

A Pilot Study of Mothers' Breastfeeding Experiences in Infants With Cleft Lip and/or Palate

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ABSTRACT

Background: Despite the recognized importance of human milk (HM) use, breastfeeding is often discouraged for infants with cleft lip and/or palate because of their anatomical abnormalities. Poor weight gain may require formula for calorie supplementation. Stresses associated with caring for infants with cleft lip /palate may decrease rates of HM provision to these infants.

Purpose: This study investigates the experiences of mothers of infants with cleft lip/palate (CL/P) to determine choices and factors associated with providing HM to their infants.

Methods: A retrospective telephone survey was administered to a cohort of mothers of infants with CL/P.

Results: Fifty mothers agreed to participate in the survey. Most (78%) initiated use of HM for a median duration of 4 months, 32% provided HM for 6 months or more, and 79% exclusively expressed their HM. Poor supply was the most frequent challenge to providing HM and led to cessation in 46% of the mothers. Formula was used to supplement for poor supply or poor infant weight gain in 90% of the mothers. The best predictors of a mother's use of HM were child not in day care, genetic diagnosis, and gestational age at birth. Only 36% of mothers reported individual encouragement to provide HM, and 18% reported they were specifically discouraged from providing HM for their infants.

Implications for Practice: Although initiation rates were high, there are opportunities to improve support for mothers to increase duration of HM provision in children with CL/P.

Implications for Research: This study establishes a baseline for future prospective studies looking at the impact of active encouragement and provision of lactation support within the cleft team setting.

Key Words: breastfeeding, cleft lip, cleft palate, feeding methods, human milk, lactation

BACKGROUND AND SIGNIFICANCE

The United States Surgeon General, the American Academy of Pediatrics, and the World Health Organization have all released statements encouraging mothers of newborns to increase their exclusive use of human milk for at least 6 months, primarily through direct breastfeeding.¹⁻³ The Surgeon General's *Call to Action to Support Breastfeeding* (2011) defines steps that communities, healthcare systems, healthcare providers, employers, public health professionals, and other organizations can take to support and empower lactating mothers.¹ Nutritional research of healthy newborns has generated much scientific support for the use of human milk as well as recommendations on how to increase maternal initiation and duration of breastfeeding.⁴⁻⁷ There is much literature supporting human milk use in the

neonatal intensive care unit (NICU) setting for premature and very low birth-weight infants. These studies also typically highlight challenges associated with expressing milk for infants who cannot feed directly at the breast such as those with orofacial anomalies.^{5,7-15} There is limited data, however, on the rates and duration of mothers providing human milk to infants with special health conditions such as cleft lip and/or palate.

There are only a few circumstances when a mother's milk is not recommended for her infant such as mothers with HIV infection, mothers receiving chemotherapy, or mothers taking street drugs.³ Human milk is otherwise considered the optimal nutritional option for all infants and has been shown to provide many different preventive and protective effects for healthy and at-risk infants. Established benefits include decreased rates of necrotizing enterocolitis, respiratory infections, otitis media, childhood leukemias, and childhood obesity. Improved mother-infant bonding and early childhood cognitive function are also reported.^{1,3,12,16-18} These health benefits should be presumed to exist for all infants receiving human milk, with or without birth abnormalities. Paradise et al,¹⁹ for example, demonstrated that infants with cleft palates who received human milk

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had decreased rates of chronic serous otitis and need for myringotomy tubes. Despite these compelling benefits, breastfeeding is often discouraged in infants with cleft lip and/or palate. Anatomical abnormalities of the oral structures combined with the frequent presence of a concomitant syndrome or other health issues mean that infants with orofacial clefts have frequent feeding issues and are considered unable to breastfeed.²⁰⁻²⁴

In reality, infants with orofacial anomalies may or may not be able to breastfeed based on the severity of the anomaly and feeding should be determined by individualized assessment. Most infants with an isolated cleft of the lip (CL) or lip and gum line should be able to successfully breastfeed or take expressed milk from a regular, non cleft-specialized bottle.²⁵⁻²⁸ In contrast, infants with combined cleft lip and palate (CLP) or isolated cleft palate (CP) have difficulty breastfeeding because of an inability to achieve the negative pressure necessary to extract milk from the breast.^{20-22,28-30} In resource-rich countries, infants with CLP or CP will typically be offered specialized bottles that allow them to feed in an efficient fashion.^{20,22,23,31-34} This does not exclude infants with CLP or CP from bottlefeeding expressed human milk or receiving partial or non-nutritive feedings at the breast to promote mother–infant bonding from physical closeness.^{28,35} Often though, these infants are delivered at hospitals with limited cleft-related experience where the challenges of an unexpected birth defect and altered infant feeding may be very overwhelming for a mother and her healthcare providers.^{33,36,37} Mothers report their feelings of shock and concern and say that providers express confusion and cannot give knowledgeable support about breastfeeding or bottlefeeding their infants.³⁸ Ultimately, mothers of infants with clefts may not be appropriately encouraged to start expressing milk in a time frame that will promote an adequate sustained supply.

Infants with orofacial clefts often present with early feeding difficulties, and the establishment of consistent weight gain and growth is considered a priority of appropriate neonatal management.³⁹ Providing human milk by breast or bottle has not been actively discouraged in our cleft clinic, but the numerous management challenges surrounding new patient referrals mean that this priority does not always get the appropriate attention. In particular, newborn feeding difficulties require extensive feeding support to help ensure adequate weight gain.^{40,41} Interventions may include detailed education, monitored feedings, calorie supplementation with formula or fortifiers, specialized bottles, and frequent feedings with regular weight checks.^{5,28,29,42,43} More significant problems may require placement of a feeding tube.²⁴ Challenges to establishing regular feeding patterns or frequent changes in feeding

What This Study Adds

- Introductory data of mothers' reported practices with regard to breastfeeding and expressing human milk for their infants with cleft lip and/or palate.
- Identifying predictors of mothers' decision to provide human milk in the form of breastfeeding or expressing milk for her infant with a cleft lip and/or palate.
- Identifying opportunities for improvement in care delivery related to lactation education and recurring support for mothers of infants with cleft lip and/or palate.

strategies due to repeat feeding failures may also occur.^{20,31,35,44-47} The extra time and attention cleft feeding requires may create considerable stress for families, and stresses over infant feeding difficulties have been previously reported to increase maternal anxiety and result in poor mother–infant bonding.^{36,37,45}

Existing literature demonstrates that the intention to initiate breastfeeding varies significantly by ethnic group and socioeconomic status.^{16,48-51} Other influential factors impacting a woman's decision to breastfeed include the opinions and support of their partner/spouse, their mother, and healthcare providers.^{35,38,52-55} Since early experiences with breastfeeding can greatly affect how long a woman continues to breastfeed, lack of support from healthcare professionals can be a significant barrier to success. Mothers often identify lactation support from healthcare providers as the most important intervention the healthcare system could have offered.^{53,54} Unfortunately, few healthcare professionals are adequately trained in providing lactation support.^{1,13,48,52,54,56,57} Inconsistencies and discoordination between healthcare providers can have a negative influence for mothers.³⁵

In many regional cleft centers, including our own, families are provided with important feeding and lactation education/support during prenatal consultations when the cleft has been identified by ultrasonography. Prenatal lactation consults for infants with congenital anomalies have been shown to significantly increase initiation and duration of human milk provision after delivery.^{58,59} For mothers without a prenatal diagnosis, this support comes at the time of the initial comprehensive feeding assessment performed during the first cleft team appointment after delivery. In our team, these specialized postnatal evaluations are performed by a registered dietitian, a feeding specialist (occupational therapist or speech–language pathologist), and a lactation nurse. In many centers, however, these evaluations may occur 2 weeks or more after delivery when feeding patterns are already established. These families must then rely on local, less knowledgeable providers for initial feeding recommendations.^{35,38} Feeding and

lactation support services are always available in advance on the first cleft team appointment, but families may not be aware of these resources until it is too late to encourage breastfeeding or expression of milk if it has not already begun.

There is limited specific data on the rates of initiation or duration of human milk use in infants with orofacial clefting. In addition, it is not known which factors influence mothers of infants with orofacial clefting to breastfeed or provide expressed human milk for their infants.^{25-27,29,30,47,60} The purpose of this study was to survey a cohort of mothers of infants with orofacial clefting to determine their use of human milk and identify which factors were associated with their successes or failures with breastfeeding/milk expression.

SETTING

This study occurred at a large Midwestern tertiary pediatric hospital with an active regional cleft and craniofacial program. Our multidisciplinary team cares for approximately 1500 children with cleft and craniofacial conditions. Yearly, we are referred between 75 and 100 new infants born with CL, CLP, or CP.

METHODS

This is a single-institution retrospective telephone survey study designed to document the breastfeeding experiences from a cohort of mothers of infants referred for cleft team care at our institution. The study group included all mothers of infants born in 2012 with a diagnosis of CL, CLP, or CP referred for cleft team care. At the time of survey administration in early 2014, the children were all 1 to 2 years of age. The survey was administered to all consenting mothers who were able to be contacted using existing cleft team telephone records. Mothers were asked a variety of questions regarding their choices and experiences related to feeding their child with a cleft including initiation and duration of human milk use for infant nutrition. Surveys were administered by a single individual using a script. Questions were read to the mother and her responses recorded on a standardized data sheet. Each survey took approximately 20 minutes to complete. Mothers who did not reside with their infant during infancy were excluded. Child demographics were recorded including cleft type, gestational age at birth, NICU stay, history of prenatal diagnosis, and any other medical issues. Maternal age, parity, and work status were also noted.

The primary study measures were the rates and duration of human milk provision for infants with a cleft. Secondary measures included patient or parent factors positively or negatively associated with the provision of human milk to these infants. Descriptive

statistics were used to summarize the data. Group comparisons were made for several categories of infant and maternal factors based on initiation (or not) of human milk provision. In addition, for mothers who provided some human milk, group comparisons were made on the basis of duration of milk provision as well as maternal factors potentially associated with milk provision. Group comparisons of categorical variables were analyzed using Fisher exact tests. Group differences in continuous variables were analyzed using Wilcoxon or Kruskal-Wallis tests. All tests were 2-sided, with significance level at .05. This protocol was reviewed and approved by the institutional review board at our institution. A standardized verbal consent process was used to obtain consent for survey participation prior to survey administration.

RESULTS

Demographics

A review of hospital records identified that, in 2012, 86 infants were born with orofacial clefting and referred to the cleft team for management. For the 86 infants, 54 mothers were successfully contacted and 50 mothers (58%) consented to participate in the study. Infants included 20 females and 30 males. Cleft types included 13 CL, 18 CLP, and 19 CP. Eleven mothers (22%) reported their child had a syndrome or chromosomal abnormality, and 7 additional infants (14%) had Pierre Robin sequence. Gestational age was reported for 45 of the 50 infants: 35 were born at or beyond 38 weeks' gestation (range, 38-41.5 weeks), and 10 infants were born before 38 weeks' gestation (range, 32-37 weeks). Overall mean gestational age was 38.6 weeks (SD = 1.95). Eighteen mothers (36%) reported their child's cleft condition was prenatally diagnosed, but only 11 received prenatal counseling about the condition. Sixteen participants (32%) reported they were first-time mothers. Twenty-six mothers (52%) returned to work after delivery, and 19 children (38%) attended day care outside the home (Table 1).

Overall Initiation, Duration, and Exclusivity of Human Milk Use

Maternal report of infant nutrition included initiation and duration of breastfeeding, milk expression, and formula supplementation. Of the 50 mothers surveyed, 39 (78%) reported they initiated either direct breastfeeding or expression of human milk after the birth of their infant. Median duration of human milk provision was 4 months (Interquartile range (IQR) = 2-9). Forty-one percent reported they provided some human milk for at least 6 months. Ten percent of mothers provided human milk exclusively. Mothers of infants with CP had the highest rate of initiation of human milk provision compared with mothers of CL

TABLE 1. Associations of Child and Maternal With Initiation and Duration of Human Milk Provision

Factors	Number Providing HM	P Value Comparison of Initiation ^a	Median (IQR), Months of HM Provision	P Value Comparison of Duration ^b
<i>Infant factors</i>				
Cleft type				
CL	9/13	.579	8 (5-9)	.09
CLP	14/18		6 (1-11)	
CP	16/19		4 (1.5-4.5)	
Gender				
Female	14/20	.31	3.8 (0-5.5)	.27
Male	25/30		4 (0.5-10)	
Gestational age				
<38 wk	6/10	.09	0.5 (0-7)	.14
38+ wk	30/35		4 (1-9)	
NICU stay				
Yes	14/19	.73	2 (0-6)	.20
No	25/31		4 (0.5-9)	
Genetic diagnosis				
Syndrome	6/11	.08	0.5 (0-4)	.18
PRS	7/7		4 (3.5-6)	
No	26/32		4 (0.5-9)	
Prenatal diagnosis				
Yes	12/18	.17	1.3 (0-9)	.66
No	27/32		4 (0.5-6)	
Prenatal counseling ^c				
Yes	9/11	.14	7 (1-10)	.07
No	3/7		0 (0-0.5)	
<i>Maternal factors</i>				
Mother's age				
Teens/20s	26/32	.49	3.8 (0.5-6)	.71
30s/40s	13/18		4 (0-9)	
Single parent				
Yes	7/10	.67	4 (0.5-8.5)	.19
No	32/40		1.3 (0-4)	
First-time mother				
Yes	14/16	.47	3.8 (0.5-7)	.80
No	25/34		4 (0-7)	
Working mother				
Yes	18/26	.18	4 (0-7)	.67
No	21/24		3.8 (0.5-7.5)	
Child in day care				
Yes	12/19	0.08	2 (0-7)	.42
No	27/31		4 (0.5-8)	
Distance from cleft team				
≤1 h	21/27	1.00	2 (0.5-7)	.40
>1 h	18/23		4 (0.5-9)	

Abbreviations: CL, isolated cleft lip; CLP, combined cleft lip and palate; CP, isolated cleft palate; HM, human milk; IQR, interquartile range; NICU, neonatal intensive care unit; PRS, Pierre Robin sequence.

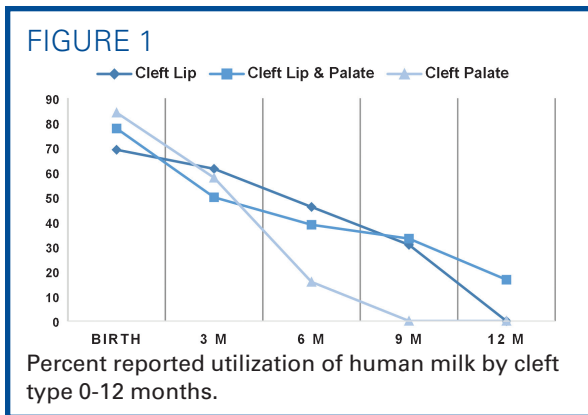
^aFisher's exact test.

^bWilcoxon/Kruskal-Wallis test.

^cAmong cases with prenatal diagnosis.

and CLP, but this group also had the fastest rate of cessation, with 81% stopping before 6 months (Figure 1). Most mothers (72%) who supplemented

human milk feedings with formula indicated they did so because of poor milk supply or it was recommended for improved infant weight gain. The



remainder cited reasons of convenience, separation from their infant, return to work, and transition to cow's milk.

Relation of Mother and Infant Factors to Initiation and Duration of Human Milk Use

Many differences were seen in the rates of both initiation and duration of human milk use based on certain mother and infant factors, but none reached statistical significance. The patient and family factors and their association with rates of initiation and duration of providing human milk are listed in Table 1. Differences in gestational age showed that only 60% of infants born before 38 weeks' gestation received human milk compared with 86% of infants born at or after 38 weeks' gestation ($P = .09$). NICU attendance showed that the median duration of human milk use for infants admitted to the NICU was 2 months compared with 4 months for those not admitted to the NICU ($P = .2$). The role of prenatal diagnosis/counseling showed that mothers who received a prenatal cleft diagnosis and counseling initiated human milk use 82% of the time for a median duration of 7 months. Only 43% of mothers who received a prenatal diagnosis without prenatal counseling initiated human milk use for a median duration of 0 months ($P = .07$). Other maternal factors such as first-time mothers, stay-at-home mothers, younger mothers, and mothers of children not in day care showed 80% to 90% rates of human milk use but for shorter median durations than their counterparts. One factor that made no difference in rates of initiation was driving distance from cleft team ($P = 1.00$).

Mother-Reported Facilitators and Barriers to Providing Human Milk

For the 32% of mothers who provided human milk to their infants for at least 6 months, the reasons they most frequently cited were immune protection for the infant, that human milk is a "healthier" choice, or that it's "the best option." Three mothers each indicated they chose to provide human milk because it costs less than formula, that it would help

the infant recover from surgery, or that they breastfed previous children. Mothers who chose not to provide human milk reported reasons including lack of milk supply, it's "too complicated," or "too stressful." One mother commented that breastfeeding "felt like taking care of twins," another simply "chose not to," and a third "didn't like the idea." One mother reported she decided not to because she had another child with a cleft who was not able to breastfeed. Mothers who provided human milk for less than 6 months most frequently reported their reasons for stopping as loss of supply, that it was "too difficult," or because of "infant's health." Ninety percent of mothers who provided human milk for less than 2 months total reported loss of supply caused them to stop (Figure 2). These mothers were more likely to be first-time mothers or inexperienced with breastfeeding than those who breastfed for 2 months or longer. They were also less likely to report receiving lactation support (Table 2).

A majority of mothers who chose to provide human milk reported at least one challenging factor. Most common were poor latch, poor suck, and poor milk supply. Only 18% of mothers who provided human milk reported no particular problems. Not surprisingly, mothers who did not perceive challenges had a longer median duration of human milk provision (Table 3). When asked specifically about their challenges with expressing milk, 42% of mothers complained about milk supply. Others reported that expressing milk was time-consuming or that it was painful. Only 2 mothers, however, reported difficulty in accessing a breast pump.

Mother-Reported Supports for Providing Human Milk

Mothers were asked open-ended questions about any sources of breastfeeding encouragement or lactation support. Sources of encouragement were frequently reported as "everyone," delivery room nurses, or NICU staff. Other mothers reported their pediatrician or their family encouraged them, but only 1 mother reported encouragement by members of the

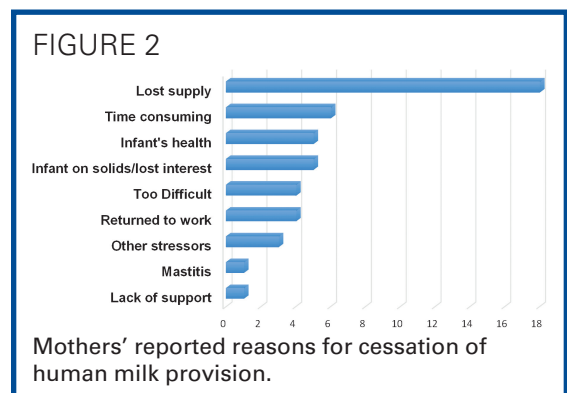


TABLE 2. Mothers Who Provided HM for Less Than 2 Months Versus Those Who Provided HM for 2 Months or More

Factors	<2 mo HM (n = 9)	≥2 mo HM (n = 30)	P
First-time mother			
Yes	5	9	.24
No	4	21	
First HM experience			
Yes	7	11	.055
No	2	19	
Lactation support			
Yes	6	28	.07
No	3	2	

Abbreviation: HM, human milk.

cleft team. Unfortunately, 36% of mothers reported that no one encouraged them to provide human milk. Eight mothers (16%) reported active discouragement of breastfeeding, most frequently by their own family. Interestingly, all of these mothers ultimately chose to provide human milk and continued for a median duration of 5 months (Table 3). For the surveyed mothers who did not provide any human milk, 73% reported no active encouragement and none reported any active discouragement. Some form of lactation support was reported by 87% of mothers who provided human milk. Most frequently, this support came from hospital nurses after delivery.

Mother-Reported Breast Pump Use

Only 1 mother in the survey reported exclusive breastfeeding at the breast without the use of a pump. Her child, as might be expected, had a CL. The remaining mothers reported using a breast pump either in conjunction with direct feeding at the breast or exclusively to express milk to be given via bottle. Twenty-two mothers (58%) purchased a breast pump, 4 mothers rented, 3 mothers both rented and purchased a pump, and 10 mothers reported they borrowed a pump from a friend or relative. Interestingly, those mothers who borrowed their breast pump provided human milk for the longest, with a median duration of 6 months. Those who exclusively rented a pump provided milk for the shortest amount of time (Table 3). All survey participants were asked whether a hospital- or clinic-supplied breast pump would have helped them. More than 60% of breastfeeding mothers indicated that a cleft team-provided pump would have been beneficial. Two of the mothers who did not provide any human milk indicated a breast pump would have been helpful, suggesting they might have initiated breastfeeding in those circumstances. The remainder did not feel this would have helped them, suggesting that the decision not to provide human

milk was tied to other factors beside the availability of a breast pump.

DISCUSSION

On the basis of our existing cleft team model for newborn referral and evaluation, we hypothesized that the rates of breastfeeding and/or providing expressed human milk were low compared with national averages. To study our theory, we elected to survey a cohort of mothers of infants with clefts to determine how many provided human milk and which factors were associated with their successes or failures with breastfeeding/milk expression. This was planned as a pilot project for baseline comparative data in advance of prospective outcomes studies of cleft team interventions designed to increase the rates of human milk provision to this vulnerable population. We anticipated this survey would demonstrate low numbers of cleft team mothers providing human milk to their infants. We were surprised to find that mother-reported rates of initiation mirrored national averages of all breastfeeding mothers (78.0% vs 79.2%, respectively). Rates of continuation, however, fell behind the national average of 49.4%, with only 32% of surveyed mothers providing human milk for 6 months. Cleft team mothers surpassed the regional averages for initiation rates of breastfeeding in our catchment area (69.9%-77.4%), but rates for continuation again fell below the 6-month regional averages.⁶¹ We recognize that many mothers stop breastfeeding early due to perceived challenges or disappointing results. Mothers officially reported “loss of milk supply” as the most common reason for stopping, but the many potential physiologic and psychosocial factors impacting a mother’s milk supply make this a more complex issue.

This study shows that factors of gestational age, NICU stay, and even gender may potentially impact rates of human milk provision in the cleft population. Mothers of premature infants and/or those infants with altered health status are going to face more significant challenges to build and maintain an adequate milk supply. Research of mothers of infants with congenital heart defects shows institutional breastfeeding culture and provider experience can positively impact rates of initiation of human milk provision.⁵⁹ Hospital nurses provide additional early support for these mothers, but after discharge, breastfeeding support should come from other sources including the cleft team and other ambulatory providers. If referral to the cleft team is made prior to hospital discharge, all efforts should be made to visit with the family to provide initial cleft care education including the use of human milk.

When consulting with a first-time mother, a single parent, a mother returning to work, or one placing a child in day care, healthcare providers should recognize

TABLE 3. Comparative Experiences of Mothers Who Reported Providing Human Milk to Their Infant With a Cleft

Factors for Mothers Who Provided HM	Number	Median (IQR) Duration of HM Provision, mo	P Value for Comparison of Duration ^a	Mean (SD) Duration of HM Provision, mo
Mother's age				
Teens/20s	26/39	4 (1-7)	.18	5.1 (4.4)
30s/40s	13/39	7 (4-10)		6.5 (3.8)
Single parent				
Yes	7/39	4 (0.5-6)	.22	3.7 (3.1)
No		5 (2.5-9.5)		5.9 (4.3)
First-time mother				
Yes	14/39	4 (1-9)	.46	4.9 (4.2)
No		5 (3-9)		5.9 (4.3)
Working mother				
Yes	18/39	5.5 (4-10)	.33	6.0 (4.0)
No		4 (2-9)		5.1 (4.4)
Prior experience lactation				
Yes	21/39	3.8 (0.5-6)	.046	4.2 (3.9)
No		6 (4-9)		6.7 (4.2)
Challenges with lactation				
Yes	32/39	4 (1.25-8)	.25	5.2 (4.1)
No		8 (3-12)		7.3 (4.4)
Mothers discouraged				
Yes	8/8	5 (2.5-6.5)	.83	4.8 (3.1)
No	31/42	4 (2-9)		5.7 (4.5)
Lactation support				
Yes	34/39	5 (3-9)	.14	5.9 (4.2)
No		1 (0.5-4)		3.2 (4.1)
Use of breast pump				
Borrowed	10/38	6 (4-10)	.15	6.8 (5.0)
Rented	4/38	1.5 (0.8-3)		1.9 (1.5)
Bought	24/38	5 (2.5-9)		5.7 (4.0)
Challenges with expression				
Yes	22/39	4 (1-9)	.39	5.3 (4.7)
No		5 (4-9)		5.9 (3.6)
Milk expression support				
Yes	21/39	4 (1-10)	.93	5.9 (5.0)
No		4.5 (3-7)		5.1 (3.1)
Formula supplementation				
Yes	35/39	4 (1.5-9)	.50	5.3 (4.0)
No		4.5 (4-11)		7.5 (6.4)

Abbreviations: HM, human milk; IQR, interquartile range.

^aWilcoxon or Kruskal-Wallis test.

the need for ongoing lactation support if the mother has initiated breastfeeding or expressed milk.⁵⁸ First-time mothers had a high rate of initiation but a sharp drop-off in human milk provision over time. Helping a new mother learn appropriate ways to build her milk supply, identify supports, and manage stressors could improve overall duration rates by helping her through early breastfeeding difficulties. Single mothers had slightly lower initiation rates than average and an increased rate of cessation prior to 6 months. Time constraints are likely challenging for these mothers, and efforts to teach efficient breastfeeding and milk

expression skills and encourage social supports may improve long-term human milk provision. Working mothers and those with children in day care also had lower rates of initiation of breastfeeding but slightly longer durations. These mothers are challenged with maintaining supply while separated from their infant during the day. Working mothers also describe many problems finding appropriate time and place to express milk while at work, the stress of which can further blunt a milk supply.^{7,15,48,52,53,55,62,63}

One protective factor noted in this study was the positive impact of prenatal counseling. As has been

shown by other investigators, mothers who received prenatal counseling for a cleft diagnosis in their unborn child appear to initiate breastfeeding at higher than average rates and continue providing human milk for longer periods of time.^{58,59,64,65} This was a very successful subset of breastfeeding mothers in the survey group. During a prenatal consult at our institution, mothers meet with a group of specialist providers from neonatology, plastic surgery, occupational therapy, lactation, genetics, and social work. The family is educated about the expected cleft diagnosis including potential feeding challenges and how to access feeding and lactation supports after delivery. Acquiring a breast pump is also recommended with a list of helpful resources. Preparing parents before delivery appears to translate to improved breastfeeding outcomes for these infants. Comparatively, mothers who knew about the cleft diagnosis but did not receive prenatal counseling had the worst breastfeeding outcomes in the survey group. These families may have relied on the Internet or other unreliable resources for prenatal information that discouraged breastfeeding these infants. Missing a prenatal counseling opportunity might also suggest family difficulties with accessing available resources, transportation, or medical compliance, which could ultimately impact several aspects of their infant's cleft care.

Existing breastfeeding research indicates that mothers value and respond to support from their own families and healthcare professionals.^{1,35,38,48,53} Our failure as a cleft team to register as a source for active encouragement of breastfeeding shows us where we can work to improve our families' experiences. Studies of premature and other vulnerable infants confined to the NICU indicate that the initiation of breastfeeding and expressing milk is higher with direct provider education, easy access to certified lactation specialists, and peer support from other mothers.^{9,12,52,58,59,66,67} Data from mothers of healthy outpatient infants and those discharged from NICU care also suggest ongoing peer, provider, and specialized lactation support and predict better breastfeeding outcomes.^{54,58,68-70} As a team, we can use these facts to improve our breastfeeding statistics by supporting these mothers through continued cleft team interactions providing necessary education and counseling. Parent-based cleft-specific support could also be considered as an additional resource.^{12,34,52,71}

Effectively supporting cleft team mothers requires specific education for expression of milk with a pump when infants have CLP or CP. Typical breastfeeding education focuses on mothers feeding an infant directly at the breast, with limited teaching about milk expression. For exclusive milk expression to succeed, there is additional information to know for building and maintaining a supply and for safe storage and

handling of the milk.^{13,15,72} In the limited studies on human milk expression, women report they practice milk expression for many reasons including storing milk for unexpected separations, relieving engorgement, maintaining supply, and for use after they return to work.^{7,13,55,73,74} For women who need to exclusively express their milk for their infant, many barriers have been described including establishing and maintaining adequate supply, increased time, and cost/access issues related to pump acquisition.^{1,12,13,56,62,75,76} The special challenges of exclusively expressing human milk often go unnoticed by friends, family, and healthcare providers. Many mothers report that traditional breastfeeding support groups react negatively to women who are primarily expressing milk, presuming it is for reasons of convenience rather than for clear health indications.^{75,76} These mothers deserve to feel supported and respected as much as possible for their efforts on behalf of their infants.^{12,13,66,75,76} Online support groups exist for mothers who express milk exclusively, but our mothers also need specialized lactation support that accounts for the dual challenges of exclusive milk expression and caring for an infant with cleft lip and palate.

Obtaining an appropriate breast pump through insurance used to be a challenge prior to passage of the Affordable Care Act (ACA). Many insurance policies did not cover the cost of lactation support or equipment related to breastfeeding, and families were not reimbursed for expenses incurred through pump rental or purchase. Research on programs that directly provided breast pumps to mothers prior to ACA showed dramatically improved rates of human milk provision for their infants.^{56,77,78} Although ACA legislation had already been passed at the time study was investigating, the requirement for breastfeeding provisions went into effect for new insurance policies on or after August 1, 2012, and were not required of preexisting policies.⁷⁹ These coverage gaps may explain the variety of ways in which our mothers obtained and utilized their pumps. Nonetheless, the practice of borrowing/sharing single-use breast pumps is not advised or encouraged. We now encourage mothers to investigate their insurance plan's provisions for covering the cost of breast pump rental or purchase and for coverage of pre- and postnatal breastfeeding education by a lactation specialist or other trained provider.^{17,52,63,79,80} Since this time, we have empirically seen overall improvements in mothers' access to breastfeeding resources. Early studies have shown some improvements in duration of human milk provision but not in rates of initiation as a result of ACA implementation.⁸¹

Limitations

The primary limitation of this study is the potential for recall bias in the responding mothers. Because of our interest in understanding breastfeeding practices

Summary of Recommendations for Practice and Research

What we know:

- Children with cleft lip and/or palate can present with feeding challenges that may limit a mother's ability or interest in breastfeeding or expressing human milk for her infant.
- Mothers of children with cleft lip and/or palate may be discouraged from providing human milk by medical providers who are uncomfortable or unfamiliar with cleft feeding standards and recommendations.
- Individual child and maternal factors can affect the rates of human milk provision for children with clefts.

What needs to be studied:

- Formalized education and lactation support programs designed to promote sustained human milk provision in the ambulatory setting.
- Provider attitudes and knowledge regarding human milk provision in the multidisciplinary cleft care setting.
- Prospective comparison of breastfeeding outcomes between prenatal and postnatal diagnoses of cleft lip and/or palate.

What we can do today:

- Encourage mothers of infants with cleft lip and/or palate to provide human milk to their infants starting as soon as the cleft is identified.
- Provide recurring ambulatory assistance for these mothers in the form of education, lactation support, and medical-grade breast pumps to facilitate human milk expression if the infant is unable to feed directly at the breast.
- Make breastfeeding and human milk provision to these vulnerable infants a priority of multidisciplinary cleft-related care.

over the first year of life, all children were 1 to 2 years of age when their mothers were surveyed. This naturally creates a time delay that increases the potential for inaccurate reporting of data including the duration of breastfeeding, initial reasons for starting or stopping, or instances of encouragement or discouragement. The stress surrounding the birth of a child with a cleft, associated feeding issues, and 1 or more cleft-related surgical procedures in the first year of life might further contribute to poor recall of details related to this issue.

Other issues include the relatively small size of the survey group. We elected to study this particular group of children and their mothers because they were cared for prior to the institution of specific changes in our cleft team protocols for intake, education, and support. This group will serve as a baseline for comparison for any future research on the impact of breastfeeding interventions in our cleft lip and palate population. Our inability to contact 32 of our mothers reduced our total survey responses. Nonetheless, we successfully surveyed more than half of the potential mothers and the fairly consistent data we obtained suggest that the remaining mothers could reasonably be expected to represent a similar picture of our breastfeeding mothers' activities and experiences.

CONCLUSIONS

Breastfeeding in the cleft lip and palate population is a complex, multifactorial issue for every affected family. This survey of mothers of children with cleft conditions revealed a relatively high rate of initiation of breastfeeding or expression of human milk. While we had a 78% rate of initiation, only 32% continued

supplying human milk for the recommended 6 months or more. Cleft team providers were not cited as a particularly memorable source of support or encouragement for breastfeeding despite having a nutritionist, a lactation nurse, and a feeding therapist meet with all families of newborns at their first cleft team visit. We have identified areas where we, as healthcare providers, can do more to support our families in their choice to provide human milk to their infants with cleft conditions. These families may benefit from earlier contact, directed education, informational handouts, peer support, and the ready availability of breast pumps. Potential strategies to improve breastfeeding outcomes should include validating mothers' concerns, continuing supports for the long term, and engaging family participation/support for breastfeeding mothers. This study has allowed us to establish a baseline for future prospective studies looking at the impact of active encouragement and provision of breastfeeding support in the cleft team setting. By directly acknowledging the increased challenges faced by families caring for infants with clefts, we can help mothers overcome many common obstacles to providing human milk for their infants.

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Editor Spotlight: Paula Forsythe



Paula Forsythe, MSN, CNS; recently retired as CNS for Neonatal Services for 31 years from Rainbow Babies and Children's Hospital, University Hospitals Cleveland Medical Center. Currently Adjunct Assistant Professor at Frances Payne Bolton School of Nursing, Case Western Reserve University assisting with neonatal physical assessments.

I have been a NANN member and Editorial Board Member for twelve years.

I became a board member to educate and impart knowledge to colleagues and to publish current, relevant information and create/maintain a respected professional reference source for neonatal nurses. Information changes rapidly as new facts/discoveries occur and the ANC journal is the method by which this information is shared.

Fun fact: I am a curler (game played on ice) and my team won a national ladies' curling championship.

