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Cleft Lip and Palate: Supporting Oral Feeding From Birth Through Palatoplasty

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Objectives

• Explain oral structures and their responsibility to support oral feeding
• Describe how commercial cleft bottles support more efficient oral intake with patients with cleft lip and palate
• List other interventions to support best outcomes for feeding
Embryology

- Clefting is the result of failure of fusion during embryonic development of the face.
- Can be caused by complex multi-factorial conditions: both genetic and environmental
  - Complex genetic interactions
  - Exogenous factors
    - Exposure to therapeutic agents, alcohol consumption, cigarette smoking, maternal nutritional status, folic acid deficiency, pregestational diabetes

Embryology, cont.

- 4th Week
  - Develop median frontonasal prominence and paired maxillary prominences and mandibular prominences
- End of 4th week
  - Inferior frontonasal prominence divides into medial and lateral nasal prominences
  - Nasal alae are formed by elevation of the lateral nasal prominences
- End of 6th week
  - Upper lip and primary palate complete formation by fusion of bilateral maxillary prominences with 2 medial nasal prominences.
**Embryology, cont.**

- **6th to 7th week (Secondary palate)**
  - Bilateral palatal shelves of maxillary processes begin vertical growth phase and transition to horizontal growth
  - Palatal shelves fuse in midline and fuse to primary palate anteriorly as well as with nasal septum

- **8th week**
  - Ossification occurs of anterior aspect of secondary palate (differentiates hard from soft palate)

- **10th week**
  - Palatal development is complete

(Hartzell et al, 2014; Development of The Palate, Review of MEDICAL EMBRYOLOGY, BEN PANSKY, Ph.D, M.D., 1982)

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**Embryologic Development**

- Well orchestrated process of cellular division which turns primitive tissue into muscles, nerves connective tissue and skeleton of head and face

Classification

- Unilateral or bilateral
- Incomplete or complete
  - Cleft Lip
    - Complete: cleft of lip and alveolus extending into floor of nose
    - Incomplete: intact nasal sill (may or may not involve a cleft alveolus)
  - Cleft Palate
    - Complete: primary and secondary palate
    - Incomplete: secondary palate but may be of the hard and soft palate, soft palate only or submucous cleft

- Clefts can occur of:
  - Cleft lip with or without cleft palate
  - Cleft palate
- Size and location impacts function
  - (Reid et al, 2007; Mizuno, 2002; Hartzell et al, 2014)

Impacts of Anatomy on Phases of Swallowing

- In infancy until repair
  - Oral Preparatory and Oral Phase
  - Pharyngeal Phase
  - Esophageal Phase
Statistics

- Incidence
  - 1 in 700
  - Syndromic malformation (over 400 syndromes implicated with orofacial clefting)
    - 10-37% for CL+-P
    - 40-50% for CP
- Incidence varies between racial groups
  - Higher rates in Asian populations, intermediate rates in white populations, low rates in African populations.


Associated Syndromes

- Chromosome Anomalies
- Opitz G/BBB
- OAV/FAV/Hemifacial Microsomia
- Amniotic Bands
- Diabetic Embryopathy
- Fetal alcohol syndrome
- CHARGE
- Van der Woude
- Popliteal Pterygium
- Ocular-facial-digital
- Stickler
- Velo Cardio Facial
Family Adjustment

- Critical to realize impact of infant with CL+-P
  - Increase of diagnosis in utero
    - Provides team time to prepare family with education regarding clefting and specifically initial care/feeding
  - Caregivers’ ability to provide adequate nourishment to their infant is integral to their development of a family that perceives themselves as capable.
    - Bonding, competence of caregiver and infant.
  - With expertise/education, can best support this.

(Lindberg et al, 2013; Martin et al, 2014; Sawicki, 2016)

Comprehensive Care

- Team provides global multidisciplinary care to assure all needs of pt and caregivers are addressed
- Disciplines will have varied roles throughout the infant/child’s care

(Tighe et al, 2011; Hartzell et al, 2014)

- Includes:
  - Family
  - Neonatologist
  - Pediatrician
  - Dietitian
  - Lactation
  - SLP
  - Nurse with specialization
  - Geneticist
  - Plastic Surgeon
  - Audiologist
  - ENT
  - Pediatric dentist
  - Psychologist
  - Orthodontist
  - Oral and maxillofacial surgeon
Therapeutic Feeding Assessment and Intervention

Newborn Stage

Successful Early Oral Feeding

Dependent upon ability to

- initiate and maintain coordinated suck-swallow-breathe sequences
- with adequate airway protection
- with vital signs stable
- for intake of recommended volume of BM/formula to support adequate nutrition and hydration for growth (weight, length, head circumference)

• Integral
  - Development of early infant-caregiver interaction/bonding for evolving family competence and confidence
Newborns Wired to Eat!

Building blocks for Success

• Intact anatomy
• Underlying/supportive systems
  • Neurological (tone, motor, organization, state)
  • Respiratory
  • GI
  • Cardiac
• Hunger drive

Infant Oral Feeding “Built for Efficient Oral Feeding”

• Small oral cavity
  • Buccal fat pads – lateral supports
  • Lips – support nipple and provide anterior seal
  • Tongue – fills oral cavity – seal along alveolar surface; maintains nipple in place; central groove/movement to channel intake backward
  • Intact palate – seals cavity, surface for compression
  • Physiological flexion
    • Head, neck, trunk alignment
• Supports
  • Non-nutritive and nutritive suck
    • Negative Pressure: suction
    • Positive Pressure: squeeze
  • Reliant upon
    • Sealed cavity
    • Surfaces for tongue to work off of
• Together work for efficient:
  • Bolus extraction
  • Bolus collection
  • Posterior Transfer
  • Pharyngeal swallow

continued
Cleftings Impact on Oral Feeding

- Cleft Lip
  - Decreased anterior seal affecting nipple positioning, negative and positive pressure and anterior loss
- Cleft palate
  - Decreased seal with affect on negative pressure
  - Decreased surface to work against affecting positive pressure
  - Opening to nasopharynx which allows for reflux
- Overall impact may include:
  - Decreased efficiency with reduced sucking effect
  - Increased anterior loss
  - Bolus collection
  - Posterior transfer (residue)
  - Piecemeal delivery to pharynx affecting SSB
  - Increased nasal reflux
  - Increased air swallowing
- Resulting in:
  - Increased feeding time
  - Decreased overall intake
  - Increased liquid loss
    - Anterior
    - Nasal reflux
    - Emesis
    - Premature satiation
- Affecting:
  - Growth, health, development and surgical timing

(Reid, 2007; Bissell, 2011)

Research Findings

Sucking Pattern in prospective cohort of non-syndromic CLP (n=50) and infants without cleft (n=20)

- Shorter sucking bursts
- Greater use of positive pressure
- Impacts of decreased ability to generate negative pressure during feeding (Mizuno, 2002; Reid, 2007)
  - Prolonged feeding times
  - Decreased intake
  - Decreased weight gain
Research Findings

In a systematic review completed by Reid (2004) interventions that showed moderate to strong evidence for use include:

• Use of squeeze bottle
• Providing supportive education for caregivers

Regarding family reports of education received (Young, 2001): families reported:

• Education must include good demonstrations of bottle and breast feeding.
• Education must include information about specialized bottle systems available.

Newborn Stage Feeding: Goal and Components of assessment

Goal: minimize effect of structural differences on function to maximize independent oral feeding

• History
• Physiological Considerations
• State/Endurance
• Positioning and Movement
• Oral Structures
• Oral Reflexes
• Non-Nutritive Oral-Motor Skills
• Secretion Management
• Oral Feeding/Clinical Swallowing Skills
• Additional Information
History

- Prenatal, delivery, perinatal concerns
- Additional diagnoses
- Feeding
  - How feeding completed
  - Success
  - Concerns

Physiological Considerations

- Evaluation at rest, with functional activities, feeding
- Respiratory rate:
  - Stable, elevated, breath hold, WOB, stridor
- Heart rate
  - Stable? Tachycardic/bradycardic?
- Color and changes
  - Stable or mottling, ruddy, dusky?
- Work of breathing (retractions)
  - Respiratory pattern remain calm or does infant/child “work” to pull in air?
- Oxygen saturation
  - Stable or desaturations?
- Effect of positioning on physiological system and functional skills
  - Non-nutritive and nutritive skills
State and Endurance

- Indicator of energy
- Rest/sleep important
- State maintenance and transitions
- Cues (clear, consistent)

Therapeutic Supports

- Protect rest
- Limit feeding time but regular feeding experience builds endurance
- If agitated, containment
- Caregiver involvement

Positioning and Movement

- Typical positioning
  - Physical flexion
- Observe
  - Tolerance of handling
  - Types/quality of movement
  - Supports needed
    Therapeutic Supports

- Positioning important for feeding:
  - Upright or elevated/side-lying
- Swaddling to assist organization
Oral Structures

• Symmetry of facial structures
• Cleft lip type
  • Unilateral, bilateral
  • Incomplete, complete, asymmetric
• Tongue position
  • Midline, neutral, retracted, protruded
  • Frenulum restrictive of movement?
• Cleft palate type
  • U-shape posterior soft palate
  • Unilateral, bilateral
  • Complete, incomplete, asymmetric

Assessment of oral structures

• Unilateral incomplete cleft lip (right side)
  • Minimal impact on feeding given appropriate support*
• Unilateral complete cleft lip (left side)
  • Flattening of nare
Assessment of oral structures

- Small, Unilateral incomplete midline cleft of soft palate.
- Large unilateral incomplete cleft of soft palate that extends into hard palate.
- Examples of common cleft palate types.
  - Can see variation with extent of opening and impact on surrounding tissues.

Consider impact on mucosa

- Monitor mucosa
Oral Reflexes, Non-Nutritive Oral-Motor Skills, and Secretion Management

• Oral Reflexes
  • Root, suck, swallow, gag
  • Should be prompt

• Non-Nutritive Sucking
  • Rhythmical with rate of 2 sucks/sec.
  • Fair strength, minimal suction
  • Should be able to maintain stable work of breathing

• Secretion Management
  • Excess secretions are indicator of decreased frequency or strength of swallow

Oral Feeding/Clinical Swallowing Skills

• Interest
  • Eager vs fair/poor
  • Acceptance, intake, volume

• Coordination of suck-swallow-breathe
  • Pacing
    • Self, requiring external

• Goal volume vs partial
• Length of time feeding
• Ability to accept assistive squeeze and manage bolus
  • Rate/force of assistive squeeze

• Vital sign stability, work of breathing
• Clinical signs of swallowing difficulty
• Caregiver skills
Breast Feeding

- Family goals should be discussed and education regarding clefting and breast feeding be provided
- Peer support
- To successfully BF
  - Suction necessary for: attachment to the breast, maintaining breast in mouth and extracting milk
  - Lips flange around breast to seal oral cavity
  - Compression
- Breast feeding trials should be supported: team approach
  - Lactation Specialist: individualized assessment of strengths/challenges
  - Individualized assessment
    - With cleft lip, may be successful
    - With cleft palate, consider impact of cleft on:
      - Negative pressure: latch/maintain nipple in mouth and extract fluid
      - Compression effect
      - Anterior seal

Breastfeeding Considerations

- Interventions:
  - Supplemental nursing system
  - Kangaroo Care
  - Critical to monitor weight gain and hydration
- Always support providing breast milk (pumping) for presentation in bottle if unable to breastfeed
  - Protective benefits of BM (Otitis media)

General Therapeutic Considerations

• Psychological Considerations
• Baseline Potential for Feeding Difficulties
• Anatomical Variation
• Association between craniofacial and other conditions
• Surgery and feeding outcome dependent on good preparation

THERAPEUTIC INTERVENTIONS- Newborns

GOAL: counseling and direct intervention to support best feeding practices
• Breastfeeding
• Bottle/Nipple Choices
• Oral Support
• Positioning
• Burping
Interventions-Breastfeeding

• Education/counseling increases breastfeeding rates (Alperovich et al., 2016; Burca et al., 2016; Reilly et al., 2013; Goyal et al., 2012; La Leche League International, 2004)
• Collaboration with IBCLC important
• Proper positioning

Adaptive Equipment

• Supplemental Nursing System (Shetty and Khan, 2016)
  • Assurance of delivery of nutrition
  • No altering method of presentation

Positioning and Strategies to Support Breastfeeding (Reilly et al., 2013)

• Hold so Cleft Lip is oriented toward top of breast
• Occlude CL with thumb and finger and/or support infant’s cheeks
  • to decrease width of cleft and closure around the nipple
• CL “face on”/straddle position may be more effective than other positions
• Semi-upright
  • reduce nasal regurgitation and reflux
• Position breast toward the side of the palate that has the most intact bone
  • facilitates compression and decrease nipple from being pushed into cleft side
• Support chin to stabilize jaw during sucking and supporting breast to it remains in infant’s mouth
Interventions-General Bottle Feeding Counseling

- Cue-based but awareness of goal
- Infant sets pace of feeding
- Avoiding grazing
- Adequate volume but not forcing
- Requesting help if concerns arise ASAP

Interventions-Nipples

Nipples: individualize to match infant’s structure, sensory processing, and function

- Shape
- Pliability
- Size/length
- Flow rate
- Holes/# and size
- Placement – maximize contact for increase affect
Interventions-Bottles/Nipples

- Adapted specifically for infants with cleft palate
  - Modified feeding systems increases feeding outcomes (Shetty, 2016; Reid, 2004; Devi et al., 2012)
- Allow volume with compression alone (*and their ability to produce positive pressure*)
- Allow added volume with assistive squeeze

Haberman Feeding System

- System that contains bottle, nipple with 3 flow rates, and one-way valve
  
  **Customizable**
- Can allow infant volume via compressions alone or via assistive squeeze.
- Line Lengths-Flow Rates
- Has “mini” version with shorter nipple
- Sanitizing bag system for hospital use
- Requires staff and parent education
- Requires specific feeding plan
Mead Johnson Cleft Lip/Palate Nursing System

• System: bottle and long, cross-cut nipple
• Can replace nipple with choice
  • Allows variability for flow rate and nipple shape
• Easy to assemble and use
• Can use compressions alone or assistive squeeze
• Should be accompanied with feeding plan specific to infant

Pigeon Nipple/Bottle

• System includes pliable bottle, Y-cut nipple, and one way valve
  • Underside of nipple is soft to maximize effect of compression
• Can allow infant volume with compressions alone or assistive squeeze
• Nipple size large for some infants.
• Cannot replace nipple.
• Requires staff and parent education regarding assembly and use
• Should be accompanied with feeding plan specific for infant.
Dr. Brown Specialty Feeding System

- Standard bottle with unidirectional valve

**BENEFITS**
- No assistive squeeze required
  - Liquid through infant compressions
  - Avoids mis-timing with assistive squeeze
- Range of Dr. Brown brand nipple flow rates to meet specific infant’s needs
- Cost
- Appears similar to standard bottles
- Ability to sanitize


Interventions-Oral Support

Decrease impact of opening by creating artificial closure
- Nipple size to fill the space
- Finger support to lip/cheek (Reilly et al., 2013)
- Obturator
### Interventions-Obturators: Acrylic Plate to Close Cleft Space

**GOAL**
- Provides surface to improve both compression and negative pressure effect (improve feeding/weight gain)
- Prevent maxillary segment collapse, irritation of nasal septum
- Decrease pharyngo-nasal reflux

**ISSUES**
- Poor fit
- Oral hygiene
- Need to replace due to rapid infant growth/cost
- Irritation


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### Interventions-Positioning

**Upright**
- Gravity assists with flow to decrease upward movement into nasal cavity

**Semi-Upright**
- Gravity supports flow and can decrease anterior loss by directing liquid posteriorly

**Side-lying**
- Gravity controls rate of flow
- Can alter elevation level

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### Interventions-Frequent Burping

- Swallowing excess air common
- Increased air swallowing
  - Premature satiation
  - Reflux
  - emesis
- Burping
  - Allow for maximal volume
  - Decrease emesis

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Brown, 2016  [http://www.right4education.org/all-topics/childcare/advice-on-breastfeeding-your-baby/](http://www.right4education.org/all-topics/childcare/advice-on-breastfeeding-your-baby/)
Feeding Plan

- Identifying information
- Brief description
- Bottle Used
- Positioning
- Feeding Supports
- Cues

Goals: Newborn Stage

Goals based on assessment

Samples

- Demonstrate oral intake of goal volume via ### bottle in <30 minutes without coughing, choking, or nasal regurgitation.
- Tolerate assistive squeeze via ### bottle and maintain interest and no aversive response such as increased congestion, coughing, choking, or nasal regurgitation.
- Caregivers will demonstrate ability to assemble adapted feeding bottle, position infant for feeding, provide feeding in appropriate time frame (<30 minutes) and respond to infant’s feeding cues.
Post-Operative-Lip Repair (Augsornwan et al., 2013)

- Differences by center with post-operative recommendations
- Concerns post-operatively focus on avoiding wound dehiscence
- No statistically significant differences with regard to wound dehiscence in patients who bottle/breast fed compared with those who were spoon/syringe fed (p=0.320)
- Parents of bottle/breast feeding more relaxed post-operatively

Therapeutic Intervention

Transitional Stage
- Puree/Solids
- Cup Drinking
Transitional Stage Feeding: Puree

- Timeline for Introduction: ~6 months
- Importance of beginning Puree
  - Promotes motor and sensory skills
- Concerns of Caregivers
- Considerations
  - Positioning Supports
  - Spoon Considerations
  - Trials and Reinforcement
  - Infant Responses

Positioning Options

- Options
  - High Chair/ Feeder Seat
  - Lap
- Positions
  - Semi-upright
  - Upright
- Time in chair
Spoons

- Size
- Bowl depth
- Texture
- Refillable

Trials and Reinforcement

- Begin as Experience
  - Acceptance and Experience vs Volume as goal
- Progress to 1-2 feedings/day
- Advance to 3 meals + 2 snacks
- Progress Volume as tolerated
Infant Responses

• Engagement vs. Disengagement
• Normal anterior-posterior tongue movement
• Allow messy face!
• Allow infants to participate

Goals: Puree

• Infant will demonstrate acceptance of dry spoon with licking and oral exploration.
• Infant will accept 3 small tastes of puree presented via spoon to anterior oral cavity without disengagement
• Infant will licking and swallowing and without increased congestion, coughing, or choking.
• Infant will demonstrate acceptance of spoon presentation of at least 5 bites with acceptance, initiation of oral movements and no disengagement cues.
Transitional Stage Feeding: Cup Drinking

- Timeline for Introduction: ~6 months
- Importance of beginning Cup Drinking
  - Promotes motor and sensory skills
    - Jaw stabilization
- Concerns of Caregivers

Cup Drinking: Materials and Equipment Considerations

- Lid vs open cup
- Spout vs no spout
- Valve vs no valve
- Straw/squeeze
Goals: Cup Drinking

- acceptance of tastes of formula via cup in single sips without signs of disengagement in at least 3 trials.
- small volumes (could specify 15 mls as example) of formula via cup in single sips without increased congestion, coughing, choking, or nasal regurgitation.
- acceptance of goal volume (95 mls) of formula via cup in single and chain swallows within 30 minute feeding period and no demonstrate signs of increased congestion, coughing, choking, or nasal regurgitation.

Therapeutic Intervention

Palatoplasty and Feeding

- Preparation
- Post-Operative
- Follow-Up
Palatoplasty and Feeding: Preparation

- Preparation begins from birth
  - Timeline
- At 6 months
  - Beginning trials via cup and puree via spoon
  - Ongoing practice with substantial amount of fluid via cup without difficulty
- Just before Surgery

Palatoplasty and Feeding: Immediate Post-Operative Period

- Multiple reasons feeding challenging on day of palate repair.
- NPO prior to procedure (hunger)
- Procedure often with associated needs
- Infant status following surgery
- Restraints to avoid hands to mouth
- All issues lead to stress and anxiety.
Palatoplasty: family experience

- Anxiety, stress, fear, concern
- Pain management
- Hunger
- Hydration
- Expectations

Materials/Thoughts to Support Feeding in Post-Operative Period

- Address pain and comfort
- Manage stress and anxiety
- Begin with small volume goals
- Consider sensation of foods
Palatoplasty and Feeding: Preparation for discharge and follow-up

• Goal for Discharge
  • Feeding
• Expectations
• Education Prior to Discharge
  • Nutrition and Hydration
• Follow-Up Plan

In Closing…

• Infants with craniofacial anomalies run the spectrum with regard to feeding
• Intake and success greatly impacted by endogenous and exogenous factors
• Support success with
  • Education
  • Support
  • consistency
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