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IPWSO Summit on *Preventing unexpected death in PWS: Recognizing risk, responding early and learning from families*

Subclinical Swallowing Impairments in PWS

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Little known facts

Swallowing is not a simple brainstem reflex.

Each swallow relies on sensory information to produce a “customized” motor output.

The presence of a swallow does not guarantee the competency of the swallow.

There is no relationship between the gag reflex and swallowing function.

There is no pharyngeal peristalsis.

The airway is always open, except during the swallow.

Swallowing requires sensory and motor integration

Many types of sensory input combine so that the body knows what to do:

- Oral sensation
- Pharyngeal sensation
- Visual input
- Smell
- Taste
- Texture
- Respiratory status
  - There is an optimal breathing-swallowing pattern (Exhale-Swallow-Exhale)
  - The larynx is an organ of swallowing beyond closure of the true vocal folds.
  - The subglottis contains a rich sensory bed of pressure receptors.
  - Swallowing motor output can be altered by sensory input from the larynx (laughing can inhibit the swallow).

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Lateral view anatomy review





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Role of the epiglottis

CLOSURE OF LARYNGEAL VESTIBULE=

BASE OF EPIGLOTTIS TO ARYTENOID CARTILAGE



LATERAL DEFLECTION OF BOLUS/AIRWAY SHIELD



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Normal swallowing



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Aspiration

Any non-gaseous material that enters the airway and reaches below the true vocal folds.

Aspiration can occur from above

Aspiration can occur from below (from hypopharynx and/or esophagus)

Two distinctions of aspiration:

Tracheal aspiration which may be cleared with coughing.

Pulmonary is aspiration is much deeper and linked to pneumonia.

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Airway obstruction= Unable to breathe

Can occur from a blockage above as in choking on food that is above, on, or between the true vocal folds.

Can occur from below if solid material comes back up from the esophagus and enters the upper airway.

Can also occur from the esophagus if esophageal stasis material is large enough to bulge into and compress the tracheal airway.

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Dysphagia in PWS often has no symptoms

- The need for the Heimlich maneuver, death from choking, and pulmonary infection occur in a disproportionally high number of persons with PWS.
- The widely held belief was that eating behaviors are solely responsible for choking and aspiration; yet, no investigation had sought to determine if swallowing impairments were present in persons with PWS.

To address this research and clinical gap:

Gross, R. D., Gisser, R., Cherpes, G., Hartman, K., & Maheshwary, R. (2016). Subclinical dysphagia in persons with Prader-Willi syndrome.

Am J Med Genet A, 173(2), 384-394.

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Participants and study procedures

- 30 Volunteers
- 15 males, 15 females
- Age ranged from 5 to 35 years
- 37% were on or had received HGH

To minimize radiation exposure thin liquids and solid (cookie) were given in random order.

Subjects were seated in a comfortable chair.

Participants ate and drank under two conditions: measured amounts and spontaneous.

Swallowing function was recorded using videofluoroscopy.

Respiratory signals were recorded simultaneously using a nasal cannula.

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Study results

Under videofluoroscopy, the cohort showed disordered pharyngeal and esophageal swallowing in both conditions with disturbances in timing, clearance, and coordination of swallowing with the respiratory cycle.

No participant showed a sensory response such as attempting to clear residue or coughing; thereby supporting the lack of overt symptoms.

- 30/30 participants had significant stasis in the esophagus with no sensation or awareness of its presence.

In typical persons, regardless of age, approximately 2-10% of swallows are followed by inhalation.

- In the PWS group, inhalation after the swallow occurred in 21-30% of liquid swallows and 30-42% of cookie swallows.
- Liquid residue observed in 20/30 subjects (67%) Solid residue observed in 29/30 subjects (97%)

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Study conclusions

We concluded that the high death rate from choking and pulmonary infection in children and adults with PWS may be related, in part, to underlying, asymptomatic dysphagia.

The combination of rapid eating and dysphagia can increase the risk of airway obstruction and aspiration-related morbidity and mortality.

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13 year old male (UPD, HGH, BMI 24) Diagnosed with rumination



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Esophageal stasis PWS



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Findings from randomization of solids and liquids

We observed that when liquids of 10 cc or greater were given after a solid bolus, residue was significantly reduced or eliminated.

This observation was translated into therapy and meals.

Persons with PWS appeared to notice a change. One person even wrote the SLP a thank you note.

The “Pace and Chase” was born.

Why is “Pace and Chase” important?

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Sometimes when I eat, food gets stuck in my throat, but I don’t feel it.



I take a drink after two bites so that all the food goes to my belly. This is called “Pace and Chase.”



People remind me to take drinks. They care about me and want me to be safe.



I ask for water when my first drink is empty.



At the end of my meal, I drink my “flush” to make sure there is no food in my throat.

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Recommendations for evaluation of swallowing function

A videofluoroscopic swallowing evaluation (Modified Barium swallow) that includes an A-P view of the esophagus is necessary for persons with PWS.

Fiberoptic endoscopic evaluation of swallowing (FEES) cannot evaluate esophageal clearance; therefore, is not optimal for persons with PWS.

A typical esophagram/Barium swallow is not a deglutition study because of the density of the preparations and actual food is not given.

FEES exam (Fiber Optic Endoscopic Evaluation of Swallowing)



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Thank you very much for this opportunity!

