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Feeding Therapy and Techniques for Children with Cleft Lip/Palate

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FEEDING THERAPY AND TECHNIQUES FOR CHILDREN WITH CLEFT LIP AND/OR
PALATE

by

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Bachelor of Arts, Purdue University, 2009

A Research Paper
Submitted in Partial Fulfillment of the Requirements for
the Master of Science Degree

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Reports of feeding difficulties, as a result of cleft lip and palate, date back to 1619 by Fabricus of Aquapendente (Reid, Reilly, & Kilpatrick, 2007). It was recognized when children with a cleft lip, cleft palate, or a combined cleft lip and palate were unable to adequately suck and often died of malnutrition. Fast forward a few centuries and failure-to-thrive continues to be a concern regarding infants with cleft lip +/- palate.

The high rate of morbidity and high occurrence of death in infants makes cleft lip +/- palate an important category of congenital defects (Amstalden-Mendes, Magna, & Gil-da-Silva Lopes, 2007). It is estimated that one in every 750 to 1,000 live births has a cleft lip +/- palate which occurs during embryonic development (Mizuno, Ueda, Kani, & Kawamura, 2002). It has been found that feeding difficulties associated with the presence of a cleft are due to insufficient suction, regurgitation through the nasal cavity, and reduced food intake (Amstalden-Mendes et al., 2007). Feeding is an immediate concern due to the delay in growth of children born with clefts as compared to those without clefting (Glenny, Hooper, Shaw, Reilly, Kasem, & Reid, 2008). This can be a major concern for infants who will be undergoing surgery to correct their

cleft. These infants need to maintain a healthy weight to tolerate a major surgery.

Different feeding techniques are appropriate for different types of clefts including: cleft lip, cleft palate, and cleft lip and palate. Feeding techniques found to be useful for cleft lips +/- palates include: manual nipple stimulation and movement, nipple modifications, palatal prostheses, and other appliances (Reid, 2004). Feeding problems related to cleft lip +/- palate are not only an issue for the infant, but for the family as well. Lack of maternal bonding and other family problems due to stress can co-occur with feeding problems. There are multiple feeding difficulties associated with cleft lip +/- palate, and appropriate feeding techniques should be used with particular clefts.

Speech-Language pathologists are greatly influenced by clefts of the lip +/- palate. The SLP may be involved from the time of birth, and sometimes into childhood. The child may be affected by the cleft in several ways (low weight, failure to thrive, malnutrition, etc), and thus the SLP will work with them in many of these areas. The SLP should understand the function and purpose of the oral and nasal

structures to provide the best possible care for children with these malformations.

Cleft Lip +/- Cleft Palate Defined

A cleft lip is a craniofacial malformation that occurs during the embryonic stage of life (Amstalden-Mendes et al., 2007). The embryonic stage of life occurs from implantation of the fertilized egg until about the tenth week of pregnancy, when the embryo becomes a fetus. The Cleft Lip and Palate Association in the UK describe a cleft lip as "an opening in the upper lip between the mouth and the nose. It can range from a slight notch in the coloured portion of the lip to the complete separation in one or both sides of the lip extending up into the nose" (Glenny et al., 2008 p.2). A cleft lip can be unilateral or bilateral, and can be partial or extend all the way up into the nose.

Cleft lips can, and usually do, negatively affect the feeding process of infants (Glenny et al., 2008). Without adequate closure around the nipple, the infant may have problems producing a suck powerful enough to extract milk from the breast or bottle nipple. Infants with bilateral cleft lips sometimes have problems with intraoral muscular movements (Clarren, Anderson, & Wolf, 1987). However, with

a mild unilateral cleft lip, closure can generally be obtained, and feeding can be successful (Glenny et al., 2008). Appropriate feeding techniques need to be used for the different severities of a cleft lip to assure adequate nutrition for development and growth.

A cleft palate is another type of craniofacial malformation that occurs during the embryonic stage of life. Glenny et al. (2008, p.2), describe a cleft palate as occurring when "the roof of the mouth is not joined completely. This can range from just an opening at the back of the soft palate, to a nearly complete separation of the roof of the mouth (soft and hard palate)". This type of opening can cause many problems with the infant's feeding and swallowing.

Sometimes infants are born with a cleft lip and palate (i.e. cleft lip + palate). This type of cleft extends from the lip to the hard or soft palate. Infants with this type of cleft normally have extensive feeding difficulties and are often unable to breast-feed successfully (Klein et al., 1994) A cleft of the lip and palate will usually result in an inability to form a complete seal, and negative air pressure cannot be generated efficiently enough to expel

the milk and trigger a successful swallow (Arvedson & Brodsky, 1992)

There is great variability in feeding abilities of infants with a cleft palate. This variability can range from little or no feeding problems at all, to extensive feeding problems with nasopharyngeal reflux, choking, prolonged feeding time, and slow or little weight gain (Arvedson & Brodsky, 1992). A primary feeding concern associated with cleft palate is the formation of negative air pressure, necessary for adequate swallowing (Arvedson & Brodsky, 1992). Without negative air pressure, a swallow cannot be properly triggered and aspiration or choking may occur.

Early Feeding-Related Challenges

Weight gain during infancy is affected by the presence of a cleft. Infants who are born with a cleft lip +/- palate are reported to have average birth weights that similarly compare to infants who are born without a cleft lip +/- palate (Arvedson & Brodsky, 1992). However, infants with a cleft lip +/- palate have been found to have significantly lower weight gain in the first two years of life than infants without clefts (Arvedson & Brodsky, 1992). Male infants with a cleft lip +/- palate are more

likely to be affected than female infants (Arvedson & Brodsky, 1992). According to a study by Turner et al., (2001), weight gain was the poorest in infants with a cleft palate only.

Infants with an intact lip and palate are able to create negative intraoral pressure. They are able to do this because their lips make a tight seal around the nipple, whether it is a breast or bottle nipple (Arvedson & Brodsky, 1992). Also with an intact palate, the tongue is able to produce a rhythmic suckling pattern for extracting milk from the nipple. With an intact palate, the posterior soft palate elevates to close off the nasopharynx, this is not possible for infants with a cleft palate (Arvedson & Brodsky, 1992). Due to the inability to create intraoral pressure and use a suckling pattern, these infants with a cleft condition have complex feeding difficulties, and are at a high risk of laryngeal penetrations and aspiration (Reid et al., 2007). Recurrent aspiration for these patients can result in respiratory infections including pneumonia, and even death (Reid et al., 2007). Clinical signs and symptoms associated with the inability to develop negative intraoral pressure include: inefficient or ineffective suck, and excessive air intake. This excessive

air intake may result in choking and/or gagging (Arvedson & Brodsky, 1992).

Infants with bilateral cleft lip have more involved complications associated with feeding. These infants may require more care than infants with a unilateral cleft lip alone (Arvedson & Brodsky, 1992). Infants who cannot get sufficient nutrients from breast-feeding may need supplemental feeding from bottles, and some infants who cannot feed from either may need tube feeding to increase their weight (Arvedson & Brodsky, 1992).

Infants with a cleft lip +/- palate also experience more intraoral muscle dysfunction than infants without a cleft lip +/- palate. This is evident in their sucking performance. Successful sucking depends on coordinated muscle movements (Arvedson & Brodsky, 1992). Due to this lack of coordinated muscle movements, negative intraoral pressure is not easily achieved. This problem is most common in infants with a cleft palate, especially those who also experience central nervous system deficits (Arvedson & Brodsky, 1992). Clefting of the hard palate may also limit the normal use of the tongue to compress the nipple, whether it is a breast nipple or a bottle nipple (Glenny et al., 2008). There is generally insufficient suction to

extract the milk from the bottle or breast (Glenny et al., 2008).

Infants with cleft palates experience nasopharynx reflux and even nasal regurgitation during nipple feeding because the nasopharynx is not closed off properly, causing an opening between the oral and nasal cavities (Arvedson & Brodsky, 1992). The soft palate is not intact and therefore, when it is elevated it does not create a barrier in which food and liquid cannot pass through the nasopharynx. Signs and symptoms associated with the inability to seal off the nasal cavity include: nasal reflux, and inefficient or ineffective suck (Arvedson & Brodsky, 1992). Another problem infants experience in association with cleft palate is sticky or pasty foods getting stuck in the cleft (Masarei, Sell, Habel, Mars, & Wade, 2007).

The impact of a cleft is not necessarily restricted to the oral cavity. There may be airway deficits due to a cleft palate. Clinical signs or symptoms associated with an upper airway obstruction are: inspiratory stridor (i.e. a high-pitched wheezing sound heard during inspiration), Glossoptosis (i.e. abnormal down or back placement of the tongue), Micrognathia (i.e. unusually small jaws)(Arvedson

& Brodsky, 1992). There may also be neurological impairments present as well. Clinical signs or symptoms related to neurological impairments coinciding with a cleft include: incoordination of suck, swallow, and respiratory sequence, hypotonicity, and hypertonicity (Arvedson & Brodsky, 1992).

Role of Early Intervention Providers

Speech-language pathologists and early intervention providers can assist in training families to utilize techniques for facilitating feeding. For many mothers, breastfeeding is the goal. Success of breast-feeding depends on many factors, including the size of the breast, the size of the baby, and the severity of the infant's cleft (Delaney, 1994). To start the flow of milk when breast-feeding, the feeder should massage out a little milk before feeding begins. In some instances "plugging" (p.250) the cleft may prove to be effective (Clarren et al., 1987). To help create the needed suction, a mother can gently hold the upper lip together while breast-feeding (Delaney, 1994). When successful breast-feeding cannot be achieved with these infants, an artificial nipple with a large soft base may be desirable (Clarren et al., 1987).

Supplementary nursing systems can also be used. This means that the mother may pump, and the milk may be used for bottle feeding, along with direct attachment to the breast. Advantages for this technique include: (a) assurance of food for the infant whether or not the nursing is actually successful, (b) no confusion about nipples since all feeding occurs at the breast, and (c) the infant improves the sucking technique because the sucking urge is satisfied with the expulsion of milk (Arvedson & Brodsky, 1992.) Klein and Delaney (1994, p. 381) stated that "these babies often use more of a chewing action on the nipple than a sucking one". In many instances, these infants need supplementary nutrition to ensure proper growth and development. Many bottle nipples may be used with infants who have a cleft lip +/- palate. These infants need a nipple that will respond to compression without the need to build up intraoral pressure for feeding (Arvedson & Brodsky, 1992). Popular options for nipples appropriate for infants with cleft lip +/- palate include: a standard nipple with a fairly large cross-cut at the tip, the Mead-Johnson cleft palate nurser, and the Haberman feeder (Arvedson & Brodsky, 1992).

The Haberman feeder is specifically designed for cleft lip +/- palate use. Its elongated nipple can be compressed if the infant has difficulty in applying adequate negative pressure (Mizuno et al., 2002). Nipples with a Y-cut on the end, and a long and wide shaft are also useful for infants with cleft lip and palate (Mizuno et al., 2002). The Haberman feeder has been proven to be helpful with feeding because it has flow lines on the nipple that assist in helping the infant achieve optimal flow from the nipple (Arvedson & Brodsky, 1992). It is also popular because the flow can be monitored without the necessity of squeezing the bottle. Finally, it is popular because of the valve that prevents back flow, which reduces the excessive air buildup (Arvedson & Brodsky, 1992.) The excessive air buildup can cause uncomfortable gas and stomach problems as well as burping. It is important to burp your baby frequently to relieve excessive air buildup. SLPs can provide recommendations on feeding tools such as nipples or bottles to facilitate safe and adequate oral nutrition.

In conjunction with proper nipple selection, positioning and pacing during feeding are utilized to promote oral feeding. Infants should be in an upright position with good head neck and trunk support (Klein et

al., 1994). According to a study by Reid (2004), feeding times should be limited so that infants do not experience hunger and unsatisfactory feeding. These feeding techniques listed above can be helpful in ensuring that the infant is getting appropriate nutrition and is feeding in a safe and timely manner.

Different techniques work for individual infants with cleft lip +/- palate. However, each of these infants has an increased risk of feeding difficulties. In a study by Clarren et al. (1987), 53 infants with cleft lip +/- palate were assessed for the most successful feeding technique. The general solution for successful feeding was to deliver the milk directly into the mouth (Clarren et al., 1987). The infants were not able to feed well using a bottle or the breast. They were unable to form a seal with their lips or their velopharynx. Because of the opening in their palate, the infants were also unable to appropriately position the nipple for compression. They were unable to form efficient suction on a bottle nipple. The most appropriate feeding technique was any type of device that delivered adequate milk into the mouth, and allowed the infant time to swallow. When bottle feeding, a soft plastic bottle was effective, because the feeder was able to

control the amount of milk expelled into the infant's mouth. When breast feeding was desired, the mother expressed milk by placing the infant in a supine position and expressing milk directly into the infant's mouth. The device, "Lact-aide" (Clarren et al., 1987, p.152), was used for infants in whom mothers wanted to keep the infant approximating breast feeding. The "Lact-aide" (Clarren et al., 1987, p.152) delivers milk into the baby's mouth through a small tube while the infant is placed at the breast. This may be helpful in improving the infants sucking ability by satisfying their sucking action.

Feeding is not the only activity that infants with cleft lips +/- palates require special care. Oral care after feeding is also very important. Once the infant is finished feeding, the areas around the cleft should be cleaned (Arvedson & Brodsky, 1992). If food is left to accumulate it can mix with mucous secretions from the mouth and nose and form a hard crust that becomes a potential source for infection (Arvedson & Brodsky, 1992). To clean these areas, you can use clean water, or water with hydrogen peroxide (Arvedson & Brodsky, 1992). Place it on a wash cloth or gauze (Arvedson & Brodsky, 1992). If the cleft lip becomes dry, it can be moistened using mineral

oil externally, without letting the mineral oil get into the infants mouth (Arvedson & Brodsky, 1992).

Sugar intake of babies old enough to have teeth with cleft lip and palate is also a reason oral care is important. In patients with a cleft lip and palate it is more difficult to properly clean the maxillary incisors due to the clefting (Dalben, Costa, Ribeiro-Gomide, & Teixeira das Neves, 2003). Cleaning after surgery may also be a problem due to scar tissue and immobility (Dalben et al., 2003). According to a study by Dalben et al. (2003), a sample of babies 7 to 12 months, and 12 to 18 months, born and living in Brazil, were used to analyze the number of daily contacts with sugar. It was found that only three percent were breast-fed. More than half of these babies studied had their first contact with sugar in the first month of life. This contact occurred primarily through milk. However, by the time of the interview, juice was the most popular source of sugar for these babies (Dalben et al., 2003). The percentage of babies drinking soft drinks from the bottle was also very high (Dalben et al., 2003). Because the breast-feeding of these infants was not successful they had contact with more sugars and earlier than infants who are breast-fed successfully. According to

Dalben et al. (2003), a specific oral prevention program for these babies should be used and should stress parental education, and plaque control.

Burping the infants after feeding is another important step in making sure they have a successful feed. Burping is important because with a cleft lip or palate extra air is easily swallowed (Arvedson & Brodsky, 1992). This can cause discomfort and an inability for the infants to consume as much milk. With regular frequent burping pressure from the extra air swallowed is relieved, and there is more space available for milk instead of the air (Delaney, 1994).

Transitioning to Solid Foods

Spoon feeding for infants with a cleft lip +/- palate should begin at approximately six months of age just as it would for children without a cleft lip and/or palate (Arvedson & Brodsky, 1992). Strained, thin pureed, foods should not be a problem for infants with clefts (Arvedson & Brodsky, 1992). These infants should be introduced to spoon feeding to enhance normal development in the use of spoon-feeding (Arvedson & Brodsky, 1992).

When spoon feeding, avoid thickened foods to ensure that these consistencies do not get lodged in the cleft area (Arvedson & Brodsky, 1992). Also, spicy foods should

be avoided, due to the sensitivity of the nasal mucosa (Arvedson & Brodsky, 1992). Specific foods to avoid when spoon feeding is used are: peanut butter, cooked cheese dishes (because of the sticky consistency, leafy vegetables, and any other food that is fed in small pieces (Arvedson & Brodsky, 1992). By avoiding these types of foods, spoon feeding can be successful for infants with cleft lip and/or palate preoperatively as well as postoperatively.

It may be appropriate to introduce and practice cup-drinking pre-operatively. If cup-drinking is desired postoperatively it should be introduced preoperatively even if it is at an early age (Arvedson & Brodsky, 1992). The infant should be help in an upright position and an open cup should be used to release liquid into the infant's mouth (Arvedson & Brodsky, 1992). The infant may do better handling a thickened liquid rather than their formula or juice (Arvedson a& Brodsky, 1992). This should be practiced frequently and at short durations to be beneficial for the infant with a cleft condition (Arvedson & Brodsky, 1992).

For some infants with a cleft palate +/- lip, a prosthetic piece may be beneficial. A prosthetic appliance is used to cover the open space in the cleft of the

infant's mouth. Many claims have been made that both bottle and breast feeding improved with the use of a pre-surgical orthopedic, and that the orthopedic relieves low and frustrated feeding, reduces choking episodes, improves growth, and improves parent's psychosocial well-being (Masarei et al., 2007). In a study by Turner et al., (2001), five infants were studied to examine the effect of lactation education and use of palatal obturation in regard to decreasing time to feed, increasing intake, and to measure the infants' growth. A prosthetic obturator appliance was used with these children. Results showed that with the combined use of the palatal obturator and lactation education, feeding time was reduced, volume intake increased (Turner et al., 2001). This resulted in appropriate growth for these infants. Mothers who wanted to breast-feed were able to do so using this appliance. The obturator supported high-volume intake, decreased infant fatigue, and provided breast milk for nutrition (Turner et al., 2001).

The amount of feeding information regarding cleft lip +/- palate may be overwhelming for a new parent. Amstalden-Mendes et al. (2005) conducted an interview with 26 parents or caregivers of infants born with a cleft lip +/- palate

in a two-year period. In this study the majority of the families reported that they received helpful feeding guidance while they were still in the maternity hospital. They indicated that most of this information was given to them by nurses or physicians. They had early contact with multi-professional teams to ensure early care and systematic monitoring of these infants. Amstalden-Mendes and colleagues (2005, p.333) advocated, "Specific neonatal attention for cleft babies should be included as routine training of all health professionals of primary care as part of the health care policy".

Conclusion

Early intervention for infants with cleft lip +/- palate is very important. According to Reid et al.(2007), there was a significant decrease in failure-to-thrive rates for infants with cleft palate after an early intervention feeding program was implemented. This program included domiciliary visits, breast-feeding support, feeding education, and monitoring of growth. Early intervention can come in many forms including feeding equipment, feeding techniques, prostheses, and nutrition/lactation advice (Reid, 2004). Early education combined with a nutrition intervention protocol can improve outcomes including:

weight gain, feed velocity, and fluid intake for infants with clefts (Reid, 2004).

Infants with cleft lip +/- palate are a significant population born with congenital defects that will likely require the services of early intervention providers, including speech-language pathologists. They are at risk for many health difficulties including malnutrition that can lead to morbidity and failure to thrive. They are also at a high risk for laryngeal penetration and aspiration that can lead to pneumonia. However, evidence based practice shows that with intervention techniques oral feeding can be successful and infants can thrive. Until infants are ready for surgery, care that will enhance their quality of life is critical for early development. This can be done by using feeding modifications, or using actual prosthetics. Feeding modifications can range from consistency modifications given to the infant, adapting breast-feeding techniques, to nipple shape. These modifications are vital in assuring that the infant is getting proper nutrition prior to cleft palate surgery.

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