OROPHARYNGEAL ASPIRATION IN CHILDREN WITH DOWN SYNDROME

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CHEO Down Syndrome Clinic: How We Got Started

• Clinic initiated in 1992 in order to meet the complex needs of children with DS in our community
• Goal was to:
  – provide standard of care as per health preventative guidelines (this wasn’t being done systematically in our region)
  – provide multidisciplinary care with one main point of contact for these families who had multiple providers
• The vast majority of patients in CHEO catchment area with Down syndrome are followed regularly in our clinic throughout their childhood and adolescence
DOWN SYNDROME CLINIC

• Have followed 455 patients in total since inception in 1992:
  – 206 females
  – 249 males
• Currently there are 350 active patients
  – 157 females
  – 193 male
PATIENT NUMBERS

- Active patients
  - 0-2 years: 41 patients
  - 2-5 years: 53 patients
  - 5-13 years: 162 patients
  - 13-adult: 94 patients

- There have been 105 inactive files (> 2 years inactivity)
  - Of these, only 2 have been lost to follow-up
  - Rest have either moved out of region or transitioned to adult services
  - Therefore, we have good follow up and are providing regular ongoing care
INTRODUCTION

• Feeding difficulties are common in children with Down Syndrome and are related to oral, and anatomical/structural differences
  • 50-80% frequency of feeding issues in children with Down Syndrome (Pipes and Holm, 1980: Van Dyke et al, 1990)
• Issues seen in DS population which contribute to feeding difficulties:
  • Poor suck and lip closure
  • Uncoordinated swallow leading to choking, gagging and coughing
  • Underlying Respiratory/CVS issues may exacerbate
  • Chewing difficulties
A HAPPY FEEDER!!
SWALLOWING DISORDERS: DEFINITIONS

DYSPHAGIA: problems in one or more phases of the swallow

1. Oral phase
2. Initiation of swallow
3. Pharyngeal phase
4. Esophageal phases

Complications of swallowing issues/dysphagia:
- Aspiration ***
- Recurrent pneumonia
- Chronic respiratory illness
- Poor nutrition
- Failure to thrive
Swallowing Mechanism at Rest

- Hard Palate
- Soft Palate (Velum)
- Lips
- Teeth
- Tongue
- Mandible
- Hyoid Bone
- Vocal Folds
- Cricopharyngeal Sphincter
- Esophagus
- Posterior Pharyngeal Wall
- Vallecular Sinus
- Epiglottis

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SWALLOWING MECHANISM
DEFINITIONS

• LARYNGEAL PENETRATION: food bolus enters the vestibule above the true vocal cords but does not pass through

• OROPHARYNGEAL ASPIRATION: passage of food, fluids or saliva below the level of the true vocal cords into the trachea (may be antegrade or retrograde)
Aspiration

- There are three instances when aspiration can occur: before, during or after the actual swallow.

- Aspiration before swallowing is either the result of insufficient closure of the oral cavity during the preparatory phase or inability to start the swallow reflex when contrast enters the pharynx.

- Aspiration during swallowing is due to insufficient closure of the larynx.

- Aspiration after swallowing is the result of stasis of contrast in the pharynx - when the larynx opens the contrast leaks into the trachea.
OROPHARYNGEAL ASPIRATION

- Factors contributing to recurrent aspiration include:
  - Dysphagia
  - GER
  - Excess oral secretions and drooling
  - Upper airway obstruction

- Respiratory signs of OPA include:
  - Noisy breathing
  - Gagging, coughing, congestion
  - Apnea / tachypnea
  - Chronic cough
  - Recurrent wheeze
RESPIRATORY CONSEQUENCES OF OPA

- Exacerbation of underlying asthma or BPD
- Chronic or recurrent aspiration pneumonia
- Interstitial lung disease
- Diffuse aspiration bronchiolitis
- Bronchiectasis
- Pulmonary fibrosis
OPA: EVALUATION

- Videofluoroscopic Swallow or Feeding Study (VFSS/VFFS): gold standard for evaluation of swallowing mechanism
- VFSS allows one to:
  - Assess the phases of swallowing
  - Assess for laryngeal penetration or aspiration
  - Assess for adequate clearing of aspirated material with coughing or gagging OR
  - Assess whether aspiration is silent
  - Playback for reassessment of subtle findings
INDICATIONS FOR VFSS

1. To identify normal and abnormal anatomy and physiology of the swallow
2. To evaluate integrity of airway protection before, during, and after swallowing
3. To evaluate the effectiveness of postures, manoeuvres, bolus modifications, and sensory enhancements in improving swallowing safety and efficiency
4. To provide recommendations regarding the optimum delivery of nutrition and hydration (e.g., oral versus nonoral)
5. To determine appropriate therapeutic techniques for oral, pharyngeal, and/or laryngeal disorders
6. To obtain information in order to collaborate with and educate other team members, referral sources, caregivers, and patients regarding recommendations for optimum swallow safety and efficiency

G.Gramigna: GI Motility, 2006
LIMITATIONS OF VFSS

1. Time constraints due to radiation exposure
2. As the procedure only samples swallow function, it does not fully represent mealtime function
3. Contrast materials such as barium increase the viscosity and alter liquid and solid food composition and are not natural foods. This may result in discordance between the results of VFSS and real meals
4. Limited ability to evaluate a fatigue effect on swallowing, unless specifically evaluated
5. Barium is an unnatural food bolus with potential for refusal.
6. User variability
7. Does not always allow for assessment of retrograde aspiration and will miss cases if aspiration is intermittent.

G. Gramigna: GI Motility 2006
ANATOMY

- Lateral projection of the videoprint of a videographic swallowing study shows the epiglottis (E), pyriform sinuses (P), tongue (Tg), trachea (Tr), and vallecula (V). Paik et al, May 2012: emedicine.medscape.com
OROPHARYNGEAL ASPIRATION

• Lateral projection of the videoprint of a videographic swallowing study shows residues on vallecula (Vr) and pyriform sinuses (Pr) and a small amount of aspirated liquid barium in the trachea (As).
SUPRAGLOTTIC PENETRATION

- Lateral projection of the videoprint of a videographic swallowing study shows supraglottic penetration.
SUBGLOTTIC ASPIRATION

- Lateral projection of the videoprint of a videographic swallowing study shows subglottic aspiration.
CHEO DOWN SYNDROME COHORT

- OPA is a diagnosis commonly made in children with Down Syndrome and other developmental disabilities.
- Respiratory complications are common and early diagnosis based on clinical symptoms is important to prevent long term morbidity.
CHEO DOWN SYNDROME COHORT

• PRIMARY OBJECTIVE:
  – To determine the prevalence of oropharyngeal aspiration (OPA) in a cohort of children with Down syndrome less than 18 years of age followed at a regional Down Syndrome Clinic at the Children’s Hospital of Eastern Ontario (CHEO) in Ottawa, Canada

• SECONDARY OBJECTIVES:
  – peak age at diagnosis
  – sex predilection
  – most predictive symptoms
METHODS

- Retrospective review of all VFSS (video fluoroscopic swallow studies) completed on children followed at the Down Syndrome clinic at CHEO since institution of electronic reporting in 2000.
METHODS

• Retrospective chart review:
  • Identified all children from our DS clinic cohort who had videofluoroscopic swallow study (VFSS)
  • Referral for VFSS based on several clinical symptoms including:
    – Coughing, gagging or choking with feeds
    – Recurrent pneumonia/chest congestion/wheeze
    – Upper airway congestion post feeds
    – Failure to progress with textures, feeding refusal or to assess safety of oral feeds
METHODS

- VFSS completed by Pediatric Radiologist and Occupational therapist experienced in feeding and swallowing disorders
- Children were NPO for > 4 hours for best intake
- Infants and children were positioned in a tumble form chair to simulate as closely as possible a presumed eating posture
- Parents and caregivers were in room to help keep child calm and comfortable.
- Parents encouraged to feed children if possible
METHODS

• Food textures presented and methods of administration varied depending on child’s developmental and swallowing ability
• Textures selected to try to match those being consumed by child on a daily basis
• Parents were asked to bring child’s favorite purees
• Liquids were given using child’s own bottle or cup and purees given with child’s utensils wherever possible.
METHODS: What Was Offered

- Liquids were given in 4 possible consistencies:
  - Extra thin liquids (H2O: Barium-75:25)
  - Thin liquids (50:50)
  - Nectar consistency thickened liquids (Barium Concentrate full strength)
  - Honey consistency thickened liquids (Barium paste or liquids thickened to honey)

- Purees
- Soft solids
METHODS

- Ideally, order of liquids presented would be thick, thin and then extra thin.
- Because of poor cooperation:
  - Purees offered first as most kids most comfortable with this texture and taste of barium does not over power it
  - Extra thin given next
    - If aspiration or penetration noted, would move on to thin, nectar and honey to find best texture tolerated by child
    - If safe with no aspiration or penetration, no other textures necessary
METHODS

- 5-6 swallows of each texture preferred

OR

- Ideal goal would be to drink sequentially to observe any fatigability or quality changes in later swallows
METHODS

• Radiologist report:
  • Commented on quality of swallow phases, consistency of food taken in, and evidence of laryngeal penetration or aspiration

• Occupational Therapy report:
  • Relevant medical and feeding history
  • Behavior, positioning and feeding equipment used
  • Food textures tried with clinical report of findings (bolus formation transport and swallow, oromotor issues, and evidence of aspiration or penetration
  • Reliability of study with comment on whether fatigability was assessed
  • Summary and recommendations
RESULTS

• 429 patient files reviewed
• 73 patients had 103 feeding studies done looking for OPA
  – those with more than 1 study done to:
    – Document safety with thinner consistency liquids
    – Document ability to progress with textures
    – Document resolution of OPA
    – Repeat study for poor cooperation or unreliable study
RESULTS

- 73 patients had VFSS done looking for OPA:
  - **Reasons for referral included:**
    - Coughing/choking/gagging w/ feeds 18/73
    - Recurrent pneumonias: 17/73
    - Wheezing/stridor or wet sounds post 19/73
    - Swallowing difficulties/feeding difficulties (aversion/failure to progress with textures) 9/73
    - Safety with oral feeds (anatomical/GT) 8/73
    - Apnea in young child 1/73
RESULTS

- 73 patients had VFSS done looking for OPA
  - 43/73 or 58.9% of patients were male
  - 30/73 or 41.1% of patients were female
  - Median age of first positive VFSS was 18 months (age range: 0.75 months – 9 years)
RESULTS

• 17/73 (23%) demonstrated clear aspiration below the vocal cords with thin or extra thin liquids

• 18/73 (25%) demonstrated pooling or laryngeal penetration of liquids (risk for aspiration but NO overt OPA noted on study)

• Therefore 35/73 (48%) were shown to aspirate or were at risk of aspiration

• 15/103 (14%) studies were of poor validity due to poor patient cooperation (no clear assessment could be made)
RESULTS

• Reason for referral for those children who showed aspiration or risk of aspiration on VFSS:
  – Coughing, choking or gagging with feeds: 6/35 (17%)
  – Wheezing, stridor or wet respirations: 8/35 (23%)
  – Recurrent pneumonias: 9/35 (26%)
  – Assess safety w/ oral feeds/feeding difficulties: 10/35 (29%)
  – Apnea: 1/35 (3%)
RESULTS

• Based on our results:
  – The calculated risk of OPA in the CHEO Down Syndrome cohort is
    • 35/429 or 8%
  – However, if there are concerning symptoms found on history (choking/gagging/coughing recurrent pneumonias or respiratory disturbances):
    • 35/73 or 48% of children were found to be aspirating or at risk of OPA based on VFSS
RESULTS

- **6/35 (17.1%)** of kids had clear clinical signs of aspiration during feeds ((choke/gag/cough)

  
  **BUT**

- **17/35 (48.6%)** of children did not show classic signs of choke/gag/cough during feeds
  - instead had other manifestations post feeds including recurrent pneumonia and other respiratory manifestations. These kids may be considered to be **SILENT ASPIRATORS**
RESULTS

• AGE WHEN ASPIRATION OR RISK WAS IDENTIFIED:
  - 0-6 mos: 10
  - 6-24 mos: 15 (range: 10-20 months)
  - 2-4 years: 7
  - > 5 years: 3
OT RECOMMENDATIONS

• 27/35: thicken to nectar consistency
• 3/35: unsafe for all liquids (G-Tube)
• 2/35: thicken to honey consistency
• 1/35: thicken to more than nectar
• 1/35: avoid extra thin liquids
• 1/35: proper positioning and slow feeds/ no thickening suggested
THICKENERS

- Rice cereal
- Pureed foods (bananas, yogurt, pudding)
- Gum thickeners
  - Simply Thick (gum based)**
  - Thicken up (Cornstarch based)##

**not in kids < 36 weeks G/A
## some ethnic groups may not tolerate?
MORE OT SUGGESTIONS

• Ensure no neck extension
• Sit to drink (no distractions!!)
• Pace feedings (tendency to overstuff)
CONCLUSIONS

• Children with Down Syndrome are at risk of oropharyngeal aspiration
  – 8% of the CHEO Down Syndrome cohort
  – 48% of the cohort with symptoms of feeding difficulties including:
    • Choking, coughing, gagging with feeds
    • Recurrent pneumonias/respiratory infections
    • Wheezing, stridor or respiratory sounds post feeds
    • Feeding difficulties/aversions/anatomical issues requiring G-Tube feeds
CONCLUSIONS

• Almost 50% of children with or at risk of aspiration did not show clinical signs of aspiration during feeds (choking, gagging or coughing).
• Other respiratory manifestations should make one consider the possibility of “silent aspiration”
CONCLUSIONS

• A VFSS should be done on all children with Down Syndrome with symptoms of choking, gagging, or coughing, recurrent pneumonias, and respiratory symptoms post feedings on clinical history.

• Ideally this should be performed by therapists/Radiologists experienced in feeding assessment.
CONCLUSIONS

• Most children with or at risk of OPA can be managed conservatively with thickening of fluids to the nectar consistency.
• Only 3/429 (0.7%) of children in our population required long-term G-tube feeds because of ongoing issues with OPA.
• Clinically, the majority of these children eventually develop the ability to tolerate all textures of liquids without thickening.
CONCLUSIONS

- VFSS have limitations and modifications in feeding strategy may be indicated if there are strong clinical suspicions, if the study is not reliable due to poor cooperation, or if VFSS is not readily available:
  - consider a trial or thickener (nectar consistency) to see if respiratory manifestations improve

- Further studies to look at the average length of time before thickening is no longer required would provide useful information to families and clinicians

- Further prospective studies are needed to document age of highest risk, age of resolution of OPA and better delineation of most predictive clinical symptoms
STUDY LIMITATIONS/FUTURE DIRECTIONS

• Did not look at impact of reflux and potential for retrograde reflux
• Prospective studies would allow us to better delineate clinical indications for referral for feeding study
• Prospective studies would allow for closer follow up to determine when OPA would have resolved and when feeding modifications could be discontinued
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