

Feeding Information and Considerations for Infants with Cleft Lip and/or Palate

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Author Note

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When an infant is born with cleft lip and/or palate, the parents become instantly tasked with the important job of how to best care for their new baby with special needs. In addition to the surgical and therapeutic decisions from healthcare professionals that need to be considered by the parents, proper feeding care for the infant must be considered and implemented. Until the infant's primary palatoplasty is performed at approximately nine months of age, adjustments typically need to be made to accommodate the infant's abnormal feeding needs (Perry, 2012). In addition to healthcare professionals ensuring that the infant's needs are being met, it is also important for healthcare professionals to provide support for the parents' needs as they adapt to their new situation, especially in the area of emotional well-being.

Overview of the Normal Feeding Process in Infants

In order to appreciate the feeding process and challenges associated with infants born with cleft lip and/or palate, it is important first to understand the normal feeding process for infants. Infant feeding consists of two major parts: sucking and swallowing (Clarren, Anderson, & Wolf, 1987). In order to achieve sucking, an infant must be able to generate negative intraoral pressure combined with oral muscular movements (Clarren et al., 1987). For negative intraoral pressure to be achieved, the infant must be able to create a closed intraoral system by sealing the lips and the velopharyngeal port (Clarren et al., 1987). Once this seal is created, the infant then expands the intraoral cavity, through contraction of the musculature of the tongue or the contraction of the musculature of the mandible, and thereby creates negative intraoral pressure (Clarren et al., 1987). The created negative intraoral pressure allows for the fluid from either the bottle or the mother's breast to flow into the infant's oral cavity, at which time it can be

swallowed by the infant. Additionally, normal feeding in infants includes a feeding pattern that is organized and has a rhythmic sucking and pause pattern (Masarei et al., 2007).

Overview of the Feeding Process in Infants with Cleft Lip and/or Palate

Infants born with cleft lip and/or palate are not able to necessarily participate in the feeding process as are infants both without cleft lip and/or palate. While an infant with cleft lip and/or palate may otherwise be born healthy, and therefore be able to attempt the normal feeding processes of sucking and swallowing, this does not remediate the loss of feeding functionality due to anatomical compromise (Clarren et al., 1987).

Cleft Lip Only

Typically, an infant born with cleft lip only does not present with feeding difficulties (Perry, 2012). Since the infant's intraoral anatomy is intact, the ability to create a seal for negative intraoral pressure is not compromised. Initially, the infant may have some difficulty with latching on due to the abnormal formation of the lip (Perry, 2012). However, as the infant adjusts to his/her own anatomy, this feeding problem disappears unless the infant is experiencing air leakage through the cleft lip (Clarren et al., 1987; Perry, 2012). In this case, the infant would be unable to generate the necessary negative intraoral pressure and accommodations would need to be made (Clarren et al., 1987).

Cleft Lip and Palate or Cleft Palate Only

The focus of feeding support for infants with cleft lip and/or palate will primarily be for those who have cleft palate only or cleft lip and palate.

Sucking. An infant born with cleft lip and palate or cleft palate only is presented with the inability to create the seal necessary to generate negative intraoral pressure (Perry, 2012). This is due to a lack in structural integrity and/or muscular ability (Perry, 2012). Since the infant

with cleft lip and palate or cleft palate only is unable to generate negative intraoral pressure, this means that the sucking process that is seen in the normal feeding processes of infants is unable to occur. In addition to the difficulty in generating negative intraoral pressure, Masarei et al. (2007) found that infants with cleft lip and palate or cleft palate only exhibit a disorganized sucking pattern that, relative to the sucking pattern in infants without cleft lip and/or palate, includes shorter sucks, accelerated sucking rate, and a higher suck-swallow ratio. Also, as might be expected given an inability to properly generate negative intraoral pressure, Masarei et al. (2007) found that infants with cleft lip and palate or cleft palate only generated greater positive intraoral pressure when attempting to suck. As such, given all the findings discussed, compensatory feeding options need to be tried until one is found that is appropriate for the infant with a compromised sucking ability. These feeding options will be further discussed in a later section of this paper.

Swallowing. It is generally accepted that infants with cleft lip and/or palate possess an oral phase dysphagia, although this is typically less of a problem for infants with cleft lip only (Clarren et al., 1987; Masarei et al., 2007). There is, however, disagreement among researchers as to the presence of a pharyngeal phase dysphagia in infants with cleft lip and/or palate (Masarei et al., 2007). Clarren et al. (1987) assert that infants with cleft lip and/or palate swallow normally. However, Perry (2012) states that nasal reflux is an issue for infants with cleft lip and/or palate. Furthermore, Zickefoose (1957) and Tisza and Gumpertz (1962) suggest (as cited in Masarei et al., 2007) that infants with cleft lip and/or palate have compromised airway protection. Again, even with the various dysphagias that can occur, it is crucial to use available compensatory strategies and feeding options to ensure successful feeding for infants with cleft lip and/or palate.

Breastfeeding and Assisted Feeding Options for Infants with Cleft Lip and/or Palate

There are several feeding options available to infants with cleft lip and/or palate including many assisted feeding options and, when possible, breastfeeding (Perry, 2012). When a feeding plan is being developed the feeding method wishes of the parents must be honored and considered on an individual basis (Perry, 2012).

It is important to take note that infants, both with and without cleft lip and/or palate, utilize different feeding techniques for breastfeeding and bottle feeding (Clarren et al., 1987). In both cases, negative intraoral pressure is used (Clarren et al., 1987). However, in the case of breastfeeding, the tongue is the primary intraoral structure infants use, and positioning and stabilization is achieved through the use of negative intraoral pressure (Clarren et al., 1987). For bottle feeding, the gums are the primary structure used to both position and stabilize the bottle while also extracting the fluid (Clarren et al., 1987). The tongue and palate are used secondarily to aid this feeding process (Clarren et al., 1987). These differences are important to keep in mind when designing and selecting a feeding plan for an infant with cleft lip and/or palate.

Breastfeeding

Organic. Breastfeeding is not typically a viable option for infants with cleft lip and palate, nor is it a viable option for infants with a wide cleft palate only because of the infant's inability to generate the necessary seal for negative intraoral pressure (Clarren et al., 1987). However, Clarren et al. (1987) found that breastfeeding typically works in infants with either a narrow cleft palate or a posterior cleft palate because these infants are still able to stabilize the mother's nipple sufficiently to generate negative intraoral pressure through the use of the anterior palate and the tongue. Additionally, it was found that breastfeeding is typically successful in

infants with cleft lip only due to the pliable nature of the mother's breast to mold to and fill any gap in the infant's lip (Clarren et al., 1987).

Non-organic. For parents who feel strongly that their infant with cleft lip and palate or a wide cleft palate only still achieve the breastfeeding experience, there are options available. One available option is the "Lact-Aide" which is a milk delivery system in which the mother mechanically pumps her breast milk, puts her breast milk in a milk bag, and feeds it to the infant through a small, plastic tube that is attached to the milk bag (Clarren et al., 1987). In this method, the mother controls the delivery of the milk to the infant (Clarren et al., 1987). When using the "Lact-Aide" as the feeding method, the infant simultaneously sucks on the mother's nipple and the small, plastic tube, thus allowing for the infant to experience the natural process of sucking, that is involved in breastfeeding, while still receiving nutrition (Clarren et al., 1987).

Bottle Feeding with a Regular Bottle and Regular Bottle Nipple

Traditional bottle feeding, with a standard bottle and a standard bottle nipple, is not typically indicated for infants with cleft lip and/or palate (Clarren et al., 1987).

Bottle Feeding with a Bottle and/or Bottle Nipple Modification

Bottle and/or bottle nipple modification is needed for most infants with cleft lip and/or palate (Clarren et al., 1987). Fortunately, there are a wide variety of available options (Kummer, 2008). The following sections will explore several of the options that tend to be the more effective selections from what is available (Kummer, 2008).

Mead Johnson cleft lip/palate nurser. The Mead Johnson Cleft Lip/Palate Nurser is one of the more popular assisted feeding options for infants with cleft lip and/or palate (Perry, 2012). This option is comprised of a soft, squeezable bottle and a long, soft nipple with a cross-cut hole (Kummer, 2008; Perry, 2012). With the longer nipple, the fluid is able to be placed

further back in the infant's mouth which aids the feeding process (Kummer, 2008; Perry, 2012). When using this assisted feeding option, the infant is not required to suck, and instead the infant extracts the fluid from the bottle by chewing on the nipple (Perry, 2012). Additionally, the parent feeding the infant is the one to control the rate of flow of the fluid through squeezing the bottle (Kummer, 2008; Perry, 2012). As such, this model would be best for an infant with cleft lip and palate or cleft palate only, especially if the cleft of the palate is wide (Clarren et al., 1987; Kummer, 2008). An additional benefit of the Mead Johnson Cleft Lip/Palate Nurser is that the special nipple can fit a standard bottle and a standard nipple can fit the special, squeezable bottle (Kummer, 2008; Perry, 2012).

Haberman feeder. The Haberman Feeder is another one of the more common and popular assisted feeding options for infants with cleft lip and/or palate (Perry, 2012). This option has a soft nipple with a slit hole (Kummer, 2008). The rate of flow is controlled by the person feeding the infant through the positioning and orientation of the slit-hole in the infant's mouth (Kummer, 2008; Perry, 2012). Additionally, this assisted feeding option allows for the person feeding the infant to squeeze the bottle to assist with the infant's intake of fluid (Kummer, 2008). The Haberman Feeder is designed such that the infant does not need to suck and the fluid is dispensed through the infant compressing the nipple (Kummer, 2008; Perry, 2012). An additional benefit of the Haberman Feeder is that it provides the option of a spoon attachment through which the parent feeding the infant can pour the fluid into the infant's mouth if this method became necessary (Perry, 2012). Given all of the aforementioned features, this model would be best for an infant with cleft lip and palate or cleft palate only, especially if the cleft of the palate is wide (Clarren et al., 1987; Kummer, 2008; Perry, 2012).

Ross cleft palate nurser. The Ross Cleft Palate Nurser could be an assisted feeding option for infants with cleft lip and palate or cleft palate only. This option consists of a bottle that has a special nipple which is long and thin (Kummer, 2008). A beneficial feature of this option is that the nipple is compatible with standard bottles (Kummer, 2008). The Ross Cleft Palate Nurser allows for the fluid to be delivered into the infant's mouth with little need for the infant to suck (Clarren et al., 1987). The nipple on this bottle is soft and has a large hole for fluid delivery (Kummer, 2008). This option may be good for some infants with cleft lip and palate or cleft palate only because the long nipple: may be able to bypass the cleft palate, minimizes the need for sucking, and could be attached to a squeezable bottle since it allows for transfer to different bottle types (Clarren et al., 1987; Kummer, 2008). However, the healthcare professional and parents must be careful when using this option (Kummer, 2008). Due to the long length of the nipple, the Ross Cleft Palate Nurser could cause the infant to gag (Kummer, 2008). Additionally, because this bottle's nipple has a large hole, the fluid flows out quickly and thus increases the risk for aspiration for the infant if the infant is unable to coordinate his or her breathing and swallowing systems to handle this bottle's rate of fluid delivery (Kummer, 2008).

NUK nipple. The NUK nipple is another specially designed nipple that can help infants with cleft lip and/or palate (Clarren et al., 1987; Kummer, 2008). Typically, this nipple is indicated for infants with cleft lip only (Clarren et al., 1987; Kummer, 2008). The NUK nipple has a wide, flat base, and it is made out of more pliable material (Kummer, 2008). An infant with cleft lip only is typically successful with the NUK nipple because the wide, flat base conforms to the gap in his or her lip, thus allowing the infant to achieve the required lip seal for negative pressure generation for feeding (Clarren et al., 1987; Kummer, 2008). The NUK nipple is able to be transferred to a squeezable bottle so that the parents can assist in fluid delivery to

the infant, if necessary (Kummer, 2008). It should also be noted that while this type of nipple with a wide, flat base is commonly referred to as a NUK nipple, other manufacturers, including Gerber and Playtex, have also created their own versions of this type of nipple (Kummer, 2008).

Pigeon nipple. Another specially designed nipple is called the Pigeon nipple (Kummer, 2008; Perry, 2012). This nipple is special because one side of the nipple is hard and one side of the nipple is soft (Kummer, 2008; Perry, 2012). When feeding the infant with cleft lip and/or palate, the hard side of the nipple is positioned toward the infant's hard palate, and the soft side of the nipple is positioned toward the infant's tongue (Kummer, 2008; Perry, 2012). The Pigeon nipple has the added benefit that it can be used on other standard bottles (Kummer, 2008).

Preemie nipple. Preemie nipples are soft nipples that are also thin and small, and they provide fast fluid delivery (Kummer, 2008). Using a preemie nipple is another option for infants with cleft lip and/or palate, and it is typically best suited for infants with a narrow or posterior cleft palate only provided that they are able to coordinate their breathing and swallowing systems to handle the faster fluid delivery (Clarren et al., 1987; Kummer, 2008). When using a preemie nipple, the combination of the pliability of the nipple and the faster flow of the fluid make for a more successful feeding situation for the infant with cleft palate only, given that a strong suck is not required; however, it is likely that the additional use of a squeezable bottle with a preemie nipple would be necessary so that the parents can aid in fluid administration to the infant (Clarren et al., 1987; Kummer, 2008).

Associated Issues in the Feeding of Infants with Cleft Lip and/or Palate

Timely support and implementation of a successful feeding plan is highly important for a variety of reasons. It is not only important for the well-being of the infant, but it is also important for the well-being of the parents (Perry, 2012). Satisfying both the infant's needs and

the parents' needs are crucial to having a successful transition for families (Perry, 2012).

Without this success, several associated issues could take place.

The Infant

Infants who are born with cleft lip and/or palate, and without an accompanying syndrome, are presented with obstacles from the moment they are born in comparison to infants who are born without cleft lip and/or palate. Fortunately, these obstacles are typically overcome with time and extra effort from the infant's parents (Perry, 2012). The discussion of infants with cleft lip and/or palate and an accompanying syndrome will not be addressed as it is beyond the scope of this paper.

Failure to thrive. Differences have been shown across research studies as to whether an infant born with cleft lip and/or palate and without a syndrome will have a problem with failure to thrive. In a retrospective study of 307 infants with cleft lip and/or palate and without a syndrome, Zarate et al. (2010) found that while there were some percentile decreases in weight and length in the infant's first year of life, these findings were not clinically significant, and with time, the infants recovered from this decrease. However, Beaumont (2008) found, in a retrospective research study of 145 infants with cleft lip and/or palate and without a syndrome, that infants with cleft palate only experienced higher levels of failure to thrive. Beaumont's study from 2008, is unclear in its findings because, while the conclusions of the study stated that infants with cleft palate only experienced higher levels of failure to thrive, it was not stated if these conclusions apply to infants with cleft palate only who have or do not have a syndrome. Earlier in Beaumont's study from 2008, it seemed to be indicated that failure to thrive was not too great of a concern for infants with cleft lip and/or palate without a syndrome, but again, the findings of the study are just unclear. Additionally, the study stated that a disproportionate

number of infants with cleft lip and/or palate and low birth weight were used in the study (Beaumont, 2008). Regardless of the contradictory findings in the studies regarding failure to thrive, what is important to remember are the additional findings of Zarate et al. (2010) in which they found that early feeding interventions and feeding education for parents seemed to have positive effects on the growth of infants with cleft lip and/or palate without a syndrome.

Infant stress and fatigue. It is important to manage any presence of stress and/or fatigue for infants with cleft lip and/or palate. For an infant who is already having difficulty with feeding, added stress from potentially having a difficult time securing a successful feeding method only exacerbates the problem (Perry, 2012). Additionally, if an unsuccessful feeding method is being used, then it will take the infant longer to feed, and he or she will need to feed more often (Perry, 2012). This process would lead to the infant becoming quite fatigued (Perry, 2012). If successful feeding of the infant with cleft lip and/or palate is delayed too long, this will undoubtedly cause the infant's parents to feel stress, which in turn will transfer to the infant, and the stress of the infant will only hinder successful feeding from occurring (Perry, 2012).

The Parents

While it is of utmost importance to ensure the infant's nutritional needs are being met through proper feeding care, it is also highly important to provide a successful feeding program so that parents' needs are met.

Parent and infant bonding. Research studies have looked at the difficulty in bonding between mothers and infants with cleft lip and/or palate. After completing a research study with 126 mother and infant pairs, Endriga, Speltz, Maris, and Jones (1998) found that, during feeding, infants with cleft lip and palate were less communicative with their mothers than infants without cleft lip and palate. This resulted in a diminished mother-infant bond (Endriga et al., 1998).

Endriga et al. (1998) also found that this disparity in decreased infant communication regarding feeding resolved itself by 12 months of age for the infant. A different research study found similar results. Speltz, Goodell, Endriga, and Clarren (1994) found that, when compared to infants without cleft lip and/or palate, infants with cleft lip and palate or cleft palate only had less clear communication, related to feeding, with their mothers and that mothers of infants with cleft lip and palate or cleft palate only had a more difficult time picking up cues from their infants. The infants with cleft lip and palate were found to smile less, have decreased ability to signal their readiness to eat, and have decreased ability to display before and after differences in tension regarding feeding when compared to infants without cleft lip and/or palate (Speltz et al., 1994). The infants with cleft palate only also exhibited similar deficits; however, these deficits were not found to be statistically significant (Speltz et al., 1994). Given these findings, Speltz et al. (1994) expected to find decreased maternal responsiveness to their infants with cleft lip and palate or cleft palate only; however, this was not the case. Speltz et al. (1994) found that despite having an infant who was more difficult to feed and less responsive, these infants' mothers were still responsive to their infants and were found to smile at their infants just as much as the mothers of infants without cleft lip and/or palate. Both studies mentioned in this section reinforce the importance of healthcare professionals to attend to the needs to mothers and infants with cleft lip and/or palate. Since feeding is such a large part of an infant's life, assistance and education to ensure this is as effortless of a time as possible is essential.

Parental stress and anxiety. As might be expected, the birth of an infant with cleft lip and/or palate would likely be stressful and anxiety-producing for the parents involved. Chuacharoen, Ritthagol, Hunsrisakhun, and Nilmanat (2009) created a research study to examine the needs of parents, in Thailand, of infants with cleft lip and/or palate and without a syndrome.

One of the top needs of the parents that Chuacharoen et al. (2009) found was that they had concerns about the feeding care of their infant. Additionally, according to Chuacharoen et al. (2009), they had other major questions and concerns about the surgeries their infants would endure, if or how their infant would speak, and how they would fund the financial needs of their infant with cleft lip and/or palate. As mentioned above, an infant can sense when his or her parents are feeling stress or anxiety, and so, it is essential that healthcare professionals support and attend to the emotional needs of the parents to create the opportunity for success in the infant's feeding, in addition to also generally improving the health and happiness of the family (Perry, 2012).

Parental fatigue and time management. The introduction of a new infant into any family takes a toll on the parents. Many adjustments and transitions need to be made in order to ensure a healthy and happy family. However, in the case of a new infant with special needs, like cleft lip and/or palate, the family will undoubtedly have more information to process, more details to attend to, and more transitions to adjust to than a family with an infant without special needs. Parents of an infant with cleft lip and/or palate will need to attend more doctors' appointments than other parents may need to attend. Additionally, parents of an infant with cleft lip and/or palate will have to put more time and effort into keeping detailed notes about the feeding occurrences with their infant for the purposes of appointments with healthcare professionals (Perry, 2012). The parents will have to do all of these things in addition to overcoming the typical stressors that parents of an infant face (e.g., decreased sleep). It is important that healthcare professionals are mindful of, supportive of, and sensitive to the level of fatigue that the parents are experiencing, any difficulty with time management that is occurring, and whatever other needs the parents feel that they have.

Conclusion and Recommendations

There are many considerations that need to be taken into account by healthcare professionals when working with families who have an infant with cleft lip and/or palate. These families have a big transition to make, and it is important that they have assistance in this matter. Feeding, of course, does not only need to be included in this assistance but is also a high priority not only for reasons of nutrition and ability to thrive, but it is also a priority because of the emotional impact feeding has on the infant and the family. As such, it is crucial that healthcare professionals support and educate families of an infant with cleft lip and/or palate to create a successful family dynamic as early in the infant's life as possible.

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