# Clinical Issues in Neonatal Care



Continuing Education

## Promoting Breast Milk Nutrition in Infants With Cleft Lip and/or Palate

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#### ABSTRACT

**Background:** The orofacial defect of cleft lip/palate (CL/P) involves an altered physiological anatomy that affects the infant's feeding ability. Infants have cleft lip (CL), cleft palate (CP), or both (CL/P). Dysfunction in the seal, as with cleft lip, or in the ability to coordinate muscle movement to generate negative pressure, as with cleft palate, leads to feeding issues that may compromise growth and affect bonding.

**Purpose:** The purpose of this article is to present (1) scientific evidence that supports clinical feeding practices for the infant with CL/P and (2) teaching strategies for staff and parents.

**Methods:** Evidence was synthesized using a narrative review of randomized controlled trials, qualitative studies, systematic reviews, professional guidelines, and position statements. Findings were used to present specialized equipment and feeding techniques to support human milk feeding.

**Findings:** Special considerations for feeding infants with CL/P include assessing the infant's sucking ability, demonstrating proper breastfeeding positioning, supporting mothers to establish and maintain their milk supply, considering adaptive feeding equipment (ie, specialized bottles and nipples), and education about the benefits of human milk.

**Implications for Practice and Research:** Support from healthcare professionals, particularly lactation specialists and nursing staff, is critical. Breastfeeding and the use of human milk should be prioritized and supported. Research is needed to explore environmental, genetic, and nutritional causes (eg, folic acid deficiency) of orofacial defects.

Key Words: breastfeeding, cleft feeding, cleft lip, cleft palate, craniofacial disorders, human milk

CP) are congenital orofacial structural defects that occur when the infant's lip or mouth fails to develop properly.<sup>1</sup> A CL is defined as an opening between the mouth and the nose, whereas a CP is an opening at the roof of the mouth between the oral and nasal cavities. Both orofacial defects have varying degrees of severity. A CL ranges from a slight notch on the upper lip to an extension into the nose, whereas a CP ranges in severity from an opening of the soft palate to an extension into

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the hard palate. Although a CL has a visible presentation, a CP may not be immediately detected.<sup>2</sup> Infants may present with CL, CP, or both. In this article, cleft lip and/or palate will be referenced as "CL/P."

CL/P incidence varies with ethnicity, race, geographic origin, and socioeconomic status.<sup>3</sup> In 2003, the World Health Organization (WHO) estimated an oral cleft incidence of 1 per 700 live births each year internationally.<sup>4</sup> The incidence of CL/P is approximately 1 per 800 live births in the United States, which is low in contrast to 1 per 500 live births in developing countries.<sup>5</sup> The condition is a result of genetic and environmental factors.<sup>6</sup> Maternal deficiency in folic acid and exposure to certain medications, nicotine, and alcohol may also lead to the development of congenital orofacial defects in infants.<sup>3</sup>

The presence of a CL/P compromises the precise synchronization of sucking, swallowing, and breathing necessary for feeding.<sup>7</sup> The ability to generate suction is created when the lips seal the anterior oral cavity while the soft palate seals the posterior oral cavity. Infants with CL/P experience difficulty creating suction because the oral cavity cannot be properly separated from the nasal cavity during feeding.<sup>8</sup> In an infant with CL, the incomplete structure may hinder an infant's attempt to create a proper seal around the breast to facilitate sufficient intraoral pressure necessary for feeding.<sup>9</sup> Air flow through the cleft makes it difficult to establish the negative pressure necessary for adequate suction.<sup>10</sup>

The degree of feeding difficulty depends on the type and severity of the infant's cleft and the subsequent ability of the infant to generate sufficient sucking pressure for feeding.<sup>7</sup> However, infants with CL/P may be unable to properly feed, which may result in malnourishment, placing them at risk for "failure to thrive."11 Infants with CP have difficulty creating proper suction as evidenced by shorter sucking bursts, faster sucking rates, higher suckswallow ratios, and increased positive pressure generation.7 Infants with CL/P consume less milk, gain less weight, and measure lower on growth curves, placing those infants at risk for failure to thrive.<sup>2,12</sup> Persistent feeding issues may hinder an infant's motor, language, and behavioral development.<sup>2</sup> However, infants often catch up with normal growth values after undergoing surgical cleft repair.<sup>13</sup>

CL/P can lead to many complications. Early feeding difficulties not only limit the infant's weight gain and growth, but may lead to learning disabilities, speech disorders, recurring upper respiratory tract infections, and chronic ear disease.<sup>14</sup> Abnormal anatomy of the orofacial cavity makes cleaning the maxillary incisors difficult, later leading to higher rates of dental caries.<sup>15</sup> Because of nasal regurgitation and inadequate airway protection during swallowing, chronic ear and respiratory infections occur, and with aspiration, pneumonia and lung damage may result.<sup>10</sup> Clearly, nutrition is critical in avoiding these complications.

Feeding difficulties not only compromise growth but can affect maternal attachment and the decision to continue breastfeeding.<sup>2</sup> The milk supply of mothers of infants with CL/P may decrease as a result of inconsistent or difficult breastfeeding sessions.<sup>16</sup> In a study of 200 infants, the infant's inability to create normal suction was identified as contributing to mothers' decisions to stop in nearly 80% of the infants.<sup>15</sup> In another study, 70% of mothers (N = 215) cited the inability to latch onto the breast properly as a reason or lack of breastfeeding attainment.<sup>17</sup> Given the significant health benefits of human milk when mothers are unable or unwilling to breastfeed, they can be supported to express their human milk for bottle-feeding.

### PURPOSE

The purpose of this article is to (1) present the state of the science to support feeding practices for the infant with CL/P and (2) propose teaching strategies for staff and parents.

### **METHODS**

A narrative review of position statements, studies, and educational articles about feeding the infant with

CL/P was conducted. According to Melnyk and Fineout-Overholt,<sup>18</sup> narrative reviews focus on appraising research and other types of articles (eg, position statements, guidelines, and clinical topic articles) to serve as background for a particular issue or use. Articles were identified from CINAHL and PubMed using the search terms of cleft lip, cleft palate, cleft lip and palate, cleft feeding, human milk, and breastfeeding. Randomized controlled trials, qualitative studies, and systematic reviews were reviewed. Findings and recommendations from the studies were checked against position statements and guidelines from professional organizations. From the synthesis of both, a clinical and teaching strategy for staff and parents has been developed and is presented here.

### **FINDINGS**

#### Assessment of Suck

Infants with CL/P are evaluated on an individual basis. The recommended approach determines the infant's sucking ability to identify feeding adaptations that might be helpful. To assess the sucking ability, the evaluator places an index finger on the infant's tongue for the infant to suck.<sup>19</sup> Gently feeling the inside of the mouth and identifying the strength of the suck will allow the evaluator to locate the cleft (lip, palate, or lip and palate) and assess the severity (one side or both, partial or complete). While the infant is sucking on the evaluator's finger, assess (1) the extent to which the infant seals their lips around the finger, (2) rhythm (ie, with suck bursts), (3) suck strength, and (4) coordination by evaluating how well swallowing is paced with sucking.<sup>20</sup> From assessment of the pacing, the evaluator can estimate a suck-to-swallow ratio. A list of recommended feeding techniques on the basis of the infant's condition as part of the recommended approach is presented in Table 1.

#### **Growth and Development Goals**

The feeding difficulties of infants with CL/P are to be immediately addressed to ensure adequate nutrition and minimize complications that will affect optimal growth and development.<sup>17</sup> Initially, the infant's anthropometric measurements of weight and height are recorded and plotted for age-appropriate parameters. After the initial weight loss in the newborn period, a weight gain of 15 to 30 g per day is the goal.<sup>21</sup> Although feeding difficulties continue to exist, they tend to decrease as the infant with CL/P develops musculature with age.<sup>19</sup> In a study of 62 individuals with CL/P, reports of poor feeding in neonates decreased from 32% to 15% by 14 months of age.<sup>19</sup>

#### Importance of Human Milk for Nutrition

Infants with CL/P share the same nutritional growth requirements as other infants without craniofacial defects; however, additional calories may be required

	Assessment		
Condition	Generation of Negative Pressure	Ability to Make Mechanical Movements	Feeding Technique
Cleft lip only	+/-	+	Breastfeeding works well Artificial nipple with large base effective
Cleft palate only	+/-	+	Breastfeeding sometimes works well Soft artificial nipples with large openings effective May require delivery of milk into mouth
Cleft of soft palate	+/-	+	Breastfeeding usually works well Normal bottle-feeding usually works well Nipple shape may make functional difference
Cleft lip and palate	_	+/-	Breastfeeding unlikely Requires delivery of milk into mouth
Abbreviations: +, present <sup>a</sup> Reprinted with permission		al.	

TABLE 1. Assessment of Suck and Recommended Techniques for Infants With Cleft Lip and/or Palate<sup>a</sup>

when other systemic issues are identified.<sup>3</sup> According to the WHO, "No human milk substitute, not even the most sophisticated and nutritionally balanced formula, can begin to offer the numerous unique health advantages that human milk provides for babies."17 As such, human milk is recommended by most pediatric professional organizations including the WHO,17 the Academy of Pediatrics,22 and the National Association of Neonatal Nurses.<sup>23</sup> Human milk provides infants with a well-balanced mixture of amino acids, sugars, and fats.<sup>24</sup> The vitamins, minerals, enzymes, and prebiotics found in human milk aid digestion.<sup>24</sup> Human milk also has high levels of cholesterol to support brain growth, hormone development, vitamin D synthesis, and bile production.<sup>25</sup> The antibodies found in human milk stimulate the development of an infant's immune system and decrease the infant's risk of acquiring neonatal infections such as pneumonia, otitis media, lower respiratory tract infections, and gastrointestinal tract infections.<sup>26</sup>

#### Strategies to Establish Milk Supply

Although the benefits of human milk are scientifically proven and supported by numerous professional organizations,<sup>27-29</sup> mothers need information, equipment, and support to establish their milk supply when CL/P affects their infants.<sup>30</sup> The Academy of Breastfeeding Medicine published breastfeeding guidelines for infants with CL/P that recommend (1) breast milk should be promoted above formula feeding; (2) counseling should include telling mothers that sole direct breastfeeding is unlikely to be successful, but strategies to establish and maintain a milk supply should be learned as well as how to transition to direct breastfeeding when able; (3) an infant's ability to breastfeed should be evaluated on a case-by-case basis; (4) knowledgeable support is needed and early access to a lactation specialist who can provide instruction on feeding challenges should be a priority; (5) peer support through organizations or local breastfeeding support groups can be helpful; and (6) monitoring infant health (eg, hydration and weight gain) is critical while breastfeeding is established and balanced with supplemental feedings if needed.<sup>8</sup>

Similarly instructive but more operational, Spatz's<sup>31</sup> 10-step model to guide promotion of human milk diets in vulnerable infants can be employed. The 10-step model guides nurses to (1) supporting mothers' informed decision; (2) establishing and maintaining milk supply; (3) managing human milk handling and storage; (4) providing oral care with colostrum and feeding human milk; (5) promoting skin-to-skin contact (eg, "kangaroo care"); (6) encouraging nonnutritive sucking at the breast (particularly if enteral feeding is mainly by gavage); (7) transitioning the infant to feeding at the breast; (8) measuring milk transferred during breastfeeding (eg, with pre- and postfeeding weights); (9) preparing for discharge; and (10) coordinating care to ensure appropriate follow-up.<sup>31,32</sup> In the last 11 years, the model has been applied in numerous settings to support organizational initiatives to promote prioritization and support of giving infants (particularly high-risk infants) human milk.<sup>33</sup>

For the mother–infant dyad affected by CL/P, successfully achieving an adequate milk supply can be supported first by placing the infant skin to skin immediately after delivery and then emphasizing how human milk is like medicine in providing unmatched health benefits. Although mothers may be concerned that they did not initially plan to breastfeed, the emphasis can be shifted to their ability to provide human milk—something no one else can do as well for their baby. When establishing and

TABLE 2. Recommended Feeding Techniques for Infants With Cleft Lip and/or Palate		
Feeding Technique	Rationale	
Expressing Breast Milk	<ul> <li>Manually expressing breast milk stimulates the let-down reflex<sup>36</sup></li> <li>Increasing flexibility of breast tissue and softening the areola facilitates infant latch to seal the cleft<sup>36</sup></li> </ul>	
Positioning Upright	<ul> <li>Semi-upright positioning of the infant's body &gt;60° helps facilitate fluid transfer and minimize the risk of milk entering the nasal cavity and Eustachian tubes.<sup>7</sup></li> <li>Positioning includes head supported, trunk midline, and hips slightly flexed<sup>10</sup></li> </ul>	
Supporting Chin	<ul> <li>Jaw stabilization helps facilitate oral-motor movements for nutritive intake.<sup>7</sup></li> <li>Supporting the infant's chin helps ensure the nipple remains in the infant's mouth during breastfeeding.<sup>7</sup></li> </ul>	
Pacing	<ul> <li>Assistive squeezing, in synchrony with infant's sucking efforts, help to compensate infant's inability to create sufficient suction for fluid extraction<sup>7</sup></li> <li>May require specialized feeding equipment.<sup>7,40</sup></li> </ul>	
Burping	<ul> <li>Burping regularly decreases amount of air in stomach and reduces the chance of regurgitation after feeding<sup>10</sup></li> </ul>	

maintaining milk supply, easy access to a hospitalgrade double-electric breast pump is required. If the infant cannot go to breast, initiating pumping within 6 hours of birth is recommended and continuing every 2 to 3 hours for 10 to 15 minutes. A pumping schedule can be determined by calculating the mother's goals and 24-hour milk production. Initially the mother will not yield large volumes with pumping but should be reassured that is normal. Consistent pumping usually yields more milk.<sup>34</sup>

Securing a lactation consult within 12 to 24 hours of birth is very important. Until they arrive, the bedside nurse can deliver positive, encouraging messages about the importance of providing human milk and help the mother to initiate pumping. Because the mother's nipple should fit comfortably in the breast flange, pumping should not hurt. To maintain flow and comfort, adjust the suction as needed and encourage periodic breast massage concurrent with pumping to facilitate breast emptying. Teach mothers how to use the pump, handle the milk, and record volumes. Because a breast pump does not mimic the infant's physical closeness, encouraging infant contact during and after pumping helps to regulate hormones that affect milk volume.<sup>34</sup>

#### Breastfeeding

Breastfeeding is the preferred method of feeding because breast tissue is flexible and may be molded to accommodate the oral cavity and occlude the cleft.35 In addition, breastfeeding promotes the development and coordination of the orofacial musculature.<sup>11</sup> Although the WHO recommends that infants be exclusively breastfed for the first 6 months, infants with CL/P will benefit by breastfeeding longer than 6 months.<sup>36</sup> While breastfeeding, infants use negative intraoral pressure to stabilize the breast,<sup>37</sup> but an infant's ability to transfer milk through direct breastfeeding relates to the degree of clefting.7 Infants with CL/P benefit from the physical

act of breastfeeding because it encourages the normal physiological muscular movement and coordination of the mouth and face.<sup>38</sup> The act of breastfeeding also stimulates muscles development of craniofacial structures needed for speech.35 Skin-toskin contact between the mother and the infant also facilitates bonding and promotes the infant's immunity by exposure to the mother's skin.<sup>35</sup>

Manually expressing milk for 1 to 2 minutes before feeding can increase flexibility in the breast tissue to facilitate infant attachment to seal the cleft.35 Techniques such as applying a warm compress or massaging the breast tissue also can soften the breast tissue to stimulate let-down.<sup>35</sup> If the infant is unable to fully empty the breasts, expressing the remaining milk improves the mother's comfort level and stimulates production of adequate volumes of milk.<sup>35</sup> If the infant is unable to latch, mothers may pump human milk and bottle-feed their infants.<sup>3</sup>

#### **Bottle-Feeding**

Some mothers of infants with CL/P find bottle-feeding frustrating, whereas others describe it as an uncomplicated process that still allows physical closeness with the infant.9 Feeding human milk by bottle is the preferred approach if direct breastfeeding is not possible. Although some mothers of infants with CL/P want to be the sole feeder, other mothers are relieved that other individuals are able to feed the infant.9

#### Adaptive Equipment to Support Feeding

To receive adequate nutrition, infants with CL/P may require specialized equipment that decreases the infant's need to generate suction and increases the milk flow to regulate the infant's ability to suck and swallow.<sup>3</sup> A productive decreased sucking rate caused by increasing the bottle's flow rate will result in an increased transfer of milk volume and less fatigue during feedings, but is to be carefully

TABLE 3. Healthcare Professional Training Schedule for Feeding Recommendations				
Торіс	Important Points	Significance		
Educating caregivers	<ul> <li>Cleft lip and/or palate <ul> <li>Growth implications</li> </ul> </li> <li>Breast milk nutrition <ul> <li>Protein, carbohydrates, fats</li> <li>Vitamins, minerals, enzymes, prebiotics</li> <li>No associated expenses</li> </ul> </li> <li>Breastfeeding <ul> <li>Muscle movements</li> <li>Flexible nipples and breast tissue</li> <li>Skin-to-skin</li> </ul> </li> </ul>	<ul> <li>Adequate nutrition for optimal growth and development<sup>7</sup></li> <li>Nutrients help with digestion, hormone development, immune system, and cognitive development<sup>21</sup></li> <li>Powdered formula requires water. Contaminated water will increase the infant's risk of developing infections</li> <li>Breastfeeding stimulates orofacial muscle development and coordination<sup>20</sup></li> <li>Flexible nipple and breast tissues allow for better suction<sup>24</sup></li> <li>Skin-to-skin contact facilitates mother–infant bonding<sup>24</sup></li> </ul>		
Assessing sucking abilities	<ul> <li>Ability to generate movements</li> <li>Lip seal</li> <li>Suck burst/strength</li> <li>Suck-to-swallow ratio</li> </ul>	<ul> <li>Infant's ability to suck determines the appropriate feeding recommendations given to providers<sup>33</sup></li> <li>Refer to Table 1 for feeding recommendations</li> </ul>		
Providing recommendations	<ul> <li>Expressing breast milk</li> <li>Breastfeeding positions <ul> <li>Upright positioning</li> </ul> </li> <li>Lip, cheek, chin support</li> <li>Pacing <ul> <li>Identify cues (color, O<sub>2</sub> saturation, respiratory rate, sucking rhythm)</li> </ul> </li> <li>Burping <ul> <li>Assistive feeding devices <ul> <li>Compressible bottle</li> <li>Specialized nipple</li> </ul> </li> </ul></li></ul>	<ul> <li>Manual expression stimulates let-down reflect and increases breast tissue flexibility<sup>9</sup></li> <li>Midline orientation and neutral head and neck alignment decreases risk of nasopharyngeal reflux and facilitates proper airway protection<sup>9</sup></li> <li>Support facilitates sucking movements<sup>9</sup></li> <li>Assistive squeezing with feeding equipment in synchrony with infant's sucking patterns helps compensate infant's inability to create appropriate suction for fluid extraction<sup>9</sup></li> <li>Regular burping decreases amount of air in stomach and decreases risk of regurgitation after feeding<sup>9</sup></li> <li>Squeezable bottle in coordination with infant's suck–swallow pattern may increase fluid extraction<sup>32</sup></li> <li>Specialized nipple should be pliable enough to release fluid with minimal compression while encouraging sucking efforts<sup>9</sup></li> </ul>		

monitored to evaluate the infant's tolerance and avoid overwhelming the infant with a volume of milk greater than can be consumed.<sup>39</sup>

Specialized bottles can make feeding easier for infants with CL/P by reducing their need to generate high negative pressures.<sup>38</sup> Compressible plastic bottles force milk to flow into the tip of the nipple, and negative pressure becomes unnecessary for milk to be transferred during the suck.<sup>40</sup> In at least one study, infants with CL/P fed with compressible bottles gained more weight and required less intervention compared with infants using rigid bottles.<sup>41</sup>

Researchers propose that nipple modification may contribute to weight gain in infants with cleft palates.<sup>16</sup> The selection of the teat should be based on the infant's degree of cleft and oral-motor capabilities.<sup>7</sup> The specialized nipple should be pliable enough to release fluid with minimal compression yet firm enough to encourage sucking efforts.<sup>7</sup>

Additional considerations include the nipple's shape, length, and hole size or type.<sup>7</sup>

#### Positioning

General recommendations for body mechanics in infants with CL/P while feeding include the following: head support for neutral alignment of head and neck; arms forward, trunk midline, hips flexed; and lip, cheek, and jaw stabilization to provide a platform for sucking movements.7 Infants with cleft palates are fed in an upright position greater than 60° to allow gravity to facilitate fluid transfer and decrease the tendency for nasopharyngeal reflux.<sup>7</sup> The semiupright position facilitates burping, limits regurgitation of fluids, and prevents milk from entering the Eustachian tube and middle ear space, thus minimizing ear infections.<sup>8,10</sup>

Infants with cleft lips may initially have difficulties latching onto the breast, but with proper positioning,

TABLE 4. Online Resources on Cleft Lip and/or Cleft Palate					
Organization	Торіс	Web site			
Centers for Disease Control and Prevention	Facts about cleft lip and palate	www.cdc.gov/ncbddd/birthdefects/ CleftLip.html			
Cleft Palate Foundation	Booklets on feeding and develop- mental resources in English and Spanish	http://www.cleftline.org/parents- individuals/publications/booklets/ CLEFTLINE: 1.800.24.CLEFT			
Cleft and Palate Breastfeeding: Because you can!	Parent site with information, blog posts, success stories. Available in different languages	www.cleftlipandpalatebreastfeed- ing.com/			
La Leche League	Breastfeeding babies with special needs	http://www.lalecheleague.org/nb/ nbdisabled.html			
Rush Mother's Milk Club with Dr Paula Meier	"In Your Hands" video to promote human milk in English and Spanish	http://www.rushmothersmilkclub.com/ index.cfm?p=educational-materials			
Children's Hospital of Philadelphia with Dr Diane Spatz	"Power of Pumping"	http://www.chop.edu/health- resources/power-pumping-video#. VgBmNd9VhBc			
Breast Milk Solutions Dr Jane Morton, Stanford University	Maximizing Milk Production with Hands-on Pumping Available for purchase	www.breastmilksolutions.com/ videos.html			

they are generally able to adapt despite an incomplete seal.<sup>7</sup> During breastfeeding, the mother's breast should be supported and positioned toward the side of the palate that remains most intact to prevent the nipple from being pushed into the cleft.8 A 2013 protocol from the Academy of Breastfeeding Medicine recommends that while breastfeeding, an infant with cleft lip is oriented to the top of the breast while the mother occludes the cleft with her thumb.8 If the infant's cleft is large, the mother may tip her breast downward so the nipple remains deep in the infant's mouth. Providing external lip and cheek support maintains lip closure around the breast and increases the infant's control of oral intake.7

#### Pacing

Feeding sessions may be lengthy, lasting more than 1 hour, due primarily to uncoordinated pacing.<sup>38</sup> Infants with CL/P may become fatigued, exhausted, and fall asleep before completing a feeding.<sup>11,12</sup> In addition, infants with CL/P may experience excessive air intake and require more frequent burping.<sup>3</sup>

Infants with CL/P may benefit from a learned rhythm during feedings.<sup>3</sup> The caregiver monitors the infant's reaction during feeding and identifies cues that indicate a pause or change of pace: this includes the infant's color, oxygen saturation, respiratory rate, and sucking rhythm.<sup>7</sup> To support pacing, determine the infant's sucking rhythm by placing the index finger gently on the infant's tongue, also stimulating the suck.<sup>38</sup> Pacing the feeding in rhythm with the infant's reaction may increase the infant's control of oral intake by helping maintain organization in sucking, swallowing, and breathing.7 Weighing the infant before and after a feeding helps to determine the amount of milk transferred during the feeding. A list

of recommended feeding techniques and rationales is presented in Table 2.

#### Family Education

Nurses, occupational therapists, lactation specialists, physicians, and dietitians-all have important roles to play in supporting the family and the infant with CL/P. Education and support begins prenatally if the deformity is diagnosed in advance of delivery. Infants with CL/P of industrialized nations have shown success with nurse specialists providing prenatal support, complex feeding advice, and visiting in the home.<sup>41</sup> In 2014, a study showed that prenatal counseling reduced hospital readmission rates related to feeding issues in infants with CL/P by 50%.<sup>21</sup>

Yet, professionals lack the education to provide the support that parents need. Educational resources for the staff include written protocols, illustrative posters, and live feeding demonstrations. A suggested education schedule is presented in Table 3. Both parents and staff want information to help them adapt practices to fit an infant's needs. For example, there are a variety of resources available to teach mothers how to pump. One such resource is the Maximizing Milk Production with Hands-on Pumping video developed by Dr Jane Morton and Breast Milk Solutions. One hospital's quality improvement project downloaded an initiating pumping video on their intranet site to support their standard education for mothers who required this assistance.<sup>32</sup> Similar resources are available from the Rush Mother's Milk Club and the Children's Hospital of Philadelphia. See Table 4 for a list of online resources.

Mothers of infants with CL/P may have limited knowledge about feeding their infants and may lack information regarding regurgitation, colic, and swallowing during feedings.<sup>9</sup> Mothers may feel stressed or

Summary of Recommendations for Practice and Research		
What we know:	<ul> <li>The craniofacial defect of cleft lip and/or palate involves an altered physiological anatomy that affects an infant's ability to generate negative pressure for proper suction during feeding sessions.</li> <li>Difficulties in feeding may compromise normal growth and development as well as disrupt the maternal-infant bonding process.</li> <li>The ability to generate negative pressure and make mechanical movements will determine the recommended feeding technique for infants with cleft lip and/or palate.</li> <li>Breast milk provides infants with a well-balanced mixture of amino acids, sugars, fats, vitamins, mineral, and prebiotics for optimal growth and development.</li> <li>Infants with cleft lip and/or palate should be encouraged to be breastfed to facilitate the development, musculature, and coordination of the oral cavity.</li> </ul>	
What needs to be studied:	<ul> <li>Standardized recommendations and effective educational material to train healthcare professionals and caregivers of infants with cleft lip and/or palate.</li> <li>Inexpensive alternatives to supply milk to infants with cleft lip and/or palate who are unable to afford specialized feeding equipment.</li> <li>Evaluation criteria to determine the effectiveness of feeding interventions recommended for infants with cleft lip and/or palate.</li> </ul>	
What we can do today:	<ul> <li>Educate healthcare professionals to provide feeding recommendations to caregivers of infants with cleft lip and/or palate.</li> <li>Encourage mothers of infants with cleft lip and/or palate to breastfeed to facilitate the musculature of the oral cavity.</li> <li>Refer caregivers of infants with cleft lip and/or palate to organizations that assist with funding assistive feeding devices.</li> </ul>	

confused when various healthcare professionals provide conflicting feeding suggestions.<sup>9</sup> Feeding instructions help parents develop confidence in properly caring for their infant with CL/P.<sup>13</sup> Because best practice approaches to feeding and supporting families involve many key features that will want to be referenced at discharge, a family teaching toolbox has been developed (see Family Teaching Toolbox).

Support the infant's transition to home after discharge with follow-up appointments and home visits. Assessment data for follow-up include quantitative measurements (length, weight, head circumference, growth, adequate numbers of wet/dirty diapers, maternal milk volume and comfort, and time spent feeding) and qualitative reports from the family. At home, families benefit from regular visits by a specially trained health nurse.<sup>13</sup> In a study of 101 infants in England, early feeding success was attributed to specialized home health visitors who provided the families with feeding support.<sup>41</sup> In addition, the consistency of a visiting healthcare provider would be helpful to help parents discern what to do if they receive conflicting advice. Because the orofacial cavity develops over time, it is critical to continue follow-up and modify recommendations for feeding as the infant develops.

#### **Implications for Practice**

Although individual maternal-child practices vary by hospitals, in the absence of a policy, advice for feeding infants with CL/P will be inconsistent. Use the resources in this article to develop standardized feeding protocols to guide staff education to optimize nutrition for infants with CL/P. In the absence of protocols, caregivers and professionals may advocate for formula feedings by bottle over human milk because they lack the will or skills to implement best practice (ie, feeding human milk). A teaching toolbox is presented along with training schedules for staff and online resources. By using written protocols, illustrations, and live demonstrations, healthcare staff will be informed how to apply the required feeding adaptations for successful feeding. Return demonstrations, follow-up surveys with discussion questions, anthropometric measurements, and reassessment of sucking abilities can be used to evaluate the effectiveness of individualized feeding recommendations.

#### **Implications for Research**

Future research should continue to explore what affects various genetic, environmental, and nutritional factors, such as folic acid may have in preventing CL/P. Researching best approaches to gain a better understanding of the family's experience and methods to engage mothers in providing human milk should include early diagnosis, education, and implementation strategies for this population of infants. Comparative effectiveness of the adaptive feeding interventions (eg, special nipples and special bottles) on infant attainment of feeding and appropriate growth requires further exploration as well as the role of feeding support groups.

#### **CONCLUSION**

This article presents key considerations to support nutrition and feeding in infants diagnosed with CL/P. Review of literature was used to identify evidence-based strategies that will improve the feeding experience for both the infant with CL/P and their parents. These strategies include methods to assess sucking skills, provide feeding education, and support families as well as a selection of educational materials for staff and family. Human milk is a key element in providing nutrition and ways to prioritize as the preferred feeding method should be central to the care of these infants. Strategies to establish and maintain the mother's milk supply, support breastfeeding, assess pacing of feeding, and use of adaptive feeding devices were described.

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