Breastfeeding Essentials for Infants with Orofacial Clefting

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Disclosures

Kristen DeLuca

- Financial: Salaried employee of Joe DiMaggio Children's Hospital, Honorarium from Dr. Brown's Medical for today's webinar
- Non-Financial: ASHA SIG-5 Coordinating Committee Member

Raquel Garcia

- Financial: Salary as as Assistant Professor Nova Southeastern University, Hourly PRN for Joe DiMaggio Children's Hospital, Honorarium from Dr. Brown's Medical for today's webinar
- Non-Financial: FLASHA Executive Board Member, Hispanic Caucus, ASHA SIG 13 Coordinating Committee Member, Feeding Matters Conference Committee, NANT Peer Reviewer, NANT Conference Committee

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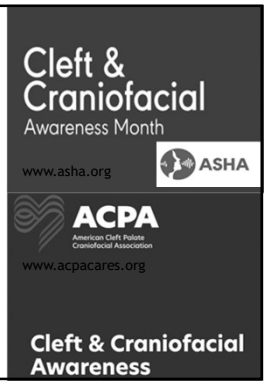
Learner Outcomes

- Examine the role of prenatal counseling for expectant families of neonates with orofacial clefts
- Determine at least one barrier for direct breastfeeding in infants with cleft palate +/- cleft lip
- Propose at least two strategies to support direct breastfeeding and/or breast milk feeding mothers of infants with cleft palate +/- cleft lip



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Orofacial Cleft Incidence and Classifications

Cleft lip and/or palate is among the most common birth defects in the United States

Occurs in approximately 1 of every 500 live births

Hammond & Dixon (2022)

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Embryonic Period

- Weeks 1-8 of gestation
- Most major organs and systems development
  - Brain
  - Spinal Cord
  - Heart
  - Central Nervous System
  - Cardiovascular System
- Most head and face development
  - Face morphology
  - Lip fusion
  - Mandibular and maxillary prominences appear (7-8 weeks gestation)
  - Hard Palate and velum fusion (7-8 weeks gestation)
  - Division of nasal cavity (8-10 weeks gestation)

Son & Naidich (2014)

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Risk Factors

Teratogen Exposure

Family History

Folic Acid

Maternal/Paternal Age

Prenatal Care

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Oral Motor Development

Swallowing & Feeding

- Pharyngeal swallow present in utero
  - 14-17 weeks
- Consistently swallowing
  - 22-24 weeks
- Potential for oral feeding practice
  - 33-34 weeks (PMA)
- Oral feeding skill development
  - 35 weeks & older (PMA)

Delaney & Arvedson (2008)

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Oral Motor Physiology

Seal Compression Suction

*** This is a pressure-driven system***

Duarte, et. al, (2016)

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Normal Infant Feeding/Swallowing

- Lip seals around nipple
- Tongue cups nipple
- Tongue moves up/down and presses against hard palate
  - Creates positive pressure to compresses nipple
  - Creates negative pressure to draw fluid from nipple

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Orofacial Cleft Impact on Feeding/Swallowing

Anatomical/Structural Deficiency

- Infants with isolated cleft lip and palate have feeding difficulties due to the inability to create negative pressure during feeding caused by a structural deficit
- Isolated cleft lip and/or cleft palate has minimal to moderate effect on feeding success
- Degree of feeding difficulty varies upon cleft type and severity of cleft

Feeding difficulties are due to atypical mechanical function vs. neurobehavioral disorder

Madhoun, et. al, (2020)

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> Cleft Palate Craniofac J. 2007 May;44(3):312-20. doi: 10.1597/05-173.

Sucking performance of babies with cleft conditions

Julie Reid [1], Sheena Reilly, Nicky Kilpatrick

Affiliations + expand

PMID: 17477747 DOI: 10.1597/05-173

Reid et al. (2007)

- Infants with CL demonstrated similar suction (negative pressure)/compression (positive pressure) as non-cleft babies
- Infants with CL + P did not generate suction
- Infants with CP only varied:
  - Complete CP = no suction
  - Small soft palate cleft = generated some suction (decreased with increase duration of feeding)
- Increased feeding efficiency found to be related to the ability to create pressures

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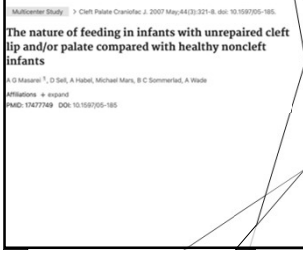
Masarei et al. (2007)



Multicenter Study > Cleft Palate Craniofac J. 2007 May;44(3):321-8. doi: 10.1597/05-185.

The nature of feeding in infants with unrepaired cleft lip and/or palate compared with healthy noncleft infants

A G Masarei [1], D Sell, A Habel, Michael Mars, B C Sommerlad, A Wade

Affiliations + expand

PMID: 17477749 DOI: 10.1597/05-185

Infants with UCLP or ICP used the following when compared to non-cleft infants:

- Shorter sucking bursts
- More sucks per minute (faster rate)
- Shorter suck duration
- Increase in positive pressure (compression)
- Higher suck/swallow ratios
  - 2.97:1 vs. 1.20: 1

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Infant Cleft MBSS

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Cleft Lip & Breastfeeding

Seal	Impaired
Compression	Normal Positive pressure • Can be achieved if NO palatal involvement
Suction	Normal Negative Pressure • Can be achieved if NO palatal involvement

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Cleft Lip and Palate & Breastfeeding

Seal	Impaired
Compression	Impaired Positive Pressure • Increase in positive pressure
Suction	Impaired Negative Pressure • Can not create negative pressure

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Cleft Palate & Breastfeeding

Seal	Intact
Compression	Impaired Positive Pressure • Increased in positive pressure
Suction	Impaired Negative Pressure • Varies dependent on cleft type • Decreases as feeding duration increases

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Research to Practice:
Recommendation for Direct Breastfeeding

Cleft Lip Only	Cleft Lip and Palate	Complete Cleft Palate only	Cleft of the Soft Palate
Recommended	Not Recommended	Not Recommended	Guarded: If recommended : • Needs CLOSE monitoring • Professional collaboration to support mother and infant

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Clinical Protocol Guidelines

> Breastfeed Med. 2019 Sep;14(7):437-444. doi: 10.1089/bfm.2019.29132.job. Epub 2019 Aug 13.

ABM Clinical Protocol #17: Guidelines for Breastfeeding Infants with Cleft Lip, Cleft Palate, or Cleft Lip and Palate–Revised 2019

Jessica O Boyce [1 2], Sheena Reilly [2 3], Jemma Skeat [1], Petrea Cahir [4]; Academy of Breastfeeding Medicine

Collaborators, Affiliations + expand

PMID: 31408356 DOI: 10.1089/bfm.2019.29132.job

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Breast Milk Feeding Practices (Kaye et. al, 2018)

- Breast Milk Feeding Practices:
  - 78% reported they initiated either direct breastfeeding or EBM following the birth of their baby
  - Median duration of human milk provision was 4 months
  - 41% reported they provided some human milk for at least 6 months
  - 10% of mothers provided human milk exclusively
- Reported Reasons for Cessation:
  - Lost supply primary factor, too time consuming, infant's health
- When asked about challenges:
  - Loss of supply, too time consuming, and pain with pumping

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Breastmilk Feeding Practices (Madhoun et. al 2019)

- Objective: Understand US rates of breastfeeding and/or breastmilk provision for infants with CL/P, feeding practices and attitudes, breastmilk provision duration and barriers and supports to breastfeeding or breastmilk provision.
  - 46% of mothers reported that breastmilk was provided until at least 6 months (direct breastfeeding, provided EBM via bottle, or both)
  - Feeding at the breast alone was typically only successful for infants with CL
  - Most mothers pumped and provided breast milk via bottle
    - 59% used the Dr. Brown's Specialty Feeding System by Handi-Craft
    - 15% used the Pigeon Specialty Feeding System by Philips
    - 13% used the SpecialNeeds Feeder by Medela
    - 7% used a standard bottle
    - 4% used other feeding means
    - 2% used Mead Johnson Cleft/lip-Palate Nurser by Enfamil

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Maternal-Reported Barriers Inhibiting Breastfeeding and Pumping (Madhoun et. al 2019)

Breastfeeding

- Difficulty Getting Milk (83%)
- Trouble Latching On (64%)
- A health professional said baby not gaining weight (41%)
- I thought my baby was not gaining enough weight (37%)

Pumping

- Pump worked, but did not get enough/much milk (49%)
- Pump was uncomfortable or painful to use even thought it did not cause injury (48%
- Pump worked, but it took too long to get enough milk (26%)

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Cleft Feeding Differences

Difficulty expressing from traditional nipple

Inefficient or ineffective compression & suction

Nasal regurgitation

Noisy / wet breathing

Excessive air intake

Inadequate volume of oral intake

Madhoun, et. al, (2020)

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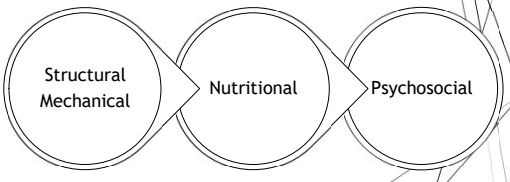
Direct Interventions for Infants with Cleft Palate +/- Lip

Direct interventions addresses



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Direct Interventions for CLAP: Structural/Mechanical

Device Selection

- Spoon/Dropper for colostrum feedings in first 1-3 days
- Adaptative Bottles
- Supplemental Nursing System (SNS by Medela)

Positioning

- Position infant in semi-inclined, 60+ degree angle
  - Assists with posterior transfer of bolus
  - Decreases tendency of nasopharyngeal reflux
- If breastfeeding, CL oriented toward top of breast
  - Football hold, "face-on" straddle (aka: upright football or koala hold)

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Device Selection

- Video

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Positioning

- Video

- Video

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Positioning

https://womenshealthtoday.blog/2018/01/11/breastfeeding-with-a-cleft-lip-and-cleft-palate/

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Direct Interventions: Structural/Mechanical

- Technique: Provide lip, cheek, and chin support
- Rationale: Facilitates sucking movements and promotes jaw stabilization

- Technique: External pacing
- Rationale: To aid/prevent disorganized SSB and help maintain appropriate respiratory patterns

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Direct Interventions: Structural/Mechanical

- Technique: Frequent Burping

- Rationale: Expels air that is ingested during swallowing. Infants with clefts ingest more air than a non-cleft infant. Burping helps to alleviate stomach discomfort and reflux

- Burp the infant every 1-2 ounces or during natural breaks in feeding

**Feeding smaller volumes more frequently may reduce discomfort and/or signs of reflux.

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Direct Interventions : Nutritional

- Smaller, more frequent feedings may reduce fatigue, decrease gas intake and/or reflux which in turn improves weight gain
- Feeding log recommended for 3 days to track 24 hour volume and feeding times
- Weekly weight checks
- If direct breastfeeding, recommend using pre-post feeding weight to estimate volume intake per feed

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Direct Interventions: Nutritional

- Fortified Feedings
  - Breastmilk generally considered to be 20 kcal/ounce, however varies dependent on mother and external factors including mother's diet, foremilk/hindmilk composition
    - Work with lactation consultant to improve breastmilk quality (supplements, use "hand-on" pumping)
  - Increased caloric density of Breastmilk and/or Formula
    - Human Milk Fortifier Powder or Infant Powder Formula can be added to pumped breastmilk to increase calories per ounce (guided by dietitian)
    - Standard Formula (20 kcal/ounce)
    - Specialized Formula (calories per ounce vary)

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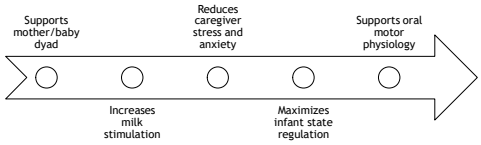
Direct Interventions for Psychosocial: Skin to Skin



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Direct Interventions for Psychosocial: Pumping Support

Prevents engorgement of the breasts	Reduces the risk of plugged milk ducts	Treats plugged milk ducts should they occur
Reduces the risk of mastitis	Maintains milk supply	Prevents suppressed lactation

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Pumping Strategies

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What is Hand-Expression (HE)

Image owner, Dr. Jane Morton, used with approval

- Expressing milk by hand
- Generally under the Lactation Consultants scope of practice to teach HE during post-natal period, however, it's been reported to be an under-utilized skill
- Research demonstrates that HE can encourage early initiation of milk and increase later milk supply
- www.firstdroplets.com

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Morton et al, (2009)

Comparative Study > J Perinatol. 2009 Nov;29(11):757-64. doi: 10.1038/jp.2009.87. Epub 2009 Jul 2.

Combining hand techniques with electric pumping increases milk production in mothers of preterm infants

J Morton [1], J Y Hall, R J Wong, L Thairu, W E Benitz, W D Rhine

Affiliations + expand

PMID: 19571815 DOI: 10.1038/jp.2009.87

Milk production was influenced by 3 factors:

- Pumping frequency in the first 2 weeks (not weeks 3-8)
- Frequency of hand expression, days 1-3
- Hands-on pumping after lactogenesis

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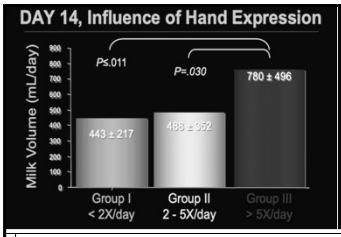

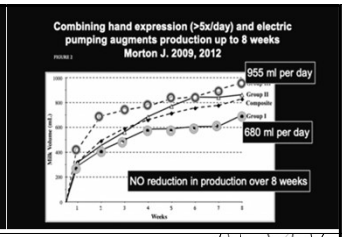

Morton et al, (2009)

Image owner, Dr. Jane Morton, used with approval

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Morton et al, (2012)

J Perinatol. 2012 Oct;32(10):791-6. doi: 10.1038/jp.2011.195. Epub 2012 Jan 5.

Combining hand techniques with electric pumping increases the caloric content of milk in mothers of preterm infants

J Morton [1], R J Wong, J Y Hall, W W Pang, C T Lai, J Lui, P E Hartmann, W D Rhine

Affiliations + expand

PMID: 22222549 DOI: 10.1038/jp.2011.195

Free article

Findings: Higher FAT composition AFTER using hands-on pumping

- >5000 samples from 52 mothers
  - Mothers contributed samples from each breast from each pumping session over 24 h once weekly for 8 weeks.
  - Protein and glucose tracked reported norms
  - Fat and caloric value increased
    - 62.5g/l fat (typical range is between 25-45 g l)
    - 892.7 cal/l = 26.4 cal/oz
    - Unrelated to production differences

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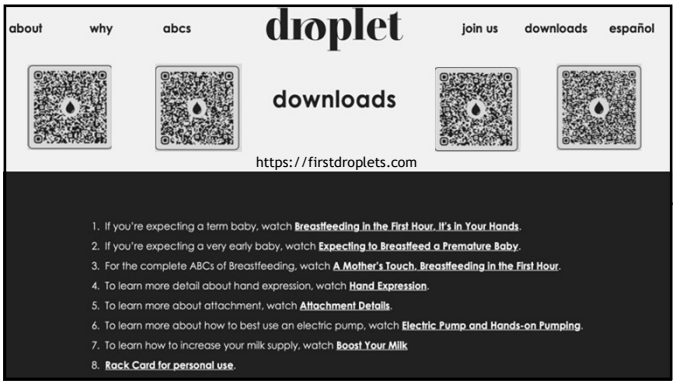

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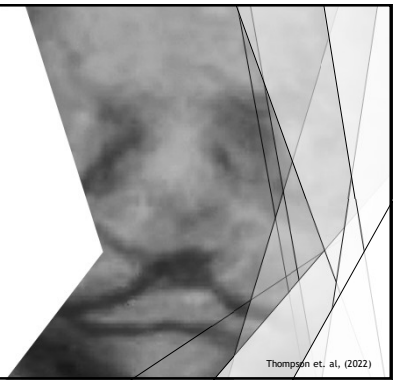
Prenatal Counseling



Thompson et. al, (2022)

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Prenatal Counseling

QOL

Decrease LOS

Confidence

Reduces Stress/Anxiety

Thompson et. al, (2022)

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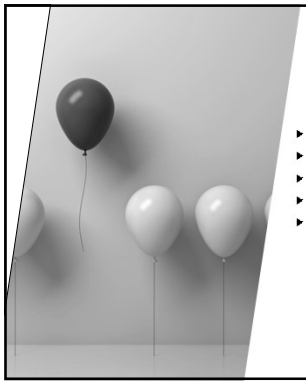

Prenatal Counseling Limitations

- Reimbursement
- Productivity Standards
- Institution support
- Scheduling conflict
- Low/reduced access communities

Coste et. al. (2022)

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Prenatal Counseling at a Craniofacial Institution

- Adaptive bottles
- Caregiver's preferences for feeding
- Hand Expression
- Colostrum feedings
- Pumping
- Letter of Medical Necessity for Pump

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Case Study (Baby A)

- 35 weeker, female born at a community hospital
- Admitted to NICU due to prematurity, small VSD, cleft of the soft palate and feeding difficulties
- Family reached out to our Craniofacial Team on day 6 of life with primary concern of feeding
- Reported discrepancies between recommendations for feeding amongst providers within the hospital
- Scheduled a telehealth feeding consult at 7 days of life

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Case Study (Baby A)

- Intraoral before/after

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Case Study (Baby A)

- Infant was on a PO/NG feeding plan, every 3 hours, goal was 60 ml per feed with a total volume of 16 ounces in a 24 hour period
- Mother was pumping EBM and supplementing with formula
- Feeding consult:
  - Immediate latch to nipple, 1:1 suck/swallow ratio, with audible gulping, anterior bolus loss, mild stress cues, and had one instance of desaturation to low 90's with slight color change. Nipple was discontinued – a total of 15 ml was accepted over 2 minutes.
  - Switched to preemie nipple and although suck/swallow ratio increased, no audible gulping, stress cues or desaturations were observed. Infant accepted another 15 ml in 3.5 minutes
  - Recommended Dr. Brown's Specialty Feeding System with preemie nipple. Also recommended smaller more frequent feedings due to A's fatigue with feedings. This was approved by the hospital as one parent was always present and able to feed infant
  - Mother had a strong desire to breastfeed. Discussed the importance of skin-to-skin and continued pumping with hospital-grade pump and lactation consultant f/u. Plan was to use the Dr. Brown's SFS bottle with the goal of discontinuing the NG tube and being discharged home

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Case Study (Baby A)

- Discharged home day of life 12
- Supported mother in desire to direct breastfeed with the help of lactation consultant

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Resources for Clinicians

American Cleft Palate & Craniofacial Association
- ▶ https://acpa-cpf.org

Cleft Lip & Palate Association
- ▶ clapa.com

Leaders Project
- ▶ leadersproject.org

First Droplets
- ▶ firstdroplets.com

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