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

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A central goal of the Academy of Breastfeeding Medicine is the development of clinical protocols for managing common medical problems that may impact breastfeeding success. These protocols serve only as guidelines for the care of breastfeeding mothers and infants and do not delineate an exclusive course of treatment or serve as standards of medical care. Variations in treatment may be appropriate according to the needs of an individual patient.

Definitions

HEN A CLEFT LIP (CL) OCCURS, the lip is not contiguous, and when a cleft palate (CP) occurs, there is communication between the oral and nasal cavities. Clefts can range in severity from a simple notch in the upper lip to a complete opening in the lip extending into the floor of the nasal cavity and involving the alveolus to the incisive foramen. Similarly, CP may involve just the soft palate or extend partially or completely through the hard and soft palates. In CP, the alveolus remains intact. A CP may be submucous and not immediately detected if there are subtle or no corresponding clinical signs or symptoms.

Background

Incidence

The worldwide prevalence of CL and/or CP (CL/P) ranges from 0.8 to 2.7 cases per 1,000 live births.³ There are differences in incidence rates across racial groups, with the lowest reported incidence among African-American populations (approximately 0.5 per 1,000)^{4,5} and white populations (approximately one per 1,000 births)³ and higher incidence among Native American (approximately 3.5 per 1,000)⁶ and Asian (approximately 1.7 per 1,000)⁷ populations.

Although reports vary considerably, it is estimated that out of the total number of infants with CL/P, approximately 50% have combined cleft lip and palate (CLP), whereas 30% have isolated CP, and 20% have isolated CL; CL extending to include the alveolus occurs in approximately 5% of cases. Clefts are usually unilateral (Fig. 1); however, in approximately 10% of cases, clefts are bilateral.

Breastfeeding and CL/P

In these guidelines, breastfeeding refers to direct placement of baby to the breast for feeding, and breastmilk feeding refers to delivery of breastmilk to baby via bottle, cup, spoon, or any other means except breast. Babies use both suction and compression to breastfeed successfully. The ability to generate suction is necessary for attachment to the breast, maintenance of a stable feeding position, and, together with the let-down reflex, milk extraction. Normally, when a baby is feeding, his or her lips flange firmly against the areola, sealing the oral cavity anteriorly. The soft palate rises up and back to contact the pharyngeal walls and seal the oral cavity posteriorly. As the tongue and jaw drop during sucking, the oral cavity increases in size, and suction is generated, drawing milk from the breast. 10 Compression occurs when the baby presses the breast between the tongue and jaw. Suction and compression help milk transfer delivery during breastfeeding. 10-12

There is a relationship between the amount of oral pressure generated during feeding and the size/type of cleft and maturity of the baby. ¹³ For this reason, babies with CL are more likely to breastfeed than those with CP and CLP. ¹⁴ Some babies with small clefts of the soft palate generate suction, ¹⁵ but others with larger clefts of the soft and/or hard palate may not generate suction. ^{15,16} Newborns and premature babies generate lower suction pressures compared with older babies. ^{13,17,18} Babies with CP or CLP have difficulty creating suction ¹⁹ because the oral cavity cannot be adequately separated from the nasal cavity during feeding. For these infants, negative consequences may include fatigue during breastfeeding, prolonged feeding times, and impaired growth and nutrition.

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FIG. 1. Unilateral cleft lip. Photo courtesy of John A. Girotto, MD.

The literature describing breastfeeding outcomes is limited, and the evidence is anecdotal and contradictory, making the recommendations that follow challenging.²⁰

Recommendations

Quality of evidence (levels of evidence I, II-1, II-2, II-3, and III) for each recommendation, as defined in the U.S. Preventive Services Task Force Appendix A Task Force Ratings, ²¹ is noted in parentheses.

Summary of recommendations for clinical practice

Based on the reviewed evidence, the following recommendations are made:

- 1. Mothers should be encouraged to provide the protective benefits of breastmilk. Evidence suggests that breastfeeding protects against otitis media, which is highly prevalent in this population. (II-2) Breastmilk feeding (via cup, spoon, bottle, etc.) should be promoted in preference to artificial milk feeding. Additionally, there is speculative information regarding possible benefits of breastfeeding versus bottle feeding on the development of the oral cavity.
- At the same time, mothers should be counseled about likely breastfeeding success. Where direct breastfeeding is unlikely to be the sole feeding method, the need for breastmilk feeding should be encouraged, and, when appropriate, possible delayed transitioning to breastfeeding should be discussed.
- 3. Babies with CL/P should be evaluated for breastfeeding on an individual basis. In particular, it is important to take into account the size and location of the baby's CL/P as well as the mother's wishes and previous experience with breastfeeding. There is moderate evidence to suggest that infants with CL are able to generate suction¹⁹ (III), and descriptive reports suggest that these infants are often able to breastfeed successfully.²⁴ (III) There is moderate evidence that infants with CP or CLP have difficulty generating suction¹⁵ (I) and have inefficient sucking patterns¹⁶ (I) compared with normal infants. The success rates for breastfeeding infants with CP or CLP are observed to be lower than for infants with CL or no cleft.^{14,24} (III) (Appendix)

4. As in normal breastfeeding, knowledgeable support is important. Mothers who wish to breastfeed should be given immediate access to a lactation specialist to assist with positioning, management of milk supply, and expressing milk for supplemental feeds. Several studies have suggested that there is a need for and benefit from having access to a health professional who specializes in CL/P, such as a clinical nurse specialist, during the newborn/infant periods for specialized advice on feeding a baby with CL/P as well as referrals to appropriate services. Surveys of parents with a child with CL, CLP, or CP indicated a desire for more instruction on feeding challenges as early as possible. [III]

- Families may benefit from peer support around breastmilk feeding or breastfeeding found through associations like Wild Smile²⁷ in addition to routine referral to breastfeeding support groups.
- 6. Monitoring of a baby's hydration and weight gain is important while a feeding method is being established. If inadequate, supplemental feeding should be implemented or increased. (See "ABM clinical protocol #3: Hospital guidelines for the use of supplementary feedings in the healthy term breastfed neonate, revised 2009."²⁸) Infants with CL/P may require supplemental feeds for adequate growth and nutrition.²⁴ (III) There is one study that demonstrated that additional maternal support by a clinical nurse specialist can both improve weight gain outcomes and also facilitate referral to appropriate services.²⁹ (III)
- 7. Modification to breastfeeding positions may increase the efficiency and effectiveness of breastfeeding. Positioning recommendations that have been recommended on the basis of weak evidence (clinical experience or expert opinion) and should be evaluated for success are: a. For infants with CL:
 - i. The infant should be held so that the CL is oriented toward the top of the breast^{30,31} (for example, an infant with a [right] CL may feed more efficiently in a cross-cradle position at the right breast and a "football/twin style" position at the left breast). (III)
 - ii. The mother may occlude the CL with her thumb or finger^{31,32} and/or support the infant's cheeks to decrease the width of the cleft and increase closure around the nipple.³³ (III)
 - iii. For bilateral CL, a "face on" straddle position may be more effective than other breastfeeding positions.³¹ (III)
 - b. For infants with CP or CLP:
 - i. Positioning should be semi-upright to reduce nasal regurgitation and reflux of breastmilk into the Eustachian tubes. 31,32,34–36 (III)
 - ii. A "football hold"/twin position (the body of the infant positioned alongside the mother, rather than across the mother's lap, and with the infant's shoulders higher than his or her body) may be more effective than a cross-cradle position.³⁶ (III)
 - iii. For infants with CP it may also be useful to position the breast toward the "greater segment"—the side of the palate that has the most intact bone. This may facilitate better compression and stop the nipple being pushed into the cleft site.³⁷ (III)

- iv. Some experts suggest supporting the infant's chin to stabilize the jaw during sucking³² and/or supporting the breast so that it remains in the infant's mouth.^{33,38} (III)
- V. If the cleft is large, some experts suggest that the breast be tipped downward to stop the nipple being pushed into the cleft.³⁰ (III)
- vi. Mothers may need to manually express breastmilk into the baby's mouth to compensate for absent suction and compression and to stimulate the let-down reflex.³⁸ (III)
- 8. If a prosthesis is used for orthopedic alignment prior to surgery, caution should be used in advising parents to use such devices to facilitate breastfeeding, as there is strong evidence that they do not significantly increase feeding efficiency or effectiveness.^{39,40} (III)
- 9. Evidence suggests that breastfeeding can commence/ recommence immediately following CL repair and that breastfeeding may be slightly more advantageous than spoon feeding. ^{41,42} (I) Breastfeeding can commence/recommence 1 day after CP repair without complication to the wound. ⁴¹ In a survey of CP surgeons regarding postoperative care after palatoplasty, two-thirds of surgeons allowed mothers to breastfeed immediately after surgery. ⁴³ (III)
- 10. Assessment of the potential for breastfeeding of infants with CL/P as part of a syndrome/sequence should be made on a case-by-case basis, taking into account the additional features of the syndrome that may impact on breastfeeding success.

Recommendations for future research

The most pressing issue for healthcare professionals working with mothers who wish to breastfeed their infants with CL/P is the lack of evidence on which to base clinical decisions. Well-designed, data-driven investigations that document feeding success rates, management strategies, and outcomes for infants with CL/P are imperative. Furthermore, investigators must clearly describe their sample of infants and intervention techniques so that the research outcomes are able to be generalized.

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Appendix: Frequently Asked Questions

Breastfeeding infants with CL, CP, or CLP

Except where noted, the literature reviewed relates to infants with non-syndromic clefts of the lip and/or palate.

1. Can infants with CL breastfeed successfully? There is no strong evidence with regard to breastfeeding of infants with CL. There was moderate (II-2) evidence that babies with CL create suction during feeding. Descriptive (III) studies have demonstrated successful breastfeeding at rates approaching the normal population. Expert opinion (III) suggests that infants with CL may find breastfeeding relatively easier than bottle feeding because the breast tissue molds to the cleft and occludes the defect more successfully than an artificial nipple. Expert opinion suggests that modifications to positioning can facilitate breastfeeding for these infants. 30-33

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ABM protocols expire 5 years from the date of publication. Evidence-based revisions are made within 5 years or sooner if there are significant changes in the evidence.

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- 2. Can infants with CP breastfeed successfully?
 - There is no strong evidence with regard to breastfeeding infants with CP. There was moderate (II-2) evidence that infants with CP do not create suction when bottle feeding. ^{15,19} Although infants with clefts of the soft palate may be able to create suction, this is not usually the case. ^{13,15} Descriptive studies indicate that breastfeeding success for infants with CP is much lower than for infants with CL. ^{25,31} There was weak (III) evidence to suggest that partial breastfeeding (with supplementation) can be achieved and that the size and location of the cleft are determining factors for breastfeeding success. ^{35,36,45} As with infants with CL, modifications to positioning are reported to increase breastfeeding success. ^{30,31,34–36} (III)
- Can infants with CLP breastfeed successfully?
 There is no strong evidence with regard to breastfeeding infants with CLP. There was moderate (II-2) evidence that infants with CLP are unable to create suction

when measured using a bottle ^{13,15,19} and moderate to weak evidence that infants with CLP are sometimes able to breastfeed successfully. ²⁶ Descriptive studies suggest breastfeeding success rates ranging from 0% to 40%. ^{22,23} Modifications to positioning to increase breastfeeding success are recommended by experts. ^{29,30,32,35,36,38} (III)

- 4. Is there evidence to guide assessment and management of breastfeeding in infants with CL/P? Aside from strong evidence regarding the use of palatal obturators (considered separately), there was moderate evidence (II-3) that lactation education is important to facilitate feeding efficiency in infants with CL/P.⁴⁶ The remaining evidence is weak (III) and focuses on (a) areas for monitoring and (b) recommendations for supplementation.
- 5. Is there evidence that palatal obturators facilitate breastfeeding success with infants with CLP or CP? Breastfeeding outcomes may be affected by the use of feeding plates (which obturate some of the cleft and attempt to "normalize" the oral cavity for feeding)³⁹ or presurgical orthopedics (prosthesis to reposition the cleft segments prior to surgery). These are collectively referred to as "obturators" for this report. There was strong (I) evidence that obturators do not facilitate feeding or weight gain in breastfed babies with CLP39 and that they do not improve the infant's rate of bottle feeding. 40 There was moderate (II-2) evidence that obturators do not facilitate suction during bottle feeding. 18 This is because obturators do not facilitate complete closure of the soft palate against the walls of the throat during feeding. Contradictory evidence exists supporting the use of obturators to facilitate breastfeeding in infants with CP or CLP, but it is from much weaker sources.^{29,44,46} (II-2, III)
- 6. Is there evidence for additional benefits of breastfeeding for infants with CL/P compared with the normal population?
 - Several moderate to weak (II-2) studies exist, with the majority of evidence representing expert opinion (III). It is well accepted that breastfeeding and breastmilk feeding convey positive benefits to both mother and baby. With regard to babies with CP, there was mod-

- erate to weak evidence that feeding with breastmilk protects against otitis media in infants with CP. ^{22,47} These babies are more prone to otitis media than the general population because of the abnormal soft palate musculature. ⁴⁷ There was moderate to weak evidence that breastmilk can promote intellectual development and school outcomes in babies with clefts. ⁴⁸ Antibacterial agents in breastmilk promote postsurgical healing and reduce irritation of mucosa (compared with artificial milk). ⁴⁹ (III) Additionally, experts have suggested that breastfeeding facilitates the development of oral facial musculature, ²⁹ speech, ^{29,36} bonding, ³⁶ and pacifying infants postsurgery. ^{29,45}
- 7. Is there evidence to indicate when it is safe to commence/recommence breastfeeding following surgery for lip or palate?
- CL repair (cheiloplasty) is generally carried out within a few months of birth, and CP repair (palatoplasty) often takes place between 6 and 12 months of age. There are several studies that have yielded strong evidence to inform this area (I, II-2). There is moderate to strong evidence (I, II-2) that it is safe to commence/recommence breastfeeding immediately following CL repair, and there is moderate evidence (II-2) for initiating breastfeeding 1 day after CP repair. There is strong evidence (I) that breastfeeding immediately following surgery is more effective for weight gain, with lower hospital costs, than spoon feeding. Contradictory evidence exists, but it is from weaker sources (III) and is divided as to recommendations.
- 8. Is there evidence to indicate whether infants with CP as part of a syndrome/sequence are able to breastfeed? There are over 340 syndromes in which CL/P appears. It is beyond the scope of this protocol to review and make recommendations for them all in detail. However, some key data are presented to guide breastfeeding practice. Moderate to weak evidence suggests that, as well as the cleft, the additional oral facial anomalies associated with these syndromes (e.g., hypotonia, micrognathia, glossoptosis) impact feeding success. 35,50,51 It is important to examine the influence of all anomalies on feeding and design treatment with this in mind.