

Developing a practice guideline for assessments and interventions with infants with dysphagia

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Objectives

As a result of this course, participants will be able to:

- Understand the process for establishing a preferred practice guideline to decrease practice variation among clinicians
- Discuss the current literature related to signs of dysphagia and risk factors in the infant population
- Recognize the considerations with using adult videofluoroscopic protocols with infants
- Understand different recommendations and treatment strategies to use with infants with dysphagia



About Children's Healthcare of Atlanta

- 622 licensed beds
- Serve 0-21 years of age
- More than 10,600 total employees
- 2016: 1,008,830 patient visits
- Access to more than 2,000 pediatric physicians and practitioners representing more than 60 pediatric specialties and programs



Speech Pathology services at Children's

- Multiple rehab offerings
 - 3 hospitals: Egleston, Scottish Rite, Hughes
 Spalding offer acute services
 - 1 comprehensive inpatient rehabilitation unit
 - 1 day rehabilitation program
 - 9 outpatient locations
- Advanced Feeding and Swallowing Competency
- Specialized Training in OPMS/MBSS & FEES



Need for project

- Infants seen in all locations for feeding therapy
 - Acute Care: PICU, NICU, TICU, Cardiac units, General Care
 - Inpatient Rehabilitation Unit
 - Outpatient Rehabilitation
 - Outpatient OPMS (Oropharyngeal Motility Study; ie, MBSS)
- Variation in recommendations among sites
- Difference in patient population among sites; patients often go to multiple sites
- Parent confusion
- Multiple medical providers involved with need for clear communication
- Determine best-practice based on evidence and clinical consensus



Purpose of project

- Develop a preferred practice guideline titled: Dysphagia Management for Infants with Oropharyngeal dysphagia
- Target Population
 - Inclusion: Infants, <1 year old adjusted age, with complex medical condition (cardiac, neurological, genetic, respiratory, respiratory plus another condition) or non-complex with identified oral pharyngeal dysphagia.
 - Exclusion: Infants with isolated sensory-based feeding issues.

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Process for Practice Variation Team

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Team Roles and Responsibilities

Team Leader

- Form core team
- Accountable for team deliverables
- Provide time and resources to team

Team Member

- Accountable for full and active participation
- Completes assigned tasks on time
- Shares responsibility for team's progress
- Communicates decisions to peers
- Communicates peer input to team

Facilitator

- Accountable for team progress and motivation
- Provides methodology support
- Facilitates discussion and keeps team on track

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Ground Rules For An Effective Team

Importance of proceeding in the face of incomplete evidence: Consistency of practice may be more important than a 'waiting till perfect evidence is available' approach – safety is enhanced with consistency.

Clinical Practice Guidelines are evidence based, but in absence of evidence, expert opinion is used. Therefore, sometimes we have to proceed based on consensus.

After adequate debate, once majority opinion is determined, all team members need to stand behind decisions made by the team. If concerns are not voiced, approval is implied.

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Ground Rules For An Effective Team

80-20 rule for applicability of guidelines: no guideline can be made applicable to 100% of patients, or it will be too prescriptive. Generally, 80-90% of patients should be able to follow the recommendations; the remaining 10-20% need management based on the clinician's discretion.

Clinical Practice Guidelines are not static, but dynamic – they need to be updated periodically based on outcomes and new evidence.

Each team member is the communication link between this team and the home department. Each team member is expected to bring the discussions & decisions back to his/her home department & seek their opinions to bring back to the group.

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Evidence-Based Practice (EBP)

The most well-known definition is that put forth by David Sackett and colleagues:

"Evidence-based medicine is the integration of best research evidence with clinical expertise and patient values."

(Sackett D et al. Evidence-Based Medicine: How to Practice and Teach EBM, 2nd edition, Churchill Livingstone, Edinburgh, 2005, p. ii)

Per ASHA, the goal of EBP is the integration of: (a) clinical expertise/expert opinion, (b) external scientific evidence, and (c) client/patient/caregiver values to provide high-quality services reflecting the interests, values, needs, and choices of the individuals we serve.



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PICO Question

- P: In infants with oropharyngeal dysphagia
- I: oral feeding/oral intake
- C: no oral feeding, standard intervention
- O: pulmonary health, overall health and development, oral feed status, weight gain



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Steps to reaching consensus

- Literature review
 - Assign articles to team members to read, grade, and bring back to group
 - Use the Johns Hopkins Evidence-Based Practice - Research Evidence Appraisal Tool to grade articles
 - Use available evidence to support our decisions
- Brainstorming activity
 - Signs of dysphagia in infants (least important, somewhat important, and most important)
 - Risk or contributing factors to consider with dysphagia
 - Strategies to use with infants with dysphagia



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Johns Hopkins Evidence Appraisal Tool

Johns Hopkins Nursing Evidence-Based Practice
Appendix E: Research Evidence Appraisal Tool
Evidence and Quality

Article Title:	Author(s):	Publication Date:
Journal:	Volume:	Issue:
Abstract:	Summary:	Conclusion:
Does this evidence address my EBP question?	Yes	No
Level of Evidence (Clearly Designing)	Level of Evidence (Clearly Designing)	Level of Evidence (Clearly Designing)
1. Is this a report of a single research study? If No, go to 2.	Yes	No
2. Was there a control group?	Yes	No
3. Was there a random assignment to groups?	Yes	No
4. Was there a double-blind study?	Yes	No
5. Was there a standardized protocol?	Yes	No
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100. Was there a standardized protocol?	Yes	No

https://www.hopkinsmedicine.org/evidence-based-practice/ebp-2017_atp.html

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Steps to reaching consensus

- Case Studies
 - Reviewed case studies on patients that we have treated
 - Team members provided recommendation and discussed how they reached their decisions
 - Allowed team members to discuss and ask questions in a safe environment. Encouraged team members to have more discussion about patient care in "real time"
- Group writing sessions
- Submit to the Clinical Effectiveness Group for review



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Assessing Swallow Function in Infants

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Risks and contributing factors for dysphagia in infants

- Neurologic (i.e. prematurity, IVH, brain tumor, stroke, abnormal tone, seizures, etc.)
- Respiratory (i.e. BPD, CLD, recurrent illness/pneumonia, trach/vent, high oxygen support, prolonged intubation, etc.)
- Cardiac (i.e. CHD with or without cardiac surgery, pulmonary hypertension, pulmonary vein stenosis, ECMO, etc.)

Newman, 2001

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Risks and contributing factors for dysphagia in infants

- Gastrointestinal (i.e. gastroesophageal reflux, esophageal disorders, EoE, failure to thrive, etc.)
- Anatomic (i.e. craniofacial abnormalities, vocal fold involvement, laryngeal cleft, EA/TEF, etc.)
- Genetic syndromes (i.e. Trisomy 21, 22q11 deletion syndrome, CHARGE syndrome, metabolic syndromes, etc.)
- Other or unknown etiology

Newman, 2001

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Bedside or clinical evaluation of infant dysphagia

- Oral motor exam
- Non-nutritive sucking assessment (when appropriate)
- Oral feeding assessment (when appropriate)

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Clinical signs of dysphagia that are supported by literature

- Coughing
- Choking
- Chest congestion
- Wet/gurgly vocal quality
- Wet breathing/respirations
- Leakage out of the child's tracheostomy
- Multiple swallows
- Poor management of oral secretions/drooling

Weir et al., 2009; Benefier, 2015; Lefton-Greif, 2008; Orenstein, 2006

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Clinical signs of dysphagia that are supported by literature- continued

- Breathing difficulties when feeding that might be signaled by:
 - Increased respiratory rate during feeding
 - Skin color changes (such as cyanosis)
 - Apnea
 - Retractions
 - Stopping frequently due to uncoordinated suck/swallow/breathe patterns
 - Stridor
 - Desaturations
 - Changes in normal heart rate in association with feeds

Weir et al., 2009; Shaker 2013

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Clinical signs of dysphagia supported by consensus

- Audible swallows and gulping
- Oral deficits including anterior leakage, oral residue, gagging, expectoration, significant oral-motor deficits
- Self limiting feeds and/or refusal behaviors

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Clinical signs of dysphagia supported by consensus- continued

- Signs of stress (for example: facial grimacing, panicked expression, wide eyes, rapid blinking, etc)
- Red/watery eyes
- Throat clearing

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So you see signs of difficulty, now what?

Immediate Swallow Study

Consider risks and contributing factors

Consider utilizing appropriate strategies

Consider referrals to other medical professionals

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Treatment Strategies for Infants with Dysphagia

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Thickening

- Commonly used as a strategy to improve swallowing
- However, the use of thickening can be controversial



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Thickening Options

Cereals (Rice, oatmeal)	Gum based (Xanthum, Guar)	Cornstarch
<ul style="list-style-type: none"> * AAP- delay cereal until 6 months adjusted age * Arsenic in rice cereal * Cannot thicken expressed breast milk * Constipation * Residue * VARIABILITY 	<ul style="list-style-type: none"> * Risk for NEC * Product vs contamination in production * FDA, do not give to babies under 12 mos. * VARIABILITY 	<ul style="list-style-type: none"> * Aspiration of cornstarch can be fatal * VARIABILITY

de Almedia , 2011; Gosa, 2015; Beal, 2012; Nativ-Zeltzer, 2017

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Benefits of thickening

- Decrease in hospital admissions
- Decrease in subsequent respiratory illnesses
- Reduces penetration and aspiration
- Slows oropharyngeal transit time
- Creates more cohesive bolus, easier to control, minimizes risk of aspiration
- Increases timing/ duration of UES opening and hyolaryngeal movement
- Reduces incidence of penetration and tracheal aspiration

McSweeney, 2016; Khooshoo, 2001; Dantas, 1990; Coon, 2016; Steele, 2015

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Negative consequences of thickening

- Decreases liquid extraction (may lead to caregiver altering nipple)
- Prolongs feeding times, and increases energy expenditure
- Accessibility for caregivers: cost, insurance
- User error and compliance
- GI/Nutrition concerns: Added calories, additives, feeling full
- Hydration concerns Increases pharyngeal residue

de Almedia, 2011; McCallum, 2011; Beal, 2012; Cichero, 2013; Stokes, 2013; Steele, 2015

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Bottom line.... It's challenging

pulmonary damage
from aspiration

VERSUS

need for caution when
prescribing thickened
fluids



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What position is best for feeding? Elevated sidelying, upright, cradle

Elevated sidelying

- ↑ O₂ sats, ↓ heart rate and respiratory rate changes, briefer apneic events, ↓ work of breathing, ↑ time to manage the flow/ ↑ opportunity for breaths
- Can spill the milk anteriorly

Cradle

- Parent/caregiver preference

Semi- upright

- Some say minimal differences between sidelying and cradle

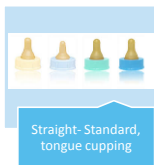
Clark, 2007; Park, 2015; Thorne, 2012; Dawson, 2013; Lau, 2013

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Bottles and Nipples: Shape and Flow Rate



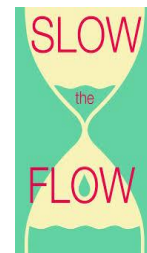
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Benefits of slow flow

- Consume larger volumes
- Shorter feeding times
- Better sucking efficiency
- Vital sign stability
- Smaller bolus size



Shaker, 2013; Chang, 2007

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Negative consequences of fast flow



- Lower sucking pressure
- Decrease in minute ventilation
- Decrease in breathing frequency
- Greater percent desaturation
- Larger bolus could result in misdirection of the milk into the airway and/or physiologic instability

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Although some studies have shown...

- Physical characteristics of bottle nipples were not found to impact the oral feeding performance of infants- Babies adapt quickly
- Milk transfer did not vary among nipples with variable physical characteristics



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Pacing and co-regulated feeding

The goal of pacing and co-regulated feeding is to *prevent* a stressful situation as opposed to responding after the fact



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What's the difference?

PACING

A set number of sucks prior to initiating a break; either bottle removal or tilt of the nipple to limit liquid expression



COREGULATED FEEDING

Individualized oral feeding based on infant's sucking, physiology and state control throughout each feeding



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Pacing benefits...

- Decrease bradycardic episodes
- Shorten NICU length of stay
- Improve sucking efficiency
- Promote more mature feeding behaviors



Law, 2003

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Cheek/jaw support- use with caution

Benefits

decreased leakage
increased rate of intake

But...

Do they need it?
Is the baby self limiting?

May be an appropriate response to inappropriate demands

Hwang, 2010; Einarsson-Baekes, 1994; Hill, 2000

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Passy Muir Valve and swallowing

Does PMV decrease laryngeal penetration and aspiration of foods and liquids in **children**?



Unlike in adults, the presence of PMV did not decrease laryngeal aspiration or penetration in children with tracheotomies. It did, however, improve pyriform sinus residue.

Ongkuzuan et al., 2014

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Assessments for Infants with Dysphagia

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When to complete?

Consider instrumental evaluation

- Clinical signs and symptoms concerning for swallow dysfunction
- Medical issues concerning for swallow dysfunction
- Able to consume at least 5mL
- Medically and behaviorally able to participate in study
- Per physician order
- For feeding and nutrition plan of care

Hold off on instrumental evaluation

- Not consistently consuming at least 5mL (except FEES for secretion management)
- Quick recovery (RSV, rhinovirus): generally wait until infant has recovered from illness
- Prolonged recovery (neuro, CLD)- prefer to wait until infant not in rapid state of recovery, complete when needed to determine treatment plan and recommendations
- End of life and quality of life considerations

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FEES or OPMS: Which Test is Best?

Benefit of FEES:

- View of vocal cords
- Assesses secretion management
- Assesses pharyngeal residue
- Assesses supraglottic penetration
- Assesses aspiration when it occurs before and after the swallow (there is a brief "white-out" period that occurs at the height of the swallow).
- Able to assess for fatigue
- No radiation exposure
- Can use with breastfeeding
- Can use non-standardized/non-barium products

Benefits of OPMS:

- Assesses oral phase of the swallow
- Assesses upper esophageal sphincter (UES) opening and upper esophageal phase of the swallow
- Assesses supraglottic penetration
- Assesses oral and pharyngeal residue
- Assesses aspiration when it occurs before, during, and after the swallow
- Non-invasive

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Indication for FEES vs OPMS/MBSS

	FEES	OPMS
Suspected pharyngeal dysphagia	X	X
Assessment of different PO consistencies	X	X
Assessment of compensatory strategies and positions	X	X
Ability to manage and swallow secretions	X	
Assess airway protection and vocal cord function	X	
Assess the effect of fatigue over a longer period of time	X	
Allows for use with medically-complex patients who may not tolerate transportation	X	
Allows for use with patients who are physically unable to participate in fluoroscopic exam due to positioning issues (ie., patients who are obese or claustrophobic, patients with severe scoliosis, etc)	X	
Biofeedback during evaluation and treatment	X	
Assess oral stage of swallow		X
Suspected esophageal dysphagia		X

Aivry, 2000; Leder, 2000; Langmore, 1991

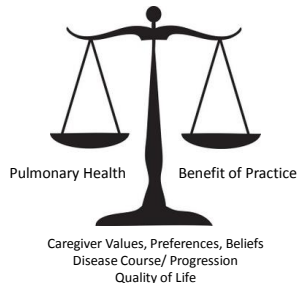
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Now what?...Determination of safest and least restrictive recommendations

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Balancing Act

Medical Team Plan of Care



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Questions to consider

- For the infant who is deemed unsafe for a full oral diet, some questions to consider:
 - Who should offer PO?
 - How much should be offered?
 - What should be offered?
 - How often should oral trials be offered?
 - When and who should make the determination for increasing oral trials?
 - When should a referral be made to other specialties?



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Who should offer PO?

Therapist Only

- Clinical evaluation period/trying strategies
- Infant unstable with feeds; needs close monitoring
- Psychosocial barriers
- Infants with lack of previous experience, needs therapeutic guidance

Trained Caregiver(s) and/or RN

- Relatively stable with small trials
- Infants who need therapeutic interventions
- Caregiver demonstrates skill carryover and knowledge

All Caregivers

- Stable with trials
- Limited need for strategies/intervention
- Infants who are volume limited or self-limiting

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How much PO should be offered?



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How often should oral trials be offered?

Dipped Tastes Only

- Very fragile
- No PO readiness
- Psychosocial barriers

Pumped Breast

- Caregiver goal for breastfeeding
- Can be used with fragile/high risk infants
- May be done in conjunction with lactation consultants

1x per day with <10mL

- Volume depending on age and results of study
- More complex/higher risk or recovering from acute illness
- Rare for home feeding plan

2-4x per day with limited volume

- Volume depending on age and results of study
- More stable patients
- May also be appropriate for patients on continuous feeds (hold tube feed and offer 1 hour volume)

Small trial prior to each bolus feed (breast or bottle)

- More stable patients
- Some patients may benefit from smaller volumes offered more frequently

* Always dependent on physician orders

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Should I recommend a volume limit or time limit?

Volume Limit

- More frequently used, especially for patients with documented aspiration or signs of dysphagia clinically
- Easier for caregiver carryover
- When preferred by physician (e.g., infants with GI issues)
- More often used for infants on continuous feeds

Time Limit

- Less significant dysphagia
- Cardiac infants
- High risk for fatigue
- Breastfeeding infants

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What to offer?

Breastmilk

- Preferred nutrition when available
- May be safer than other liquids
- Per physician orders

Formula

- When breastmilk not available
- Per physician orders

Water

- Not generally recommended by therapist
- Electrolyte based liquid per physician orders

Purees/solids

- When developmentally appropriate
- Per physician orders

Thach, 2001; Mizuno, Ueda, Takeuchi, 2002

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To Thicken or Not To Thicken?

- Recommend OPMS before establishing feeding plan with thickened liquids
- If patient demonstrates aspiration or significant difficulty with all consistencies on a modified barium swallow study despite interventions, then what????
- Age with thickening
 - Follow manufacturer & FDA guidelines
 - Physician preference
- No perfect or "right" answer; individualized to each patient's specific needs

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To Thicken or Not To Thicken?



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Changing the feeding plan?

Slowly decreasing amount of thickener

- When no need for thickening indicated by OPMS/FEES, but patient has been on thickener for a while
- Can be led by treating therapist with physician approval

Increasing oral volumes, adding developmentally appropriate textures

- Clinical signs of difficulty clear and documented; patient no longer showing signs
- Oral motor impairments
- Can be led by treating therapist with physician approval

Pending results of instrumental evaluation

- History of silent aspiration
- Medically fragile
- Per recommendations of instrumental evaluation and physician

Increasing frequency of PO trials

- Oral motor and/or sensory deficits
- Improving endurance and efficiency

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Additional referrals



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When to recommend another study?

Consider radiation exposure

- "As low as reasonably achievable"
- Amount of studies, age of patient, length/focus of study

Change in clinical presentation

- Clinical signs have increased or decreased
- Medical change in status
- When a change in feeding plan or recommendations may occur as a result of study

Acute vs Chronic Conditions

- Infants with acute illnesses may have less time between studies

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Conclusions

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Next steps

- Ongoing meetings between speech pathologists
- Involve outpatient therapists
- Frequent education and literature reviews
- Take advantage of ASHA's practice maps



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Questions?



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