, with the mission of optimizing the wellbeing of children with complex feeding and swallowing issues. Since that time, we have become leaders of medical treatment offered in this format.

Given the remarkable advancements in medical care that have been made over the past several decades, the number of children with complex syndromes and disorders presenting to medical centers across the nation has dramatically increased. Many of these children experience difficulties with safe oral feeding and require input from clinicians with special expertise in pediatric dysphagia. Our interdisciplinary feeding team, along with other experts in various aspects of patient care, has written a comprehensive and unparalleled text designed to lay the foundation for an understanding of the embryologic, anatomic, neurogenic, cognitive, and behavioral components of dysphagia. They have also familiarized readers with the disorders and syndromes associated with dysphagia, the complexities of clinical decision making, the ethical issues often involved in patient care, and most important, the need to strive for evidence-based approaches to treatment. In sum, they have shared their philosophy for collaborative care, their respect for the knowledge and skills of multiple clinical disciplines, and a willingness to learn from others.

Robin T. Cotton, MD, FRCS(C), FACS

PREFACE

Medical advancements in neonatal and pediatric care over the past several decades have led to the increased survival of infants and children with a wide spectrum of congenital conditions, syndromes, and sequences, many of which are associated with physiologic and anatomic abnormalities that result in feeding and swallowing disorders. Given the complexity of these patients, providing optimal care requires a multidisciplinary approach in which all involved health care professionals must not only assess the patient from the perspective of their own discipline, but must understand and appreciate the input and expertise of other team members. Our book reflects this model of care, including chapters written by members of the Interdisciplinary Feeding Team at Cincinnati Children's Medical Center. We cover the roles played by our medical subspecialists in otolaryngology, pulmonology, and gastroenterology as well as the roles of the nurse, advanced nurse practitioner, dietitian, speech-language pathologist, occupational therapist, psychologist, and social worker.

Our book is divided into five parts. In Part I, we provide readers with an overview of the embryologic development of aerodigestive structures that relate to swallowing, an introduction to key structures involved in the neural control of swallowing, a synopsis of oral motor development, a discussion of the various etiologic categories of swallowing disorders, and an overview of genetic disorders associated with feeding and swallowing issues. Part II covers the clinical and instrumental assessment of patients, including the interdisciplinary feeding team approach, the specific diagnostic tests commonly used in assessing feeding issues, the classification of neonatal intensive care units, and the assessment and management of feeding and swallowing issues encountered in the neonatal intensive care unit. Part III focuses on the management of pediatric dysphagia, covering a wide range of treatment strategies and interventions for children with various categories of feeding disorders. In Part IV, we present an introduction to the concept of evidence-based medicine, an important component of decision-making in regard to treatment, and a topic that we have emphasized throughout the text. Part V presents a brief overview of the role of ethics in health care and in treating dysphagic children.

It is our hope that the information in this text expands the knowledge of clinicians involved in the care of dysphagic patients, assists them in clinical problem solving and decision making, and inspires them to develop multidisciplinary models of care at their own institutions. This approach optimizes the outcomes of an extremely diverse population of complex patients, all of whom present with conditions and accompanying dysphagia.

> Jay Paul Willging Claire Kane Miller Aliza P. Coben

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Jay Paul Willging, MD, is a Professor of Otolaryngology-Head and Neck Surgery at the University of Cincinnati College of Medicine. He completed his fellowship in pediatric otolaryngology at Cincinnati Children's Hospital Medical Center (CCHMC) and has been a member of the Division of Pediatric Otolaryngology-Head and Neck Surgery at CCHMC since 1992. He is the Director of the Pediatric Otolaryngology Fellowship Training Program and also the Director of Clinical Operations for the Otolaryngology Division. He has served as the Director of the Interdisciplinary Feeding Team since 1999, and is also an active participant in numerous other multidisciplinary programs, including the Aerodigestive and Esophageal Center, the Craniofacial Anomaly Team, the Fiberoptic Endoscopic Evaluation of Swallowing Safety Clinic, and the Velopharyngeal Insufficiency Clinic. Dr. Willging has numerous peer-reviewed clinical and research publications and has been a longstanding contributor to textbooks on a wide range of otolaryngology topics, particularly feeding and swallowing disorders.

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OVERVIEW OF TREATMENT STRATEGIES

Claire Kane Miller, Aliza P. Cohen, and Jay Paul Willging

CHAPTER OUTLINE

Introduction Habilitation Versus Rehabilitation **Direct Therapeutic Maneuvers and Exercises** Intraoral Bolus Hold **Double Swallow** Supraglottic Swallow Sequence Effortful Swallow Head Rotation **Oral Motor Exercises Indirect Compensatory Techniques** Alterations in Positioning **Oral Sensorimotor Therapy** Sensorimotor Interventions in Preterm Infants Non-Nutritive Oral Stimulation Specialized Feeding Equipment Pacifiers Nipples Bottles Cups Utensils **Oral Appliances** Bolus Modification Using Differing Food Textures and Liquid Viscosities Standardization of Viscosity Nomenclature Pharmacologic Treatment Considerations

Psychosocial and Behavioral Approaches to Treatment A Multidisciplinary Approach to Treatment

Introduction

Failing to recognize the need for intervention in dysphagic children or selecting inappropriate treatment strategies may result in potentially serious respiratory, nutritional, and developmental consequences. Decision making regarding appropriate therapeutic options for infants and children therefore requires an in-depth understanding of underlying conditions, oral sensorimotor function, and swallowing physiology. However, this knowledge alone does not ensure positive therapeutic outcomes.

Successful treatment also requires the ability of clinicians to teach specific management techniques and strategies to parents (or caretakers) and patients, thereby increasing the likelihood that implementation of these approaches will carry over to the home environment. To this end, establishing appropriate treatment goals and closely monitoring patient response and progress during treatment are essential.

The dysphagia treatment paradigm consists of both indirect and direct approaches that are tailored to the needs of each patient. Direct approaches consist of maneuvers or specific exercises to change the physiology of the swallow, whereas indirect strategies refer to compensatory techniques to eliminate the symptoms of dysphagia and improve the safety and efficiency of feeding and swallowing. This chapter presents the reader with a general overview of the various components of these two broad therapeutic approaches (Appendix 38–1).

Habilitation Versus Rehabilitation

The terms *habilitation* and *rehabilitation* both refer to the process of learning skills.

The key difference between these terms is that habilitation refers to learning new skills, whereas rehabilitation refers to regaining skills that have been lost. Unlike adults, who may undergo rehabilitation following a stroke to regain the skills needed for efficient oral intake and safe swallowing, infants and children may not have yet developed the necessary oral sensorimotor skill set. It is possible that the normal developmental sequence during which oral sensorimotor skills are acquired for feeding may be disrupted secondary to medical conditions that preclude exposure to oral feeding during critical learning periods. The lack of essential sensory stimulation may negatively impact the normal trajectory of sensorimotor skill development for feeding. Treatment must therefore focus on providing compensatory strategies for eliciting the oral sensorimotor skill sequence that normally emerges (eg, learning to coordinate the suck-swallow sequence during bottle feeding, learning to develop spoon-feeding skills).

Box 38-1

Direct therapeutic strategies include techniques intended to change the physiology of the swallow to improve airway protection and swallowing efficiency. Compensatory strategies are techniques that have an immediate but short-term effect on swallowing and are designed to improve swallowing efficiency and safety.

Direct Therapeutic Maneuvers and Exercises

Problems in the feeding and swallowing process can occur secondary to failure of the airway protection complex during the swallow, decreased bolus propulsive forces to drive the bolus from the oral cavity through the hypopharynx and into the esophagus, or due to a combination of these issues. Instrumental swallowing studies provide insight into the physiologic aspects of the oropharyngeal and cervical esophageal phases of the swallow that are affected. Direct rehabilitation maneuvers and exercises are used in treatment to improve the physiology of the swallow, to improve airway protection during the swallow, and to increase the efficiency of the swallow.

Box 38-2

Although the use of direct maneuvers and exercises requires the ability to comprehend directions and may be difficult for some children, there are specific pediatric conditions in which direct rehabilitative strategies may be applied even when comprehension is limited (eg, recovery from a stroke or airway surgery).*

*Miller CK, Linck J, Willging JP. Duration and extent of dysphagia following pediatric airway reconstruction. *Int J Pediatr Otorbinolaryngol.* 2009;73(4):573–579.

Miller CK, Kelchner LN, de Alarcon A, Willging JP. Compensatory laryngeal function and airway protection in children following airway reconstruction. *Ann Otol Rhinol Laryngol.* 2014;123(5):305–313.

In view of the fact that direct strategies and outcomes have been studied primarily in adults, only limited empiric evidence exists to support the use of these strategies in children. Due to the wide range of etiologies associated with dysphagia in infants and children, well-controlled randomized trials to investigate the efficacy of these strategies are difficult to conduct. Continued research is, however, under way to strengthen the evidence base for the use of direct maneuvers in specific populations. This information will further validate selected treatment approaches.

Dysphagia treatments are based on the specific physiologic impairment in the oropharyngeal and pharyngeal swallowing process; for example, impaired lingual motion for bolus manipulation and control, delayed initiation of oral bolus transport, latent initiation of the pharyngeal swallow, and incomplete hypopharyngeal clearance following the swallow due to decreased bolus driving forces. Strategies for addressing the specific components of swallowing dysfunction are described below.

Intraoral Bolus Hold

The intraoral bolus hold is a strategy to improve airway protection during swallowing. The patient is instructed to hold the bolus orally prior to the transfer of the bolus for swallowing in order to allow time for achieving volitional airway closure. This strategy requires the patient to maintain lip closure and sustained tongue control to maintain the position of the bolus intraorally prior to transferring it for swallowing.

Double Swallow

For patients who need to clear residual material in the hypopharynx caused by decreased strength of pharyngeal constriction following the initial swallow, the use of a sequential double swallow is advantageous. The efficacy of the double swallow in clearing the hypopharynx may be objectively assessed during a videofluoroscopic swallow study (VFSS) or fiberoptic endoscopic evaluation of swallowing (FEES).

Supraglottic Swallow Sequence

The supraglottic swallowing sequence may be used to improve airway protection during swallowing in patients who have undergone procedures that involve alteration of laryngeal anatomy. The goal of this technique is to close the supraglottic and glottic areas before material is transferred for the swallow, thereby ensuring airway protection. The supraglottic sequence in adults as described by Logemann¹ is composed of four steps: (1) taking a deep breath, (2) holding the breath, (3) continuing to hold the breath during the swallow, and (4) coughing immediately after the swallow. In children with an appropriate comprehension level, this may be accomplished by using a series of simple picture sequences to teach the steps. In some clinical scenarios, modification of this sequence is required. As an example, the modified sequence in children following airway reconstruction consists of five steps: (1) coughing to clear prior to accepting food or liquid, (2) oral holding of the bolus prior to transferring it for the swallow, (3) holding the breath before and during transfer for the swallow, (4) holding the breath during the swallow, and (5) gentle coughing to clear following the swallow. The use of a thickened fluid bolus has been found to assist patients in maintaining control of the bolus while learning the sequence. Once the sequence is learned, introduction of small presentations of easily managed solids as well as single sips of liquid may be introduced.

Box 38-3

The cough serves to expel food material that has inadvertently fallen into the larynx.

Effortful Swallow

The effortful swallow is used to increase the posterior "push" motion of the tongue base during the swallow and may assist with clearing the bolus from the vallecular space. Verbal directions such as "push as hard as you can with your tongue against the roof of your mouth while you swallow," "swallow hard with all of your muscles," and "squeeze my hand as you swallow hard" can be used by the clinician to help the child exert some volitional pressure against the palate and at the tongue base. The effect of the effortful swallow may be directly assessed during either VFSS or FEES. This maneuver may also be assessed with different consistencies of food and liquid to determine its effect.

Head Rotation

In children with unilateral paresis of the pharynx, clearance of material from the hypopharynx on the affected side will be impaired. Head rotation toward the paralyzed side has been shown to close off this side from the bolus pathway, thereby improving clearance.¹ Children who demonstrate a unilateral impairment and who can follow directions pertaining to rotating their head during the swallow may benefit from this strategy. The anteroposterior view during VFSS or head rotation during FEES will reflect the potential benefit of the head rotation technique.

Oral Motor Exercises

Direct interventions that target the strength and range of oral motor movements are referred to as oral motor exercises. These exercises include active range of motion, stretching, strength training, passive exercises, and sensory applications. Although techniques and tools for incorporating oral motor exercises into the dysphagia treatment plan for both infants and children are available, empirical evidence to support the effectiveness of specific oral motor exercises and exercise protocols is scant, with few controlled studies reporting dose, frequency, and subsequent outcomes across pediatric populations. In addition, methods for the measurement of the tone, weakness, or strength of oral motor and pharyngeal musculature are not widely available.³ See Chapter 40 for additional discussion on oral motor exercises and therapeutic efficacy.

Box 38-4

Sensory treatment strategies may include the use of modalities such as cold, vibration, or electrical stimulation in conjunction with active exercises. Clinicians must stay apprised of existing and emerging evidence for diagnostic tools and interventions in order to make evidence-based treatment decisions. To this end, the American Speech-Language-Hearing Association (ASHA) National Center for Evidence Based Practice provides up-todate evidence-based systematic reviews to identify, evaluate, and synthesize the state of current evidence regarding various treatment strategies.

Indirect Compensatory Techniques

Most dysphagia treatment in children involves the use of indirect compensatory techniques. Approaches to treatment primarily comprise alterations in positioning, the use of sensory input to facilitate motor action, the use of specific feeding strategies and specialized equipment, and bolus modification using differing food textures and liquid viscosities. The therapist and the family work together to develop an overall treatment strategy appropriate for each patient. In developing individual strategies, the therapist must be sensitive to socioeconomic and cultural factors that may be a barrier to carrying out the plan in the home environment.

Alterations in Positioning

Establishing optimal positioning for both non-nutritive and nutritive activities is fundamental to the treatment process. Proper alignment of the head, neck, trunk, and extremities facilitates coordinated oral motor movements and the respiratory support needed for safe swallowing. The optimal position for infant feeding includes the head and neck being in a neutral to slightly flexed position, with neutral alignment of the trunk and orientation of the head and extremities about the body midline. Positioning recommendations during treatment depend on the patient's underlying muscle tone and postural control. Observation of head, neck, and trunk control, the hips and pelvis, and the shoulder girdle provides the speech-language pathologist (SLP) with information pertinent to optimal positioning during nonnutritive or nutritive activities. Input from an occupational or physical therapist regarding underlying muscle tone and the implications for positioning is often advantageous.

Variations in infant positioning may assist in facilitating coordination of respiration and swallowing during feeding. For example, the rationale for using side-lying positioning during feeding is to facilitate midline positioning of the upper and lower extremities, increase postural stability, and decrease arching of the back. Such positioning protects the airway during respiration by using gravitational forces to direct the flow of milk away from the airway. Descriptions of side-lying to relieve upper airway obstruction with feeding are primarily based on clinical expertise, with the rationale that the traditional cradle-hold position may allow gravity to pull the tongue into the pharynx. In contrast, side-lying or prone positioning may minimize the gravitational pull on the tongue. Evidence for using sidelying positioning during feeding in preterm infants is mixed. Some investigators have found that it promotes better regulation of breathing and allows infants to maintain physiologic stability throughout feeding. Others have reported that side-lying does not make an appreciable difference in the duration of time necessary to achieve full oral feedings in comparison to other positioning options.4-6

Some infants and children may hyperextend the head and neck to compensate for respiratory difficulties, significant extensor spasticity, or cervical spine anomalies. Excessive head and neck hyperextension is counterproductive to safe and efficient feeding, and slight modifications to help align the head and neck to the trunk are often necessary. Given the degree of impairment in craniocervical postural control in some patients, positioning with the head in the midline or with head flexion may not be possible or practical. Specialized adaptive seating may therefore be necessary to establish and maintain individualized optimal positioning for feeding. Positioning options for infant feeding and their rationale are presented in Table 38–1 and illustrated in Figure 38–1. Positioning considerations for older infants, toddlers, and children are summarized in Table 38–2 and depicted in Figure 38–2.

Oral Sensorimotor Therapy

The goal of sensorimotor therapy is to modify abnormal movement patterns during specific tasks through the use of structured sensory input. The use of this approach was first proposed for the treatment of abnormal movement patterns in patients with neuromuscular disorders such as cerebral palsy.⁷ It has since been adapted for the treatment of feeding, swallowing, and speech disorders in these children. Specific sensory input is selected to influence exteroceptive (contact) sensations to assist with modifying the functional adequacy of oral movement patterns.⁸ Such treatment models require assessment of oral reflexes, oral tactile sensitivity, oral movement coordination, and body postural control during feeding. The treatment plan incorporates optimal positioning for feeding, provision of oral tactile input prior to feedings, and hands-on interventions during a feeding activity. Components of the sensorimotor therapeutic approach have been used in clinical practice, integrating five basic treatment principles described by Sheppard.⁸

- 1. Therapeutic strategies are chosen to target a specific neuromuscular impairment following assessment of respiratory support for feeding, postural control, and oral motor manipulation skills.
- 2. Optimal postural alignment and positioning is essential, with external assist provided as needed to maintain upright positioning with appropriate support for the feet and hips, and to maintain stability of the upper extremities, the shoulder girdle, and the neck and head. Adjustments to postural support are made as needed during the feeding task.

Type of Position	Rationale
Cradle	Traditional positioning for feeding; infant is held in a cradled position in the feeder's arms with midline orientation of the head, neck, and trunk; infant can be brought into more upright position as needed
En face	Infant is positioned on the feeder's lap; the feeder's hand supports the infant's head, neck, and trunk; maximal control of head is possible.
Side-lying	Infant is positioned on its side on feeder's lap, head at the top of the lap and bottom against the feeder's stomach; head, neck, and trunk are in alignment and hips are flexed at 90 degrees
	May promote physiologic stability by enhancing respiratory support (less antigravity movement during respiration); decreases gravitational flow of milk; allows for increased control
	May relieve airway obstruction and facilitate feeding synchrony

Table 38–1. Positioning Options and Rationale for Non-Nutritive and Nutritive Activities in Infants





Figure 38–1. Positioning options for infant feeding.
A. Side-lying position.
B. Traditional cradle position.
C. Supported upright position.

В



Seating Options	Characteristics
Traditional infant seat with tray	Various options available, some may be tilted to position infant from semi-upright to upright position; side rolls and seat straps may provide extra support to maintain optimal positioning
Hook-on seat	Seat hooks onto table with clamps; safety harness for safety and positioning
Specialized therapeutic seating	Rifton™ seat; Special Tomato™ chair; Tumble Form™ seat
Standard highchair with tray	Many options available; may recline to allow for changes in upright to reclined positioning; adjustable heights on some chairs; seat belt harnesses to maintain stability and positioning in chair
Booster seat	Child must be able to sit independently; seat belt for safety, with strap between legs to prevent slipping; does not recline; may assist with transition to table from other seating options
Toddler table and chairs	Readily available; child must be able to sit independently; chair height should allow child's feet to rest on floor for postural stability

Table 38-2. Seating Options for Older Infants and Toddlers



A

B

Figure 38–2. Positioning option for older infants, toddlers, and children. **A.** Toddler Rifton[™] seat. **B.** Tumble Form[™] seat. *continues*