Feeding Children with Cleft Lip and Palate

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• Katie Walsh & Sarah Vetter have no nonfinancial relationships to disclose.

Feeding Characteristics of Children with Cleft Lip & Palate
**Feeding Characteristics of Children with Cleft Lip and/or Palate**

**Sucking Performance of Babies with Cleft Conditions**

Reid, Dip, Reilly, & Kilpatrick, 2007

**GOAL:** Measure suction and compression skill of babies with Cleft Lip (CL), Cleft Palate (CP), and Cleft Lip and Palate (CLP).

**SUCTION**
- Babies with CL or Incomplete CP generated levels of suction similar to those reported for healthy babies.
- Babies with more extensive CP or CLP did not generate normal levels of suction.

**COMPRESSION**
- Babies with CL and CP generated compression.
- Babies with larger clefts, such as CLP have less bony tissue available to compress the nipple and therefore did not generate any compression.

**Maternal Report of Feeding Performance**
- Level of suction and compression ability was directly related to parental report of good, satisfactory, and poor feeders.
- Parental report of feeding performance improved when cleft feeding equipment, which compensates for poor suction and compression, was employed.

**Types of Cleft Lip and/or Palate**

Babies with a Cleft Lip and/or Palate are GOOD eaters. Consider the following relationship when determining the best feeding plan:

- **COMPRESSION**
  - Ability to press the tongue to the palate and PUSH liquid out

- **SUCTION**
  - Ability to seal the mouth and PULL liquid out

- **COORDINATION**
  - Ability to control the flow of the liquid, while coordinating breathing and swallowing
Feeding Characteristics of Children Born with Cleft Lip and/or Palate

Common Feeding Difficulties

- Perception of parent concern; Stressful interaction between the infant and caregiver(s)
- Poor oral intake per feeding
- Poor weight gain
- Lengthy feedings of >30 minutes
- Excessive air intake: Frequent need for burping; Frequent spit-up
- Discomfort during feeding OR signs/symptoms of GI concerns: Irritability; arching; Frequent Emesis
- Nasal congestion/noise; Nasal regurgitation
- Gagging; Increased oral sensitivity
- Coughing / Sputtering during feedings
- Other clinical signs/symptoms of aspiration: Wet breath sounds; Eye widening/Eye blinking; Circumoral cyanosis; Red/Watery eyes

Miller & Kummer, 2014

Bottle-feeding Children with Cleft Lip & Palate

Types of Bottles

- Medela Special Needs Feeder
- Ark Special Needs Feeder
- Dr. Brown Specialty Feeding System
- Medela EasiFlow
- Mead Johnson Enfamil Cleft Palate Nurser
- Medela Special Needs Feeder
- Pigeon Bottle
### Bottle-feeding Children with Cleft Lip & Palate

<table>
<thead>
<tr>
<th>Type of Bottle</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
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</table>
| Dr. Brown Specialty Feeding System | - Infant driven  
- Consistent liquid flow rate  
- Easily available: Interchangeable parts. | - Specialty valve found only on-line  
- Thickened liquids flow poorly through valve  
- Lots of parts |
| Mead Johnson Enfamil Cleft Palate Nurser | - A variety of nipples fit on bottle  
- Can be used with thickened liquids | - Passive for infant  
- Initial learning curve for feeder |
| Medela Special Needs Feeder Haberman | - Encourages lingual compression  
- 3 flow rates available | - Passive for infant  
- Initial learning curve for feeder  
- Thickened liquids flow poorly through valve  
- Lots of parts  
- Expensive |
| Pigeon Bottle | - Encourages lingual compression | - Nipple collapses easily  
- Large nipple may be too big for some infants  
- Thickened liquids flow poorly through valve  
- Fast flow  
- Difficult to obtain |

### Breastfeeding Children with Cleft Lip & Palate

#### Breastfeeding and Cleft Lip

- Typically, breastfeeding can be successful if it is truly cleft lip only (i.e. no alveolar ridge involvement).

- Particularly if the cleft lip is unilateral, positioning can be utilized to "fill" in the defect and create an adequate seal.

- Bilateral cleft lip particularly when the alveolar ridge and primary palate are involved, breastfeeding can be much for difficult. A "face on" or "laid back" breastfeeding may be more successful. A mother may need to use their thumb or cheek to decrease the width of the cleft.

ABM Clinical Protocol #17: Guidelines for Breastfeeding Infants with Cleft Lip, Cleft Palate, or Cleft Lip and Palate, Revised 2013
Breastfeeding and Cleft Palate

• "Over time, lactation consultants and breastfeeding counselors have found that feeding exclusively at the breast is an elusive goal for all but a few babies with uncorrected cleft palates." (La Leche League, 2004, p. 8).
• Academy of Breastfeeding Medicine Policy Statement # 17.
• While breastmilk feeding rates in infants with cleft lip and/or palate have risen, rates have remained lower than in non-cleft peers.
• In one study, only 29.5% of infants with cleft palate were fed breast milk which is significantly below the 2016 Centers for Disease Control and Prevention national statistics 81%.
• Parents who received education in regards to breast milk feeding were significantly more likely to give breast milk than those who did not (75% vs 44%) (Alperovich, Frey, Shetye, Grayson, & Vyas, 2017).

Weight Gain in Children with Cleft Lip and/or Palate

GOAL: Examine weight gain and nutritional interventions in babies with CL/P and their ability to return to birth weight.

RESULTS:
CLEFT LIP: Took less time to return to birth weight (13.58 days), required less "intervention" (3/36) and were more likely to be fed breast milk exclusively (50%).
CLEFT PALATE and CLEFT LIP/PALATE: Took longer to return to birth weight (CP 15.88, CLP 21.93 days), increased "interventions" (CP 14/28; CLP 16/33) and less likely to be fed breast milk exclusively (CP 21.4%; CLP 30.3%).

<table>
<thead>
<tr>
<th>Type</th>
<th>Breast Milk Exclusively</th>
<th>Formula</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>CL</td>
<td>18</td>
<td>11</td>
<td>29</td>
</tr>
<tr>
<td>CLP</td>
<td>-</td>
<td>23</td>
<td>23</td>
</tr>
<tr>
<td>CP</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>19</td>
<td>14</td>
<td>33</td>
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KEY POINTS:
1) Most of these infant interventions (30/33 interventions) were related to adjusting the volume the infant was taking or caloric density, rather than major bottle modifications.
2) Once you find an adequate bottle system, from our perspective most of these infants feed rather well.
Clinically significant weight and length decreases were evident within the first year of life for children with isolated cleft lip with or without cleft palate, as well as children with cleft palate only.

These weight decreases were additionally followed by a statistically significant recovery.

Recovery was related to successful feeding interventions and caregiver education. Zarate et al., 2010

At Lurie Children’s, Linda Duffy, RN determined weight loss can be expected in the early postoperative period following palatoplasty.

Weight loss did not impact long term outcomes of infant growth.

Knowledge of these outcomes has enhanced education for caregivers and primary care physicians, alleviating concerns for infants undergoing cleft palate repair. Duffy, 2012

Babies with cleft lip & palate typically transition well to pureed & soft table solids.

Small bites or time for extra swallows can help lessen any nasal regurgitation.
Impact of Surgical Management on Feeding a Child with Cleft Lip / Palate

Pre-Surgical Medical Management
Nasal Alveolar Molding

PURPOSE
• To improve nasal symmetry and projection
• To improve alignment of the maxillary arch
• Ultimately, helps decrease complexity of subsequent surgery

IMPACT ON FEEDING
• Increases lingual-palatal compression, and may then increase flow of liquid
• Does NOT improve suction, and thus does not facilitate feeding from the breast or a normal bottle
• Initially, it may take longer for a baby to feed with an appliance in place; the baby will quickly adjust.
• Parents should be instructed not to change the feeding method during this adjustment period.
• Removed at least 1 month prior to palatal repair to heal the area in preparation for surgery.
• Sometimes the infant needs time to adjust when this occurs as well. In our experience, this typically occurs within 24 hours.

Grayson, 2014
Lurie Children’s Post Surgical Precautions

<table>
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<tr>
<th>Cleft Lip Repair</th>
<th>Cleft Palate Repair</th>
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<tr>
<td>• Immediate return to breast feeding</td>
<td>• Strictly open cup drinking for 30 days</td>
</tr>
<tr>
<td>• Immediate return to bottle feeding</td>
<td>• No bottle, pacifier, cup with spout, or straw for 30 days</td>
</tr>
<tr>
<td>• No pacifier for 30 days</td>
<td>• Solids:</td>
</tr>
<tr>
<td></td>
<td>– Puree for 48 hours post-surgery</td>
</tr>
<tr>
<td></td>
<td>– Mechanical soft solids after 48 hours</td>
</tr>
<tr>
<td></td>
<td>– Rinse out the mouth after intake of semi-solid foods</td>
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Post Surgical Feeding Options following Palatoplasty / Cleft Palate Repair

Essentially, ANY open cup is fine! Caregivers should be assured it doesn’t have to be a special contraption.

Post Surgical Feeding Options following Palatoplasty / Cleft Palate Repair

If the Open Cup isn’t working … And, continued Spoon Feeding with Side Presentation

Essentially, ANY open cup is fine! Caregivers should be assured it doesn’t have to be a special contraption.
GOAL: Examine feeding skills in babies with CL/P and determine characteristics, risk factors, and predictors of poor feeding during first 14 months of life.

RESULTS:
CLEFT LIP: Typical GOOD Feeders and never Poor Feeders.
CLEFT PALATE and CLEFT LIP/PALTE: Evenly distributed across ratings of Good, Satisfactory, and Poor

KEY POINTS:
1) Prevalence of Poor Feeding in CL/P newborns may be significant, even when no syndrome or PRS is present.
2) Nonsyndromic CP and CLP neonates are equally likely to need feeding assistance in the first months of life, but by 3 Months of Age, Poor Feeding may likely resolve.
3) Participants with Syndromes or PRS are more complex and may require feeding support services for much longer, even beyond 14 Months of Age.
Rates and Risks of Gastrostomy Tube in Infants with Cleft Palate
Cu & Sidman, 2011

GOAL: Examine GT placement in infants with cleft palate at one institution

RESULTS:
34 of 214 infants required GT placement
19 of the 34 had identified syndromes
29/34 had at least 1 system comorbidity (e.g. respiratory)

KEY POINTS:
1) Infants requiring GT placement often have many confounding factors that need to be considered
2) Comorbidities such as cardiac or respiratory conditions and/or the presence of a genetic syndrome greatly increase the likelihood that a child with cleft palate may need a GT

Considerations for Caregiver Education

What is Important?

Topics to Cover with Parents of Newborns with Cleft Lip/Palate

- Use proper medical terminology: cleft lip and palate
- Discuss difficulties with feeding and troubleshooting
- Discuss and/or demonstrate breast- and bottle feeding
- Demonstrate bottle assembly and provide resources as able
- Demonstrate positive (normal) aspects of physical examination
- Explain that the cleft is not their fault.
- Reassure that the child is not in pain.
- Review the signs and symptoms of illness, such as choking and airway obstruction.
- Arrange follow-up with specialists who can address the important issues that may be deferred in the newborn period.

(Young, O’Riordan, Goldstein, & Robin, 2001; Boyle et al., 2008)
References


