SPEAKER DISCLOSERS

Financial: Salary from Texas Health and Human Services Commission

Non-Financial: Member of the National Foundation of Swallowing Disorders, the International Association for the Scientific Study of Intellectual Disabilities, and the Dysphagia Research Society
The Objectives

- Impacts of dysphagia in people with intellectual disability (ID)
- Systems identification, assessment, and treatment
- Anticipation of Physical-Nutritional needs
- The Physical-Nutritional collaboration
- Case Study
Intellectual Disability (ID) Defined

• ID is a chronic disorder

• Significant limitations in intellectual functioning and adaptive behavior before age 18

• ~ 6.5 million people in the U.S.

• ~ 200 million people globally

(Cichero, 2006; National Center on Birth Defects and Developmental Disabilities, 2019)
The Cause of ID

- Unknown causes
- Chromosome abnormalities
- Abnormal embryonic development
- Childhood onset psychosis/Autism
- Acquired childhood diseases or injuries
- Pregnancy issues
- Perinatal morbidity

(Crocker, 1989; Arvedson and Brodsky, 2002)
Life Expectancy and ID

1929
ID - 9
General Pop - 58

1979
ID - 18
General Pop - 73

2010
ID - 55
General Pop - 76

Today
ID - 60
General Pop - 79

(Patja et al., 2000; Patja et al., 2001; Haveman, 2010; Coppus, 2013; Glover, 2017)
## Comorbidity and ID

<table>
<thead>
<tr>
<th>Condition</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory deficits</td>
<td>• strategies for deaf/blind?</td>
</tr>
<tr>
<td>Seizure disorders</td>
<td>• medication side effects?</td>
</tr>
<tr>
<td>Psychiatric disorders</td>
<td>• medication side-effects and behavioral impacts?</td>
</tr>
<tr>
<td>Limited mobility</td>
<td>• increased need for mealtime assistance?</td>
</tr>
<tr>
<td>Gastro-intestinal problems</td>
<td>• impacts on pharyngeal swallowing function?</td>
</tr>
<tr>
<td>Periodontal disease</td>
<td>• impacts on respiratory health?</td>
</tr>
</tbody>
</table>
Oral Health and ID

- Retrospective study of 4,000 individuals with ID
  - Caries (87.8%)
  - Untreated caries (32.2%)
  - Periodontitis (80.3%)
- 10 times more likely to have missing teeth

- Complex oral health related to developmental anomalies and behavioral challenges

(Gabre et al., 1999; Tiller et al., 2001; Traci et al., 2002; Morgan et al., 2012)
Oral Health and Pneumonia

• Oral Bacterial Pneumonia risk factors
  • Colonized dental plaque (Odds Ratio = 9.6)
  • Periodontal pathogens in saliva (Odds Ratio = 4.0)
  • Decayed teeth (Odds Ratio = 1.2 per decayed tooth)
  • Higher plaque scores had increased mortality rates (Odds Ratio = 3.9)

(Langmore et al., 1998; Scannapieco et al., 2003; Azarpazhooh, 2006; Awano et al., 2008)
The Natural History of Dysphagia in ID

- Persistent throughout the lifespan and increases with level of ID severity
- Aquired with aging, multiple medical disorders, medication side effects
- High prevalence of disorders in functional swallowing foundations

(Sheppard, 2006; Haveman et al., 2010)
Contributing Factors

(Dysphagia Severity

Physical disabilities

Cognitive impairment

Behavioral disorders

(Sheppard, 1991; Avredson and Brodsky, 2002; Cichero, 2006)
System Effects

- Substantial health consequences
  - Choking
  - Respiratory illness
  - Nutritional deficits

- Multiple phase involvement
  - Oral
  - Pharyngeal
  - Esophageal

- Multiple contributing systems
  - Neurologic
  - Gastrointestinal
  - Psychiatric

(Sheppard, 2006; Pace & McCullough, 2010)
DYSPHAGIA IN ID

TRANSIENT, ACUTE, AND CHRONIC NEEDS
Dysphagia in ID

- **Transient**
  - Medical instability
  - Psychiatric instability

- **Acute**
  - CVA
  - TBI
  - Neurodegenerative disease

- **Chronic**
  - Medication side effects
  - Esophageal disorders
  - Aging

(Sheppard, 2006; Calis et al., 2008)
Swallowing and Feeding in Older People with Lifelong Disability (Sheppard, 2002)

- Retrospective study of dysphagia progression in those with ID
  - 75 subjects followed for 10 years
  - Age at start of study was 23.3 (SD = 9.09)
  - Age at end of study 39.43 (SD = 9.44)
  - Subjects divided into 4 groups based on dysphagia severity at the last clinical evaluation

- Results
  - 75% deteriorated in severity level (p<.0005)
  - 71% with no deficits at onset progressed to mild swallowing dysfunction at end
  - Average age on onset of decline was 33.39
  - 12% required increased assistance
  - Modified diet needs increased from 67% to 93%
  - Number of phases of swallow involvement increased with age (oral to oropharyngeal 35% to 100%; Esophageal 1.3 – 16%)

(Sheppard, 2002)
ASSESSMENTS AND INTERVENTIONS
Barriers to Research

- Ethical restrictions related to informed consent
- Limited sample sizes
- Differing diagnostic criteria
- Heterogeneity of ID population
- Limited research funding sources
- Limited research interest/stigma
People with Intellectual Disabilities and Dysphagia: A Systematic Review (Robertson et al., 2017)

- Dysphagia is common and associated with serious health risks
  - Respiratory infection
  - Choking
  - Malnutrition

- Often underreported

- Continuing need to understand the key aspects of dysphagia management
  - Improve health outcomes
  - Reduce premature death
Assessment Strategies

- Screening
- Clinical Swallowing Assessment
- Instrumental Assessment
- Clinical Re-Assessment
- Instrumental Re-Assessment
Potential Assessment Barriers

• Lack of standardized measures
• Difficulty participating in instrumentals
• Incomplete medical history
• Poor ability to self-report reliably
• Provider bias (confirmation bias)
The Clinical Swallowing Assessment

- Mealtime Motivation
- Eating Pragmatics
- Eating Skills & Sub-skills

Functional Foundations

(Sheppard, Hochman & Baer, 2014)
<table>
<thead>
<tr>
<th>Physiologic</th>
<th>Psychosocial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body posture/control</td>
<td>Attention</td>
</tr>
<tr>
<td>Oral movement</td>
<td>Task persistence</td>
</tr>
<tr>
<td>Respirations</td>
<td>Pragmatics</td>
</tr>
<tr>
<td>Voice</td>
<td>Compliance</td>
</tr>
<tr>
<td>Saliva management</td>
<td>Social intent</td>
</tr>
<tr>
<td>Oral-pharyngeal sensory acuity</td>
<td>Independence</td>
</tr>
<tr>
<td>Gastrointestinal function</td>
<td></td>
</tr>
</tbody>
</table>
Motivation for Eating

- Physiologic discomfort
- Food preferences
- Interactions with feeding/eating partner(s)
- Environmental limitations
Eating Pragmatics

- Self-regulation
- Attention to task
- Compliance with guiding adults
- Tolerance for variety in routine
Swallowing Skills & Sub Skills

**Eating**
- Utensil use
- Biting & chewing
- Self-feeding
- Rate of intake

**Drinking**
- Cups
- Self-feeding
- Rate of intake

**Swallowing**
- Bolus transport
- Salvia swallows at rest
- During stimulated flow
- During parallel activities
Swallowing Re-Assessment

• Scheduled re-assessments are vital for those with ID and chronic dysphagia

• Frequency based on the level of severity or medical stability

• Indication for the need for a re-assessment can include
  • Illness
  • Change in eating behavior
  • Weight loss
  • Direct caregiver reports of change

(Sheppard, 2006)
The Habilitative Approach

- Health and safety: Support during meals, Dietary needs
- Quality of life: Honoring preferences, Consistent routines
- Swallowing Competencies: Implement & maintain strategies, Direct/indirect treatment to maintain/regain skills, Re-evaluations & consultations

(Sheppard, 2006; Chadwick, 2014; Cichero & Lam, 2014)
Dysphagia Management Relationships

Diet Supports
- Food textures
- Liquid consistencies
- Food preferences

Supervision Needs
- Level of assistance
- Feeding strategies

Health & Habilitative Monitoring
- Change in health status
- Change in skills & abilities

(Sheppard, 2006)
The Individualized Management Plan

- Includes activities that can be modified or regulated
  - Routines before meals/snacks
  - Environments that support optimal behaviors
  - Supervision/assistances
  - Seating/positioning
  - Specialized equipment
  - Bolus presentation/characteristics
  - Communication strategies
  - Routines after meals/snacks

- Applied to swallowing activities
  - Meals/snacks
  - Medication administration
  - Oral hygiene
  - Saliva management
# The Individualized Management Plan

## PHYSICAL / NUTRITIONAL MANAGEMENT PLAN (PNMP)

**Wonderful Person**

### HOME: ABC  
CAN#: 9029

### Risk Level Reason Individualized Signs/Symptoms

<table>
<thead>
<tr>
<th>Category</th>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Closing</td>
<td>Medium</td>
<td>History of irregularity during manic episodes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stops breathing when eating, no sounds of any kind, face/face turning blue</td>
</tr>
<tr>
<td>Communication</td>
<td></td>
<td>Has hearing loss, speak to him using slow, clear voice</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Communicates verbally in simple words, phrases, and short sentences</td>
</tr>
<tr>
<td></td>
<td></td>
<td>If his statements are not clear, ask him to repeat</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Communicates pain verbally, can use Fevon Plan Scale</td>
</tr>
</tbody>
</table>

### MEDICATION ADMINISTRATION:

**Diet Textures:**
- Pureed
- Fluid Consistency:
- Thin

**Position:**
- Individual: Sits in most upright position in chair
- Nurse: Close to eye level

**Techniques:**
- Crush all medications and mix in puree texture

**Assistive Equipment:**
- N/A

### ORAL CARE:

- Regular toothbrushing twice daily

**Position:**
- Individual: Sits in most upright position in chair
- Staff: Close to eye level

**PRECAUTIONS:** fragile bones, fractures

## PRECAUTIONS:

- Fragile bones, fractures

### POSITIONING:

- Elevate head of bed 30° for sleeping and bed positioning
- Personal recliner for alternate position, keep legs elevated when possible
- When sitting on the recliner, may apply pillow on his right when leaning excessively to the side

### HANDLING INSTRUCTIONS:

- Wears orthopedic shoes and AFO’s during waking hours
- DO NOT let him put on his AFO’s BY HIMSELF
- Monitor to ensure his shoes and AFOs are on correct feet and straps on are snug
- REMOVE GASTJECT W/SG I PING

### DINING PLAN:

**Diet Texture/Liquids:**
- Pureed / Thin

**Instructions:**
- Encourage him to pour his liquids into handy cup
- Encourage slow eating and drinking pace using verbal prompts, if he continues to eat at increased rate, provide tactile prompts to hand
- Verbally encourage to take small bites of food
- Remain upright 1 hour after meal

**Position:**
- Individual: Sits in most upright position in dining chair
- Staff: Sits as close to eye level as possible

**Assistive Dining Equipment for Meals:**
- Hi-Sided Divided dish – scooping surface and divides food
- Handy cups – co-ordination
- Flat-Built-Up Handle Infant spoon – maintain grasp and decreases amount of food

**Assistive Dining Equipment for Snacks:**
- Handy cups
- Flat-Built-Up Handle Infant spoon

**Snack Instructions:**
- Follow Dining Plan

**Precautions:**
- Seizures
- GERD

### TRANSFERS:

- Independent
- Van Transfers:
- Needs assistance x 1 staff

### MOBILITY:

- Walks with rolling walker, orthopedic shoes, AFO’s, and hands on assistance at backbend
- Assist steering walker in confined spaces (i.e. bathroom stall) and doorways
- Hands on assistance at gaitbelt for walking on grizzly surfaces without rolling walker (i.e. to get to seeing outside his home). This is appropriate for short distances ONLY
- Use extra wheelchair with seatbelt for long distances or if unsteady

### BATHING:

- Dependent
- Shower chair with seatbelt

### TOILETING/PERSOAL CARE:

- Dependent

### DRESSING:

- Dependent

### GROOMING:

- Dependent

### ASSISTIVE EQUIPMENT:

- Orthopedic shoes with AFO’s – foot abnormalities
- Gaitbelt for safe walking ONLY – remove when sitting

- Rolling walker 1/3, with basket and weights - safe mobility
- Rolling walker tray - kept on home for carrying dishes

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○ Indicates a change
The Individualized Management Plan

DINING PLAN
WONDERFUL PERSON

Dining Plan:
Diet Texture/Liquids:
- Pureed/Thin

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Precautions:
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- GERD
Physical-Nutritional Collaboration

(Ball et al., 2012)
## Case Study: Mr. X

<table>
<thead>
<tr>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>44-year-old, non-verbal, non-ambulatory, edentulous male with multiple congenital anomalies</td>
</tr>
<tr>
<td>Developmental milestones delayed; never developed speech</td>
</tr>
<tr>
<td>Fed himself/some dressing skill at age 6</td>
</tr>
<tr>
<td>Attended special education classes throughout his school years</td>
</tr>
<tr>
<td>Admitted to the ICF at his parents’ request as they found it difficult to find someone to care for him while they worked and were interested in improving his self-help and communication skills</td>
</tr>
</tbody>
</table>
Mr. X: Diagnoses

• Blindness
• Bowel incontinence
• Diabetes insipidus
• CHARGE syndrome
• Chronic constipation
• Edentulous
• GERD
• Hiatal hernia
• History of fundoplication
• Remote history of pneumonia in 2011
• Mild to moderate hearing loss
• Obsessive compulsive disorder
• Oropharyngeal dysphagia
• Osteoporosis
• Primary insomnia
• Recurrent UTI
• Rumination disorder
• Scoliosis
• Seizures
• Severe intellectual disability
• Speech impairment/non-verbal
<table>
<thead>
<tr>
<th>Medication</th>
<th>Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sertraline</td>
<td>anorexia, dry mouth, nausea, vomiting, diarrhea and constipation, insomnia, drowsiness, tremor, twitching, agitation, anxiety, and visual disturbances</td>
</tr>
<tr>
<td>Polyethylene Glycol</td>
<td>nausea and diarrhea</td>
</tr>
<tr>
<td>Zolpidemeter</td>
<td>drowsiness, dizziness, weakness, loss of coordination, dry mouth, nausea, constipation, diarrhea, and upset stomach</td>
</tr>
<tr>
<td>Simvastatin</td>
<td>nausea and vomiting</td>
</tr>
<tr>
<td>Omeprazole</td>
<td>nausea, abdominal pain, and diarrhea</td>
</tr>
<tr>
<td>Sennosides</td>
<td>nausea, vomiting, and diarrhea</td>
</tr>
<tr>
<td>Diphenhydramine</td>
<td>dizziness, drowsiness, loss of coordination, dry mouth, nausea, and constipation</td>
</tr>
<tr>
<td>Denosumab</td>
<td>osteonecrosis of the jaw, nausea, and diarrhea</td>
</tr>
<tr>
<td>Mag-Al-Hydrox-Simeth</td>
<td>constipation and diarrhea</td>
</tr>
<tr>
<td>Calcium and Vitamin D</td>
<td>anorexia, dry mouth, nausea, vomiting, constipation, diarrhea, abdominal pain, and chalky taste</td>
</tr>
</tbody>
</table>
Mr. X: Swallow Physiology Review

May 2010
- Poor bolus control, retroflow above the UES
- No penetration/aspiration
- Recommend ground with honey thick liquids
- However, due to concerns of coughing, diet was changed to puree

July 2010
- Poor bolus control
- Aspiration of thin liquids
- Recommend mechanical soft with nectar thick liquids
- Due to continued aspiration concerns, Mr. X remained on pureed diet texture with honey thick liquids

- Poor bolus control, delayed swallow onset, oral residue
- Penetration that cleared upon swallow completion and during re-swallows
- Recommend advanced from honey-thick to thin liquids

- Moderate dilation of entire esophagus
- Considerable reflux from stomach into esophagus to oral pharynx
- Continual re-swallow refluxed material
Mr. X: Rumination Syndrome

Rumination syndrome: rare behavioral disorder in which food is brought back up from the stomach and then re-swallowed
<table>
<thead>
<tr>
<th>Physiologic</th>
<th>Psychosocial</th>
<th>Eating, Drinking &amp; Swallowing</th>
<th>Eating Pragmatics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has an adaptive dining chair with armrests and seat belt but has not utilized due to refusals to transfer or walk to chair.</td>
<td>Exhibits significant grabbing behaviors of any items on table.</td>
<td>Decreased lip seal with mild anterior loss of solids/liquids.</td>
<td>Although good upper extremity range of motion and hand function, Mr. X is dependently fed due to impulsivity and limited ability for redirection during self-feeding.</td>
</tr>
<tr>
<td>Has a wheelchair that provides optimal upright support for safe eating.</td>
<td>Intermittently touches staff on legs which appears to be an attempt to ensure their location and/or to communicate that he wants more.</td>
<td>Uncoordinated lingual movement with residue coating oral structures that cleared with liquid rinse.</td>
<td></td>
</tr>
<tr>
<td>Sits with trunk erect and crosses his legs into his chair.</td>
<td>Responds to mod verbal redirection during attempts to grab items on table.</td>
<td>Limited visual awareness of spoon/cup, requiring tactile cue lower lip to open mouth.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>No s/s of aspiration.</td>
<td></td>
</tr>
</tbody>
</table>
Mr. X: Outcomes

<table>
<thead>
<tr>
<th>Findings</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Based on current clinical assessment, swallowing skills remained unchanged in the past year</td>
<td>• Continue current puree diet modifications and dining supports as the least restrictive for safe swallowing at this time</td>
</tr>
<tr>
<td>• Feeding and swallowing impairment is multifactorial and related to diagnosis of Severe Intellectual Disability, CHARGE Syndrome, and GI dysfunction</td>
<td>• Discontinue dining chair as it is no longer effective due to refusal to use during meals</td>
</tr>
<tr>
<td>• Given etiology of swallowing dysfunction, potential for improved swallowing skills is poor</td>
<td>• Continue to complete swallowing assessment annually or as requested by the IDT</td>
</tr>
<tr>
<td>• Current compensatory swallowing supports and adaptive dining equipment will likely continue to promote safe oral intake and optimal health and wellbeing</td>
<td></td>
</tr>
</tbody>
</table>


Summary

• Dysphagia in ID is complex and requires multi-system assessment via interdisciplinary team approach

• Managements must include anticipation of feeding and swallowing needs throughout the individual’s lifetime based on underlying etiologies and current changes in health status
THANKYOU!

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References


References


References


