Feeding and swallowing in cerebral palsy: Evidence-based practice and beyond

Georgia A. Malandraki, PhD, CCC-SLP, BCS-S
Jaime L. Bauer Malandraki, MS, CCC-SLP
Justine Joan Sheppard, Ph.D., CCC-SLP, BCS-S

Dept. of Speech, Language and Hearing Sciences, Purdue University
Dept. of Biobehavioral Sciences, Teachers College, Columbia University

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Speaker Name: Georgia A. Malandraki
Disclosure of Relevant Financial Relationships
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I will not discuss off label use and/or investigational use in my presentation

Speaker Name: Jaime Bauer Malandraki
Disclosure of Relevant Financial Relationships
- Employee of: Purdue University

Disclosure of Off-Label and/or Investigative uses:
I will not discuss off label use and/or investigational use in my presentation

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Speaker Name: Justine Joan Sheppard
Disclosure of Relevant Financial Relationships
- Member, Nutritional Management Associates, LLC
- Honorary Associate Professor, Teachers College, Columbia University

Disclosure of Off-Label and/or Investigative uses:
I will discuss the following investigational use in my presentation:
- The Dysphagia Disorder Survey (results of research)

Purdue I-EaT Research Lab and Clinic
(I-maging, E-valua/on and T reatment of Swallowing Laboratory)
Lab email: swallowinglab@purdue.edu

Course Outline
1. Brief Introduction - Feeding and swallowing in CP
2. Review of current literature on evaluation tools
3. Review of current literature on treatment and research evidence
4. What to do when research evidence is limited?
   1. Other types of evidence
   2. Overview of principles of neuroplasticity and motor learning for swallowing rehabilitation
5. Case studies / Discussion

Learning Objectives
Learning Objective 1:
- To be able to define specific swallowing evaluation and treatment techniques and identify those that are evidence-based.

Learning Objective 2:
- To understand the extent and limitations of current swallowing evaluation and treatment techniques.

Learning Objective 3:
- To develop skills in how to incorporate principles of motor learning and neuroplasticity into clinical practice.
INTRODUCTION

Feeding and swallowing in CP

• Physiology and Function

<table>
<thead>
<tr>
<th>PHYSIOLOGY Stages</th>
<th>FUNCTION Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-oral</td>
<td>Positioning &amp; anticipation (saliva)</td>
</tr>
<tr>
<td>Oral</td>
<td>containment, chewing, transport</td>
</tr>
<tr>
<td>Pharyngeal</td>
<td>timing, efficiency</td>
</tr>
<tr>
<td>Esophageal</td>
<td>post swallow behaviors</td>
</tr>
</tbody>
</table>

Feeding and swallowing in CP (Cont.)

• Pre-oral Stage

<table>
<thead>
<tr>
<th>PHYSIOLOGY</th>
<th>FUNCTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poor positioning</td>
<td>Instability, Poor orienting, Poor reception, inability to self-feed</td>
</tr>
<tr>
<td>Poor head control / hyperextension</td>
<td>Poor orienting, Poor reception, inability to self-feed</td>
</tr>
<tr>
<td>Cognitive challenges</td>
<td>Poor orienting, instability to self-feed</td>
</tr>
<tr>
<td>Autonomic system challenges</td>
<td>Excess saliva, Poor containment</td>
</tr>
</tbody>
</table>

Feeding and swallowing in CP (Cont.)

• Oral Stage

<table>
<thead>
<tr>
<th>PHYSIOLOGY</th>
<th>FUNCTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tongue thrust</td>
<td>Difficulty with tongue propulsion, Poor containment, Poor oral transport</td>
</tr>
<tr>
<td>Poor labial seal</td>
<td>Difficulty with tongue propulsion, Poor containment, Poor oral transport</td>
</tr>
<tr>
<td>Oral hypersensitivity / reflexes</td>
<td>Poor reception, Poor containment</td>
</tr>
<tr>
<td>Poor lingual coordination/ strength</td>
<td>Poor oral transport, Poor oral control, Inefficient chewing</td>
</tr>
</tbody>
</table>

Feeding and swallowing in CP (Cont.)

• Pharyngeal Stage

<table>
<thead>
<tr>
<th>PHYSIOLOGY</th>
<th>FUNCTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delayed pharyngeal response</td>
<td>Risk for aspiration (coughing), Residue (multiple swallows)</td>
</tr>
<tr>
<td>Pharyngeal dysmotility</td>
<td>Risk for aspiration (coughing), Residue (multiple swallows)</td>
</tr>
<tr>
<td>Reduced laryngeal excursion</td>
<td>Risk for aspiration (coughing), Residue (multiple swallows)</td>
</tr>
<tr>
<td>Reduced UES opening</td>
<td>Risk for aspiration (coughing), Residue (multiple swallows), Regurgitation/reflux</td>
</tr>
</tbody>
</table>

Feeding and swallowing in CP (Cont.)

• Esophageal and lower GI concerns (briefly):
  - GERD
  - Esophageal Dysmotility
  - Delayed gastric emptying
  - Constipation
  - And more …
Esophageal Motility Problems in Cerebral Palsy

Normal | Hypotensive LES | Hypomotility

Staiano & Martini, 2013

ASSESSMENT OF FEEDING AND SWALLOWING IN CP


Hypothesized factors

Limited Food Intake

Feeding Dysfunction
- Limited food intake
- Inadequate nutrients
- Risk of aspiration

Sub-Optimal Body Weight
- Decreased muscle tone
- Decreased mobility

Limited Food Intake
- Reduced food intake
- Nutritional deficiencies

Outcomes Observed

Feeding/Swallowing Assessment Aims

- Evaluate and maximize swallow safety and nutrition
- Identify potential risk for respiratory compromise and growth
- Increase child’s eating and drinking potential
- Reduce anxiety and stress around eating process
- Help family and child make informed decisions on feeding options (when oral feeding is not adequate)
- Develop management and habilitation plan
- Educate parents about feeding/swallowing and difficulties specific to their child

Strudwick, 2009

Steps in the Assessment of Oropharyngeal Dysphagia

- Case history
- General Gross Motor Skills
- Seating/Positioning
- Oropharyngeal Sensorimotor Assessment
- Clinical Functional Assessment
- Instrumental Assessments
- Parent report measures
Oropharyngeal Sensorimotor Evaluation

• Evaluating CN functions
  – Examination of structures at rest and during directed tasks
  – Can the child perform these functions?
    • Spontaneously
    • With Imitation
    • With Verbal Instruction

Oropharyngeal Sensorimotor Evaluation (Cont.)

• Face – Motor – CN VII
• Jaw/Face – Motor and sensory – CN V
• Tongue – Motor – CN XII
• Velum – Motor – CNs V and X
• Oral sensation and taste – CNs V, VII and IX
• Examination of primitive reflexes

Clinical Functional Assessments

• Trial Swallows
  – Assess aspects of CN function but during eating and drinking
  – “Clinical Dysphagia Evaluation” or “Clinical Bedside Swallow Evaluation”
  – No standardization between clinicians

Clinical Functional Assessments (Cont.)

• Standardized assessments (many) (Benfer et al. 2012)
  – Dysphagia Disorder Survey (DDS) (Sheppard et al. 2014)
  – Schedule for Oral Motor Assessment (SOMA) (Skuse et al. 1995)
  – Pre-Speech Assessment Scale (PSAS) (Morris, 1982)

Important terms

• Reliability = overall consistency of a measure
  – Intra- and inter-rater
• Specificity = the proportion of negatives that are correctly identified as negative
• Sensitivity = proportion of positives that are correctly identified as such (true positives)
• Validity = the extent to which a test measures what it is supposed to measure
  – Content validity (is it measuring OPD)
  – Construct validity (convergent and discriminative)

Clinical Functional Assessments (Cont.)

• Dysphagia Disorder Survey (Sheppard et al. 2014)
  – During a functional eating task: natural environment
  – Includes: five bites/sips of each texture of food and liquid that are typical in the child’s diet
  – Binary scoring of different items
    – Training and certification required
    – Reliability: $k_w = 0.4, 0.7$ (97.5% and 92.5%) (intra and inter)
    – High sensitivity: low or moderate specificity (especially in younger children)
    – Validity: content; convergent and discriminative

Benfer et al. 2012; Benfer et al. 2014; Sheppard et al. 2014
Clinical Functional Assessments (Cont.)

• Schedule for Oral Motor Assessment (SOMA) [Skuse et al. 1995]
  • Also, during eating tasks
  • Binary scoring of different items (80 items)
  • OMC scored for every food item
  • Training and certification required
  • Reliability: $\kappa_w = 0.9; 0.7$ (92.5%; 85%) (intra; inter)
  • High specificity (especially for oral phase impairments); low sensitivity
  • Validity: content (strong); limited convergent and discriminative

Benfer et al. 2012; Benfer et al. 2014; Ju Ko et al. 2011

Instrumental Swallowing Assessments

• If enough clinical signs of OPD are present an instrumental assessment is essential
  • Two types
    • Videofluoroscopy (VFSS)
    • Fiberoptic Endoscopic Evaluation of Swallowing (FEES)

Videofluoroscopy

Normal child

Child with CP

Parent Report Measures

• Vital to a comprehensive assessment!
• Informal interview
• Key questions:
  — How long does it take to feed your child?
  — Are meal times stressful to child or parent?
  — Is your child gaining weight adequately?
  — Are there signs of respiratory problems?

Arvedson, 2013

Parent Report Measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Population</th>
<th>Aim</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric Assessment Scale for Severe Feeding Problems (PASSFP) Crist et al. 2004</td>
<td>Tube-fed children with various underlying medical conditions</td>
<td>Assess development of oral feeding skills in tube-fed children</td>
</tr>
<tr>
<td>Feeding/Swallowing Impact Survey (FS-IS) Leflon-Grief et al. 2014</td>
<td>Children with medically based feeding/swallowing disorders</td>
<td>Measure the impact of feeding/swallowing issues on caregivers</td>
</tr>
<tr>
<td>Drooling Impact Scale (DIS) Reid et al. 2009</td>
<td>Children with developmental disabilities</td>
<td>Measure outcome of saliva-control interventions based on impact of drooling on child, parents/caregivers</td>
</tr>
</tbody>
</table>
**Management of feeding and swallowing**

- Aim – Optimum quality of life for child and family
  - Health and safety
    - Minimizing aspiration, choking and respiratory infections
    - Optimizing nutrition and hydration
  - Advancing eating and drinking skills and behaviors
    - Improve swallowing and oropharyngeal skills to support oral feeding and saliva control
    - Take advantage of developmental neuroplasticity for motor learning

Sheppard & Malandraki, 2015

**Management of feeding and swallowing (Cont.)**

- Exact management plan will depend on evaluation outcomes for feeding and swallowing
  - Medical
  - Developmental
  - Neuro-motor
  - Family issues

Sheppard & Malandraki, 2015

**Compensatory Strategies (Environmental Manipulations)**

- Interventions that support improved swallowing performance but results do not continue once the strategy is withdrawn
- In children, compensatory strategies may be used to support practice in less demanding eating tasks to improve skill

Arvedson, 2013; Sheppard & Malandraki, 2005
Compensatory Strategies

- Seating posture
- Diet consistencies
- Environmental changes
- Adaptive oral feeding techniques and equipment
- Gastrostomy feeding

Sheppard & Molandaki, 2015

Seating Position for Feeding and Swallowing

- Seating (by team, PT, OT and SLP)
  - The child’s postural aims
    - Lower body (hips and lower extremities) stable on supporting surfaces
    - Balance of stability and mobility in upper body; balance of flexion and extension overall
    - Head-neck with chin downward (capitol ventro-flexion)
    - Forearms supported on anterior surface

Myhr & von Wendt, 1991; Snyder et al. 2011

Seating Position for Feeding and Swallowing (Cont.)

- The Chair options for achieving aims
  - Lower and mid-body stabilization
    - Foot rest
    - Seat
    - Arm rest
    - Tray
    - Belting
  - Upper body balance – stability and tone
    - Tray height
    - Seat back/seat angle
    - Seat back height
    - Head rest

Myhr & von Wendt, 1991; Snyder et al. 2011

Illustration of “functional seating”

Myhr & von Wendt, 1991

Illustration of Supportive Seating

Myhr & von Wendt, 1991

Traditional Diet Modifications

The International Dysphagia Diet Standardization Initiative
Criteria for Selecting Diet Modifications
- Pre-oral and Oral preparation tolerances, skills and competencies
- Oral-pharyngeal competencies
- Esophageal motility
- Demands for
  - Nutrition
  - Hydration
  - Airway protection

Environmental Considerations
- Monitoring and assisting
- Encouraging/allowing independence
- Moderating acoustic and visual complexity
- Maintaining familiarity
- Establishing optimum eating-time
- Moderating stressful environments

Adaptive oral feeding techniques and equipment
- Adaptations in Technique
  - Size of bite - Smaller bites / sips
  - Rate of bite presentation
  - Alternate solids with liquids
  - Control of texture and viscosity
  - More frequent, smaller meals
  - Reflux precautions following eating

Assistive feeding devices
- Special feeding spoons and forks
- Sculptured / nosey cups
- One-way valve straws
- Wide straws
- Mechanized self-feeders

Gastrostomy Feeding
- Benefits
  - Nutritional status
  - Number of hospital admissions for chest infection
  - Quality of life for child and family
- Special considerations for dysphagia treatment
  - Medical management for transition
  - Daytime, mealtime hunger-satiation GT feeding schedule
  - Bolus GT feedings
  - Exposure to family/classroom eating environments
  - Therapeutic tastes and pleasure feedings

Sheppard, 1995
McKirdy et al. 2008; Mehta & Acero, 2015; Rempel, 2015
Habilitative Management for Dysphagia

- Medical treatments
  - Aim: Optimize esophageal and GI function

- Behavior modification strategies
  - Aim: improve eating motivation and cooperative pragmatics for eating/mealtimes

- Motor learning strategies for functional skills
  - Aim: optimize practice of goal oriented tasks for skill acquisition and improvements in performance quality for oral-pharyngeal swallow

Sheppard & Malandraki, 2015; Novak et al. 2013

Evidence for Habilitative Interventions

- Top-down approach
  - Use neuroplasticity to change function through treatments aimed at activity and participation!

- Green Light (general)
  - Context focused
  - Goal-based using motor learning approach
  - Home-based, goal-based tasks by parent supported by clinician


Evidence for Habilitative Interventions (Cont.)

- Mealtime specific insufficient evidence (weak evidence*)
  - Sensory processing
  - Oral motor treatments

* probably do not do it. Stronger evidence for task specific strategies.

Novak et al. 2013

Research Evidence for Habilitative Swallowing Treatments in CP


Interpretation: Feeding interventions demonstrate potential benefits for children with cerebral palsy. However, the current level of evidence is poor, and empirical data are lacking. Methodologically rigorous studies are required particularly investigating multimodal approaches.


Interpretation: Evidence for supports across treatments. Green light interventions – ‘use it’. Yellow Light interventions should be accompanied by a sensitive outcome measure to monitor progress – ‘probably use it’. Red Light interventions should be discontinued.

Novak et al. 2013

Evidence for Habilitative Interventions (Cont.)

- Yellow Light (Mealtime specific)
  - Dysphagia Management – safe swallowing and skills
  - Gastrostomy
  - Fundoplication

- Yellow Light (General)
  - Parent education for behavior management
  - Seating and positioning

Novak et al. 2013

Special Notes on Interventions for Drooling

- Problem: 40% of 7-14 yo children with CP
- Treatments that have been studied
  - Sensorimotor therapy and swallow improvement
  - Oral appliance
  - Systemic anticholinergic medications
  - Botulinum toxin therapy to the submandibular and/or parotid glands
  - Surgery

Johnson et al. 2004; Reid et al. 2012; Snider et al. 2011; Walshe et al. 2012
Habilitation
What do we do when research evidence is so poor??

In absence of well-documented clinical efficacy, clinicians have to base their treatment decisions on the underlying theoretical or physiological basis of a treatment or disorder respectively

Arvedson et al. 2010; Clark, 2003

Case Study 1

Case Study 2

Case Studies

• What dysphagia treatment(s) would you recommend?
  – Design and write the outline of a treatment plan for these patients
    • Compensatory strategies
    • Habilitative strategies (amount, repetitions, days etc.)
    • Duration
    • Follow-up

We will discuss this at the end of the session

Habilitation
What do we do when research evidence is so poor??

Levels of Evidence

A Framework for Thinking About Evidence

Best Available Research Evidence
Evidence Based Decision Making
Contextual Evidence
Experiential Evidence

Figure 1

Puddy, R. W. & Wilkins, N. (2011)
By enhancing our ...  

- Experiential Evidence  
- Contextual Evidence  

Experiential Evidence Enhancement  

- “Evidence-based rehabilitation programs need to be developed upon the knowledge of nervous system function and control over the sensorimotor task being rehabilitated”  
- “AND follow principles of experience-dependent plasticity and motor learning”  

Charles & Gordon, 2006; Kleim & Jones, 2008  

Experiential Evidence  

Swallowing Neurophysiology  

Highly Complex  

PNS  

NOT A MERE REFLEX ANYMORE, BUT A RESPONSE!  

Malandraki et al. 2009; 2011; Martin & Sessle, 1993; Miller, 1986; Miller, 1993  

Principles of experience-dependent plasticity and motor learning approaches  

1. Use it or lose it  
2. Use it and improve it  
3. Plasticity is experience-specific (specificity of learning)  
4. Repetition matters (maximizing opportunities for practice)  
5. Intensity matters  
6. Time matters  
7. Salience matters (attention and motivation)  
8. Age matters  
9. Transference  
10. Interference  

Kleim & Jones, 2008; Sheppard, 2008  

More motor learning approaches  

- Implicit learning  
- Rehearsal strategies  
  - Through different steps in the learning process  
  - Blocked and random practice  
  - Distributed vs. massed practice  
  - Feedback  
  - Transfer of learning  

Sheppard, 2008  

What could that look like??  

Child 11 yrs with spastic hemiplegia  

A) Not affected  
B) Mildly  
C) Moderately  
D) Severely  

Child 11 yrs with spastic hemiplegia  

A) Not affected  
B) Mildly  
C) Moderately  
D) Severely
How can you combine this information with the Research Evidence and maximize patient outcomes?

Revisiting the Case Studies

• Look at the treatment plans you designed

• What would you change to make your treatments have MORE experiential evidence?

DISCUSSION

Summary points

• Limited standardized evaluation tools, but some available

• Research evidence for interventions: sparse

• Experiential and contextual evidence are available
  – Principles of motor learning and neuroplasticity
  – Patient-family centric focus

• Overall: Compensation is ok, BUT!
  – Don’t give up on habilitation, because the …
  – Brain is a lot more plastic than we once thought!!

Selected References


