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Impact of cleft lip and/or palate on nutritional health and oral-motor development

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The birth of a child with a cleft lip and/or palate creates many altered expectations that the new parent and caregiver must address. Certainly, the emotional impact must be managed but, in addition, specific physical limitations may need to be overcome. The baby with a cleft frequently requires modifications to meet the nutritional requirements the infant needs in order to thrive and grow. Attitudes and methods to meet these needs vary, but some general principles can be identified. Failure to adjust to these needs could place the child into a potential life-threatening situation. This article reviews some of the problems and adaptations that are seen when an infant is born with a cleft.

Etiology

Many different etiologic factors have been identified or suggested as the cause of formation of a cleft lip with or without cleft of the palate, as well as of cleft palate alone. The incidence of cleft lip with or without cleft palate varies with ethnic and racial backgrounds [1,2], geographic origin [3], and socioeconomic status [4] (between 0.3/1000 births to 3.6/100 live births),

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whereas the incidence of cleft palate alone does not differ significantly throughout ethnic groups (approximately 0.4/1000 births) [5]. Usually, clefts are divided into three general classifications: those that are syndromic (part of an identified syndrome, approximately 1%–5%), those that are familial (10%–15%), and those that are nonsyndromic (the majority of clefts fall into this classification, 75%–80%) [6]. The relative risk for the occurrence of another baby with a cleft within a family must include a genetic evaluation to rule out syndromic or familial clefts prior to assigning a recurrence risk.

The causes of clefts are complex and involve both genetic and environmental factors [7]. Many groups have examined various candidate genes to try to identify a ''susceptibility gene'' that could account for nonsyndromic forms of cleft lip with or without cleft palate. Various genes that have been suggested by linkage analysis to have an impact on the presence of a cleft in some populations have been found to demonstrate no evidence of linkage in other populations [8,9]. Environmental factors and some teratogenic agents have been examined and found to potentially impact the development of a cleft if present at critical times during embryonic development. Such factors include maternal exposure to corticosteroids [10], retinoic acid [11,12], phenytoin [13], hormone imbalance [14], and diabetes mellitus [15]. Other teratogenic agents such as smoking [16–22] and maternal alcohol exposure [23–26] have been examined. Some of these studies have led to linking the effects of smoking with other genetic factors such that a gene-environment interaction has been suggested.

Dietary lack of folic acid or the ingestion of folic acid antagonists [27] has also been implicated in the formation of clefts in some studies [28,29], whereas other similar reports did not reveal any association [30]. Therefore, although there are individuals recommending folic acid supplementation to reduce the risk of having a baby with a cleft lip and palate, others feel this conclusion is unfounded. There is evidence that insufficient prenatal intake of folic acid contributes to neural tube defects that may indirectly be associated with clefting [31]. It does appear that further examination and understanding of gene-environmental interactions is required. Further genetic and epidemiologic research should ultimately improve our understanding of the formation of oral clefts [32].

Oral-motor development of children with clefts

The early growth of infants and very young children is characterized by rapid proliferation of growth and developmental behaviors. A gradual increase in the accomplishment of various motor and cognitive skills allows for the development of more complex movements. The overall developmental scheme appears to generally be consistent within both gross and fine motor skills. The development of speech also follows this general plan, beginning with the production of sounds that require little motor movements to the more complex sounds, which rely on finer oral-motor

movements. Speech is a complicated process that requires the coordination of subsystems of respiration, phonation, resonance, and articulation. During speech, all movements must be done quickly and with good accuracy. In addition, the action of every muscle is influenced by the actions of other muscles in the system. The movements of each structure are influenced by movements of other structures, and every phoneme is influenced by other phonemes surrounding it [33]. Infants born with a cleft are at a higher risk to experience developmental delays, including motor skill delay [34]. This is not to say that infants with clefts are predisposed to oral-motor delays; rather, a breakdown in the coordination of speech subsystems creates an opportunity for obligatory errors that are a direct consequence of an anatomic or physiologic defect.

Coordinated velopharyngeal function is vitally important for successful feeding. Expressing liquid requires an intraoral vacuum. In addition to the infant's ability to create a lip seal around the nipple, the function of the soft palate to rise up and close off the nasopharynx from the oropharynx is key. In the case of a cleft palate, the infant's ability to create an oral vacuum is hampered; this is the main factor that may interfere with feeding [35]. In this case, infants are rarely able to create sufficient negative pressure to obtain adequate liquid for their nutritional requirements [36]. When a cleft involves only the lip and/or dental arch, the infant can usually produce sufficient negative pressure to allow for relatively normal bottle-feeding or breast-feeding.

Infants with a cleft palate have abnormal muscle attachments and abnormal communication between the nose and the oral cavity. The levator and tensor muscles that attach along the back of the hard palate and extend across the midline in the normal situation fail to do so when a cleft palate is present. This abnormal anatomy and architecture make it relatively impossible to isolate the oral cavity, build negative pressure, and create suction. The reflexive movement of sucking and swallowing is usually intact in infants with a cleft palate; however, obtaining negative pressure is problematic. This situation can be overcome with modified feeding strategies that enable the infant to be fed orally.

Infant nutritional requirements

Early feeding modifications

Fabricus of Aquapendente [37] pointed out in 1619 that infants with cleft palate were unable to suck and often would die of malnutrition. Although the ability of children born with clefts to grow has improved since then, there are still reports of a significant number of these children being described as "failure to thrive." Pandya and Boorman [38] reported how they established the rate of failure to thrive in their patient pool and found the incidence was 32% for unilateral cleft lip and palate, 38% for bilateral

cleft lip and palate, and 49% for cleft palate alone. Adjustments and careful monitoring as to how a baby with a cleft is fed have been recommended to ensure that a baby born with a cleft will thrive and grow.

Babies vary in their ability to cope with the cleft defect just as the presentation of the cleft varies, but making some adjustments can assist the infant who is having trouble in obtaining adequate nutrition to ensure weight gain. Different methods have been described and used successfully throughout the years by various individuals and craniofacial treatment centers. Some centers have advocated the making and placement of a feeding obturator to physically block the continuity of the oral cavity with the nasal cavity [39–41]. The placement of this type of appliance is intended to facilitate the infant's ability to create sufficient negative pressure that would allow adequate sucking to pull the milk from the breast or nipple, and would decrease the amount of fluid that flows back out through the nasal cavity rather than being swallowed. Other methods rely on decreasing the need for the baby to actually suck, making the infant's responsibility in the feeding process primarily swallowing. This process can be done through the use of specialized bottles or nipples that deliver the milk to the back of the throat (see Figs. 1–3). The infant then swallows the milk, and a rhythm is learned and established between the feeder and the baby [42,43]. In addition, the caregiver is generally encouraged to feed the baby within a time frame of approximately 30 minutes so that the infant does not expend unnecessary calories during each feeding event. There have been several reports from various centers comparing different feeding techniques and, basically, most show that infants with clefts can do well with any of the various practices that are taught and advocated by that center [44–49]. The type of feeding done should be acceptable to the family, the infant, the craniofacial center working with the family, and the physicians involved in the overall care of the baby. It is important to carefully monitor the baby, especially in the first weeks and months, to ensure that adequate weight gain is achieved and maintained.

The infant born with a cleft has similar nutritional requirements as other infants born without a cleft, as long as no other systemic issues are involved [50]. The main priority during the first few months of life for all infants, including those born with a cleft, is to ensure adequate nutrition [51]. Without the infant growing and thriving early on, the outlook for the success of future surgical interventions and specialty care of the child can be compromised [52]. Feeding difficulties often experienced by infants with clefts that increase the problems with providing adequate nutritional intake include nasal regurgitation, poor suction, excessive air intake, frequent burping, and prolonged feeding times [50]. Yet, even with all these problems, the infant born with a cleft must maintain adequate nutritional intake so as to increase resistance to infection, promote adequate weight gain to allow for surgical interventions, help build strength to meet the stress of the surgery, and to promote healing after the surgery is completed. Other obvious modifications in the normal dietary intake of the infant with a cleft

Fig. 1. Medela Haberman feeder (Medula Inc., McHenry, IL). Standard bottle with a soft variable-flow nipple and a pump action one-way valve, requiring no active suction to express milk.

include alterations for acute illness similar to noncleft infants. Therefore, the major modification necessary for infants with clefts is the intake process, rather than absolute nutritional alterations.

Postsurgical feeding—lip closure

Special considerations that an infant with a cleft lip and/or palate requires include continued provision of adequate nutrition and possible

Fig. 2. Mead Johnson cleft lip/palate nurser (Mead Johnson Nutritionals, Evansville, IN). Soft bottle that can be squeezed to help the flow of milk. Any standard cross-cut nipple can be fitted to the bottle.

alterations in feeding methods after the lip and/or palate is closed. As with other surgical interventions, the dietary needs of the child in response to the surgical insult must be managed. In addition, there is concern over the method of feeding the baby after specific oral procedures have been completed. Some surgeons prohibit breast-feeding or bottle-feeding immediately after closure of the lip because of the possible stress it may place on the surgical wound postoperatively. Millard [53] recommended that after primary lip closure, the infant be fed for approximately 1 month using a rubber catheter attached to the end of a syringe, after which the baby can then return to bottle-feeding. Cohen et al [54] did a retrospective review of 80 consecutive patients treated by their service comparing infants that resumed either breast-feeding or bottle-feeding immediately after surgical lip repair with those infants who were fed through a tube and syringe for 7 to 10 days following repair. These investigators concluded that cautious breast-feeding or bottle-feeding in the immediate postoperative period was safe, and modifications to established feeding methods were not necessary [54]. These recommendations are not universally accepted or used by all craniofacial centers or surgeons throughout the United States and Canada.

Fig. 3. Cleft palate nipple (developed by Pigeon Co., Inc., Children's Medical Ventures, Norwell, MA). Nipple specially designed for feeding cleft palate infants. The cross-cut nipple has a thick and a thin side, with a one-way valve that prevents excessive air intake and allows milk to flow only when nipple is compressed by the infant.

Some centers still recommend that the nipple or breast not be used postoperatively for periods varying up to 6 weeks. The recommendations given by the surgeon usually relate to their training practices and experiences and may not reflect what other surgeons or craniofacial centers practice [55].

Postsurgical feeding modifications—cleft palate repair

There are also differences in the feeding practices postsurgically after cleft palate closure. Wellman and Coughlin [56] in 1991 surveyed 92 cleft palate teams on how the teams managed nutritional or surgical instructions presurgically and postsurgically for primary cleft palate closure. They reported that of the 49 returned surveys, most centers did not provide patients with specific dietary modifications. Many centers, however, had specific requirements on how the infant/child was to be fed postoperatively (eg, cup or syringe feeding, liquid or pureed diet, and so forth), and some suggested the elimination of certain foods for a defined period of time (citrus or sticky food). Only one center responding to the survey reported using specific dietary counseling to address increased calories, vitamins, carbohydrates, and protein after surgery. Although some teams did report that they advised using special dietary supplementation such as high-calorie liquids (eg, Pediasure; Abbott Laboratories, Abbott Park, IL) during the postoperative period,

the majority of the teams reported no special dietary supplementation recommendations [56].

Although growth and weight gain are a continual concern throughout the first few months of life in children born with clefts, it is reassuring to note that there are indications that these problems may not continue after the infant has undergone the surgical closure of the defects. Lee et al [57] examined 83 children with cleft lip and/or palate from ages 0 to 4 years. They reported that this group, as a whole, grew relatively poorly in early infancy but subsequently recovered, attaining both the expected weight and height at last follow-up (age 25.5 months). Obviously, when there are other underlying syndromes complicating growth, these concerns can remain for prolonged periods; however, because most children are born with non-syndromic clefts, the elimination of the defects should realize normal growth attainment.

Breast-feeding and infants with clefts

There are many controversies around breast-feeding infants with cleft of the lip and/or palate. There are certain groups who adamantly believe that any infant can be breast-fed adequately to grow well, regardless of the type of cleft. Pamphlets produced by various groups advocate the benefits and ease of feeding babies with any form of cleft with breast milk [58,59]. Certainly, the benefits of breast milk for infants have been documented [60]. Several reports found that breast-fed children have some protection against otitis media [61–63]. Breast-feeding also has been shown to be effective in reducing the incidence of otitis media in children with clefts [64]. Aniansson et al [65] advocated feeding breast milk to children with cleft palates for longer periods of time because they felt early cessation could contribute to an increased incidence of otitis media in these children. One of the complicating variables readily apparent in infants that may impact the effects of breast-milk protection is impaired Eustachian tube function present in children with cleft palates. This impairment is a reason for the increased likelihood of these infants experiencing more ear infections. Although Eustachian tube dysfunction does occur, it appears that breast milk still offers some protection against otitis media, even in children with cleft palates.

Infants with isolated cleft lip can often breast feed when the breast is placed in a position that allows the infant to create a seal on the breast with the intact part of the lip and alveolus. Most infants with cleft palate (including the soft palate) have difficulty breast-feeding. Some centers advocate the construction of an obturator intended to assist in closing off the nasal pharynx, thereby allowing the infant to suck and create a vacuum. This process has worked for some infants, but these obturators often cannot extend far enough posteriorly to allow for adequate closure. Other modifications usually are necessary to allow the infant with a cleft palate to

feed on breast milk. These include pumping milk from the breast and helping the infant feed using various squeezable bottles, nipples, or combinations of both. Caution should be used when encouraging a new mother to breast-feed her infant born with a cleft. Unrealistic encouragement can set the mother up for feelings of inadequacy and failure if supplemental bottle feeds are deemed medically necessary for growth issues.

Dental disease in children with clefts

It is not unexpected that children born with clefts have increased rates of dental abnormalities including supernumery, missing, or malformed teeth, especially when the cleft extends through the alveolar ridge. It is also considered common that children with clefts have an increased caries and gingivitis experience [66]. It has been shown by several investigators that dental caries occurs significantly more frequently in children with clefts than without clefts, regardless of meal frequency, method of feeding, and use of fluoride [67,68]. This increase in caries has been shown to occur in children with a cleft, even at a very young age [69]. Although multiple factors are involved in the development of early childhood caries (baby or nursing-bottle caries), two factors instrumental in its development are early infection with *Streptococcus mutans* and prolonged night feeding in infants and toddlers [70]. These findings have also been found in children with cleft lip and/or palate and certainly must play a role in the development of the caries [71,72]. Although this increase in caries is generalized to all clefts, there is some indication that the type of cleft (cleft lip, cleft lip and palate, or cleft palate) may have an impact on the caries experienced within this group of children, at least in some populations; however, further studies need to be completed before this is confirmed [73]. Nevertheless, frequent carbohydrate exposures and the presence of large numbers of cariogenic bacteria appear to remain key factors in the development of caries in children with clefts. Therefore, information regarding appropriate dietary habits, food consumption, and oral care should be given to and reinforced for parents of infants and children born with clefts.

Summary

Infants born with a cleft may require modifications in feeding practices prior to surgical closure of the defect; however, few changes in dietary recommendations are necessary. Often, the delivery method of breast milk or formula can be altered in order to require less effort by the infant and decrease caloric output, thereby increasing the calories ingested to facilitate weight gain and growth. This adaptation may not be necessary when the cleft does not include the palate but can be implemented fairly easily when the baby appears to have difficulty obtaining adequate nutritional intake. Before and after any surgical intervention, the goal remains to continue to

supply the infant with sufficient caloric intake to heal and to continue to grow. Although some surgeons may demand modifications in how the baby is fed postoperatively, many advocate cautious reinstitution of normal feeding practices.

Early referral for dental care should be encouraged in children born with clefts because these children (even the very young) demonstrate higher dental needs. Education provided to parents regarding causes of and methods to reduce dental disease could help decrease its incidence and help these children require less invasive and difficult rehabilitation therapy.

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