Early Turner Syndrome
Feeding Experiences

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Turner Syndrome

• X chromosome disorder characterized by:
  – Short stature
  – Hearing loss
    • Early: conductive
    • Late: sensorineural
  – High arched palate & retrognathia
  – Learning disabilities
  – Ovarian dysgenesis

(Zajac, 2016; Hjerrils, Motensen, & Gravholt, 2008).
Growth

(Frias & Davenport, 2003)
Turner Syndrome Feeding

• Difficulties due to inefficient sucking and swallowing refluxes
  – Impaired oral motor function

• Dysfunctional tongue movement
  – Poorly developed chewing skills

• Prevalence: 74%
  – From birth through 6 months-3 years of age
  – Slow rate, poor appetite, frequent vomit, suck & swallow problems
  – Difficulty introducing solids: poor chewing, vomiting

(Donaldson, Gault, Tan & Dunger, 2006; Frias & Davenport, 2003; Starke, Wikland, & Moller, 2003)
Feeding Study

• In-home interview, feeding observation (video recorded), and *Feeding Assessment Schedule*

• Mother of infants with Turner Syndrome
  – Introduced bottle feeding earlier and solids later
  – Only 4 of 10 had received advice about managing feeding

• Infants with Turner Syndrome
  – Very poor suck-swallow sequence coordination
  – Tongue dysfunction: poor chewing, fewer chewing attempts

(Mathisen, Reilly & Skuse, 1992).
Research Questions

• How common are early feeding disorders in girls with Turner Syndrome?

• When do these difficulties occur, and what characterizes trouble with feeding?
Current Study

- 41 participants from CIDD Turner Syndrome Clinic, 2010-2013
  - Longitudinal, cross-sectional design
- Clinical observation, parent questionnaire, *Schedule for Oral-Motor Assessment*
- Ages
  - Newborn
  - 6 months - 24 months
  - 12 months - 48 months
## Results

<table>
<thead>
<tr>
<th></th>
<th>Number of Participants</th>
<th>Mean Age (months)</th>
<th>Feeding Difficulty</th>
<th>Mean Symptoms per Child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newborn</td>
<td>8</td>
<td>1.63</td>
<td>25.00% (n=2)</td>
<td>1.34</td>
</tr>
<tr>
<td>6 months</td>
<td>22</td>
<td>6.5</td>
<td>59.09% (n=13)</td>
<td>2.77</td>
</tr>
<tr>
<td>12 months</td>
<td>28</td>
<td>11.82</td>
<td>39.00% (n=11)</td>
<td>2.43</td>
</tr>
<tr>
<td>24 months</td>
<td>23</td>
<td>22.39</td>
<td>47.83% (n=11)</td>
<td>2.09</td>
</tr>
<tr>
<td>48 months</td>
<td>7</td>
<td>48.00</td>
<td>0.00% (n=0)</td>
<td>0.86</td>
</tr>
</tbody>
</table>
Results

Total Cases by Symptom
Results

The diagram illustrates the number of clients with various symptoms across different age groups:

- **Newborn**
- **6 months**
- **12 months**
- **24 months**
- **48 months**

Symptoms include:
- Gag
- Reflux
- Vomit
- Pocketing
- Loss of Bolus
- Spitting Out
- Refuses Texture
- Poor Suck
- Choke
- Regurgitate
- Tongue Protrusion
- Non-Nutritive Sucking
- Poor Appetite

The y-axis represents the number of clients with symptoms, ranging from 0 to 16.
Conclusions & Implications

• Higher rate of feeding problems than expected from typically developing infants

• Utility of adaptive feeding equipment

• Educating families and care providers about feeding concerns upon diagnosis
Team Members

• Family
• Client
• Geneticist
• Pediatrician
• Nutritionist
• Speech Language Pathologist
• Lactation Consultant

• Counselor
• Occupational Therapist
Questions?

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References


• Zajac, D. (October, 2015). *Common Syndromes*[PDF Slides]. Lecture conducted at University of North Carolina, Chapel Hill, NC