Management of infants born with a cleft lip and palate. Part 2

The management of infants and their families during the first years of life has a profound effect on the emotional and physical health of all children, but for those babies born with an oral cleft additional difficulties may influence this outcome. Part 2 of this series considers the variation in issues of management which parents and health professionals may encounter.

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Keywords

cleft lip; cleft palate; feeding difficulties; non nutritive sucking; assisted feeding; breast feeding; airway obstruction; glossoptosis; breathing difficulties

Key points

Bannister P. Management of infants born with a cleft lip and palate. Part 2. *Infant* 2008; 4(2): 57-60.

1. Feeding difficulties due to an isolated cleft lip or cleft lip and palate can usually be resolved during the first few weeks of life.
2. Babies with an isolated cleft palate have more complex feeding problems which may be associated with breathing problems and require the use of a nasogastric tube.
3. There are considerable added advantages to feeding a cleft baby with breast milk.
4. Assisted feeding may be necessary to ensure an infant gains adequate nutrition.

Babies born with a cleft may present with a variety of feeding problems as they do not form an homogenous feeding group. Poor growth and difficulties in oral feeding may cause parents an increase in anxiety and affect their ability to adjust and modify their skills to meet the additional needs of their infant[1]. Maternal choice of feeding must be respected and accommodated in the development of a feeding plan, but it is important that parents are given help to make the necessary adjustments. The feeding difficulties associated with an isolated cleft lip or cleft lip and palate can usually be resolved in the early neonatal period and these babies can be safely nursed with their mothers on the postnatal wards. Babies born with a cleft palate, without a cleft lip sometimes present with a more complicated picture which may continue to cause difficulties for many months. For this reason it is important to consider the management of these two cleft types in the first postnatal year separately.

Normal feeding

Full term babies are born with the natural ability to feed by utilising a number of reflex activities[2]. For successful feeding a baby must be able to trigger sucking activity, maintain effective suckling and be able to co-ordinate a functional suck/swallow/breathe activity for a period of 30-40 minutes. This activity requires the support of healthy cardiovascular and respiratory systems and, as infants are obligatory nasal breathers, patent nasal airways. Both bottle and breast feeding requires the development of a negative intra-oral pressure, although its complete role remains unclear. During bottle feeding its function is thought to assist in the transfer of milk[3], whereas in breast feeding the most likely function is to position and stabilise nipple placement onto the tongue[2]. Obstetric events may affect the emergence of these normal activities.

Breast/breast milk feeding

There are considerable additional advantages to feeding breast milk to a baby with a cleft, but mothers need to be supported to achieve this outcome. Breast milk is less of an irritant to the exposed nasal mucosa in babies with a cleft palate, offers protection against infections – particularly important around times of surgery – and starving times prior to surgery can be reduced from approximately 5-6 hours to 2-4 hours[4].

An audit undertaken by the Nurse's Special Interest Group, Cleft Lip and Palate, in 2004, collected one year's national data for 291 mothers who had chosen to breast feed their cleft infant. The results confirmed previous anecdotal accounts found in the literature, that babies affected by an isolated cleft lip with or without a cleft in the alveolus (upper gum) were significantly more likely to succeed in feeding directly from the breast, whereas babies whose cleft involved the palate were more likely to feed expressed breast milk from a bottle and teat.

Early management for all mothers who have chosen to breast feed should support immediate skin to skin contact, a first breast feed following the birth, and help with positioning and latch on techniques at subsequent feeds. Manual expression of breast milk is the preferred option in the early days but electric pumps must be made available for long term use. A decision to progress to feeding expressed

milk from a bottle and teat must be mother driven and until a decision has been made any supplementary feeds required should be offered via a syringe, if only small amounts, or using a cup, scoup bottle or finger feeder. Infants with a cleft quickly learn to reject the breast if a teat is used in these early days and this may subsequently lead to a mother moving to formula milk. Other pressures around a mother's desire to leave hospital quickly can affect a decision as to whether to continue with breast milk feeding, and midwifery units need to be confident in the role of the community midwife and clinical nurse specialist to support both the development of feeding management and the maintenance of adequate nutrition.

- Immediate skin to skin contact and first breast feed
- Presentation to breast prior to any supplementary feed
- Nutritional requirements, small amounts of colostrum
- Early supplements if required via a syringe, cup, scoup bottle or finger feeder
- Mother to decide movement to teat and bottle for EBM supplement
- Availabilty of electric breast pump at no extra charge
- Effective teaching and support

TABLE 1 Important aspects of support for mothers who chose to breast feed/feed their infant with breast milk.

Cleft lip, cleft lip and palate

Feeding difficulties related to full term babies with an isolated cleft of the lip and cleft lip and palate are primarily related to a reduction in suckling efficiency. Reflex activity, intra-oral movements and tongue positioning are generally normal and the baby demonstrates the ability to organise a functional suck/swallow/breathe activity. For the infant with an isolated cleft lip, either unilateral or bilateral, problems, if any, are easily resolved by minor adjustments to the hole in the teat for the bottle fed infant and more effective nipple placement using an 'exaggerated latch on' for breast feeding[5]. A characteristic hiss may be heard when feeding, as air is sucked into the mouth through the gap in the upper lip but good placement of either the teat or breast will resolve these potential problems.

Breast feeding mothers may wish to experiment with different positions and placing the baby with the cleft under the breast tissue will help occlude the gap in the lip. It is often useful to cradle the baby around the mother's body freeing the hand to support the adjacent breast in the baby's mouth throughout the feed and breast compression during suckling increases milk flow[6]. Once a baby and mother have learnt to attach there should be no difficulty in breast feeding.

Where there is accompanied involvement of the secondary palate a more pronounced suckling inefficiency is observed which can result in the likelihood of non nutritive sucking activity. Non nutritive sucking is best observed when an infant is sucking on a dummy. There is none or very little delivery of milk and if this occurs whilst feeding, it can lead to lengthy and frequent feed times, excessive amounts of ingested air and fatigue for both the infant and parents. In the early neonatal period difficulties may arise in triggering sucking activity due to the absence of palatal tissue and the baby may have difficulty stabilising the teat/nipple as the tongue may not have developed the necessary cupping mechanism. Movement of the teat, a technique often taught by health professionals to stimulate sucking, may cause ulceration of the nasal septum and turbinates and is not advisable.

Although the nipple or teat may help to occlude the absent tissue in the hard palate, abnormal placement of the muscles in the soft posterior palate will limit movement and the creation of the necessary vacuum for effective feeding. Feeding directly from the breast will be difficult in the long term but normal early breast behaviour and practice should be encouraged. Bottle fed infants can be fed in the normal cradling position and assisted feeding is usually indicated 24-48 hours after birth following a feeding assessment.

Assisted feeding

Assisted feeding enables the infant to gain adequate nutrition, within an acceptable time frame, whilst enhancing the continued development of nutritive suckling. It enables the carer of a bottle fed infant to assist only when safe and necessary[7]. The need for help will vary within one feed, from one feed to the next and from one infant to another. A flexible bottle is gently squeezed as the baby suckles, either in a continuous or pulse squeeze action. The frequency will depend on many factors such as the type of cleft, presence of other anomalies and the age of the infant. The correct flow of milk results in a relaxed baby with no nasal regurgitation of milk whilst suckling. The introduction of this method of feeding follows a feeding assessment by a Clinical Nurse Specialist (CNS) and is not advisable in the first 24-48 hours following birth. Assisted feeding is appropriate for the majority of babies who have clefts but is not suitable where there is accompanied dysphagia or breathing problems. The most widely used teat is a soft latex orthodontic teat which can be successfully combined with a soft bottle (**FIGURE 1**).

FIGURE 1 Equipment used in feeding cleft lip and palate infants – back row soft flexible bottle, front row from left: finger feeder, size 2 teat, size 1 teat, scoop.

- Implement oral feeding following delivery if no other complications identified
- Suggest use of soft latex orthodontic teat and glass bottle
- Encourage normal reflex activity, rooting and gapping
- Initiate sucking by gently stroking intact palate tissue with teat
- Maintain teat still on central body of tongue when suckling
- Transfer to postnatal ward if no other concerns
- Await feeding assessment by CNS prior to introduction of assisted feeding
- Ensure agreed feeding plan adhered to

TABLE 2 Guidance on the early introduction of bottle feeding.

The broad shape of this teat helps to prevent movement of the teat up into the nasal cavity as it is positioned in the mouth across the nasal septum. Both a size 1 and size 2 are suitable – their use is dependent on the size and maturity of the baby. Initial feeding equipment is usually supplied by the Clinical Nurse Specialist but can be purchased by parents through a mail order service from the Cleft Lip and Palate Association.

Cleft palate

An isolated cleft palate may involve either the posterior part or both the hard anterior and posterior palate. These babies often present with a more complex management problem which sometimes cannot be resolved in the early postpartum period. In addition to the obvious anatomical defect, physiological alterations in the function of the tongue and oral pharynx may contribute to these difficulties. The most common problems associated with cleft palate are micrognathia and glossoptosis (retroplacement of the tongue). When combined these factors can cause breathing and feeding problems which in the most severe form, Pierre Robin sequence, can be life threatening. It is useful to consider these babies on a continuum of severity with those mildly affected at one end and those more severely affected at the other. Tracheal tug, lower lip recession, neck extension, head rocking and sternal recession are a few of the signs of respiratory difficulty.

In its most minor, an occasional audible sturtor may be heard when the baby is lying supine and the tongue tip will rarely be seen at the lip edge for the first few months. These minor issues are easily resolved by nursing the baby in a lateral position, with the help of a rolled blanket or guardian angel (a commercial roll), and the introduction of assisted feeding is safe. Feeding at the breast may be an option but will require supplementation and these babies can safely be nursed with their mother on the postnatal ward.

For those babies with more severe problems the position of the tongue places the baby at a high risk of upper airway obstruction and aspiration, as swallowing may be unsafe. For these babies alternative methods of feeding must be considered and the monitoring of blood gasses becomes important as the first evidence of difficulty may be reflected in a silent rise in the PCO_2 reading. If airway stability cannot be maintained in a lateral or prone position then other interventions must be considered.

- Arrange paediatric assessment
- Refer to cleft team
- Assess airway stability in supine, lateral and prone positions
- Identify appropriate feeding and airway management
- Transfer to neonatal unit only if intervention required
- Consider other medical/genetic issues and appropriate referral
- Carry out feeding assessment prior to oral feeding
- Agree plan of care
- Include within discharge planning appropriate equipment and support if required
- Consider airway safety in car seat[13]
- Arrange for readmission for O_2 /sleep studies if required
- Consider open access to paediatric ward

TABLE 3 Management of babies born with isolated cleft palate.

The use of nasopharyngeal (NP) airways has now become common practice for the majority of severe problems associated with glossoptosis[8] and their management has been described in the literature by Heaf[9]. Parents can be taught to manage NP airways but will require to be discharged home with an oxygen saturation monitor/apnoeic monitor, suction equipment and adequate material for airway replacement.

The CNS, alongside community teams, will supervise the ongoing feeding, and airway management and arrange for readmission to hospital for overnight oxygen monitoring or sleep studies prior to removal of this support. A combination of oral and nasogastric tube feeding is often indicated until, with the growth of the mandible, the tongue position improves. Early oral feeding, using an orthodontic teat and hard bottle is safer when the baby is in the lateral position with the head raised slightly. The introduction of assisted feeding must only be considered once the baby is assessed by the CNS as having a normal swallow.

A care map has been developed and is a useful tool in the care of these babies. Most CNSs, attached to regional cleft teams, have undergone training in its use. The stability of the airway in a lateral position must be established and a gag reflex obtained before oral feeding can safely be introduced. Glossoptosis may cause immediate breathing and feeding difficulties, but problems may only emerge once oral feeding has commenced. Increased respiratory effort may result in an increase in calorie requirements and oesophageal reflux may indicate breathing difficulties.

Although the most common cause of upper airway obstruction is as a result of glossoptosis[10], other causal factors have been described in the literature[11] and if suspected these babies may require alternative management. A percentage of these babies may have additional associated anomalies which may further complicate early management and growth potential. A thorough paediatric examination is recommended before any oral feeding is commenced.

Oral hygiene

During the first eight weeks it is often advisable to offer 2-3 teaspoons of cooled boiled water after formula feeds or following a posit and nasal regurgitation. For breast milk fed babies or if there is no cleft of the palate this is unnecessary. The regular application of an edible lubricant on the exposed areas of the lip and pre-maxilla will prevent the development of soreness and damp cotton wool buds may be helpful in removing debris from around the alar rim of the nostril.

Weaning

The Department of Health guidelines[13] state that milk alone is a sufficient food for babies until the age of six months. However babies may be ready for weaning foods before this age and for some babies with clefts, they are an enjoyable supplement to milk. Weaning foods are not recommended before 16 weeks' post conceptual age and about this age feeding skills are beginning to change[14]. Some parents are anxious and require support both with the first foods and the transition to mashed and finger foods. Most babies are able to enjoy a variety of consistencies prior to the repair of a cleft palate.

Summary

This article, together with Part 1[15], provides a brief overview of some of the challenges

for both the parents and health professional following the birth of a baby with an oral cleft. It is only part of the journey, as care may continue until a child is fully grown and for some families is complicated by the presence of additional anomalies. It is the responsibility of all medical, nursing and midwifery personnel to care for parents and their children in an individual and holistic manner and empower parents to regain control of their parenting and express pleasure in their children.

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