

To Investigate Infant Feeding in Children born with a Cleft in the West of Scotland

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Abstract

This study aimed to look at feeding practices amongst infants who are born with a cleft and the feeding difficulties and challenges that the parents of these children experience especially in the first hours and months after birth.

Aim

This study aims to look at feeding practices amongst infants who are born with a cleft in the West of Scotland and the feeding difficulties and challenges that the parents of these children experience especially in the first hours and months after birth.

Objectives

1. To determine the proportion of infants who are breastfed.
2. To determine the proportion of infants that are bottle-fed or use assisted feeding methods.
3. To ascertain whether demographics are a factor in the choice of feeding method used.
4. To assess the duration of feeding times.
5. To assess the incidence of ear infections.
6. To look at the use of feeding modifiers.
7. To assess feeding habits which would compromise dental health.
8. To look at the support and feeding advice given to their parents by both the Cleft Team and non-cleft Health Care Professionals.

Method

Parental questionnaire to 90 parents who had a child born with a cleft within the last 5 years and who attend the 'Oral Orthopaedic Prevention Clinic' at Glasgow Dental Hospital. The questionnaire was a 'face-to face' interview of 50 questions involving both open-ended and closed questions.

Results

90 questionnaires were completed. We found that the incidence and prevalence of breastfeeding amongst the cleft population was lower than in the general population in Scotland. Table A shows the breastfeeding rates at different times and compares them with Scottish national figures (Infant Feeding Practices 2000, Infant Feeding Survey 2005).

Table A. Breastfeeding rates in our study compared to Scottish national figures in 2000 and 2005.

Incidence and Prevalence of breastfeeding	Cleft study	2000	2005
At Birth	54%	63%	70%
1 week	49%	50%	57%
6 weeks	30%	40%	44%
6 months	13.3%	24%	24%

Cleft type had a significant impact on whether the infant was breastfed ($P < 0.054$). 80% of cleft lip only infants breastfed initially and 60% went on to breastfeed for at least 6 months, whereas 61.3% of infants with a cleft palate with or without a cleft lip (CP +/- CL) breast-fed initially and only two continued for 6 months. These two infants and the infants with a cleft lip only were actually breastfed; all the rest received expressed milk. 86% of infants with a cleft palate were fed using formula milk and a bottle as a method of choice. 96% of those infants who had a naso-gastric tube to assist feeding had a CP +/- CL.

Although it was not specifically asked in the questionnaire, it was found that only 13% had any prior knowledge of the cleft. 62% found out at birth but 25% of cleft palates were undiagnosed at birth although by 24 hours postnatal some 84% of cases had been diagnosed.

88% of parents received feeding advice in hospital and 91% received advice at home. 93% of respondents understood the advice and gave a favourable rating for the cleft team's advice in the hospital. 96% gave a favourable rating of the advice given at home. By comparison, the advice given by health care professionals who were not members of the cleft team was rated favourably in only 55% of cases in hospital and 68% at home. There appeared to be a basic lack of knowledge about clefts amongst the general nursing staff in the maternity wards and the Health Visitors who visited the mothers at home from the comments given by the parents. This led to some parents undergoing frustrating and negative experiences in the first hours and days of the birth of their baby. Some parents did have a positive experience of non-cleft health care professionals but this seemed to be down to chance on an individual basis. Parents found it difficult to find the right feeding methods for their baby until the Specialist Cleft Nurses arrived. Although things improved with knowledge and understanding about the cleft and the use of specialised feeding methods, establishing regular feeding patterns were in the minority. There was significant positive support for the Specialist Cleft Nurses. Meeting the cleft team (approximately 12 in number) was mostly a positive experience although many parents felt the setting was too formal.

Summary

There has been no external audit of infant feeding practices in the cleft population in the West of Scotland. This study investigated these practices by interviewing the parents of 90 children born in the West of Scotland between 2001 and 2006. The low rates of breastfeeding were analogous with the literature. The help and support given by the cleft team especially the Specialist Cleft Nurses was positive in over 95% of cases but was less for the non-cleft health care professionals. (55% for nurses, 68% for Health visitors) This study recommends the employment of more Specialist Cleft Nurses and an improvement of the knowledge of non-cleft health care professionals. These recommendations would improve the number of parents experiencing a more positive experience in the hours and days following the birth of their child.

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1. Cleft Nurses Audit Questionnaire
2. Cleft Nurses Observation Chart

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Thank you to my sister, Lisa Dysch for her IT skills and sympathetic ear! Lastly (and of course by no means least) to my husband, Kenneth and our three children Eilis, Shauna and Rory - lets get back to normal!

Author's Declaration

All data presented in this thesis is the original work of the author except the following:

The questionnaire in this study (Appendix 9.3) was developed from two questionnaire sources;

- I. A questionnaire designed by Dr Kay Hood and Dr M.T. Hosey for potential research purposes;
- II. A questionnaire used by the Specialist Cleft Nurses, Shirley Wallace and Ann Crawford at the Royal Hospital for Sick Children (Yorkhill) to annually audit their services (see accompanying material).

Sarah McDonald

Definitions

Incidence of breastfeeding – The proportion of babies who are breastfed initially

Prevalence of breastfeeding – The proportion of babies who are still breastfed at a specific age.

Duration of breastfeeding – The length of time that mothers who initially breastfed continued to do so.

Chapter 1 Introduction

Cleft lip and cleft palate is the most common craniofacial abnormality affecting about 1 in 700 births in the UK. A cleft lip is described 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 complete separation in one or both sides of the lip extending into the nose. A cleft palate can range from an opening at the back of the soft palate to nearly complete separation of the soft and hard palate. Clefts of the lip and the palate may occur independently or together (cleft lip and palate). The cleft may be on one side (unilateral) or both sides (bilateral) of the midline (CLAPA 2001).

The European prevalence of cleft palate (CP) and cleft lip and/or palate (CLP) per 1000 births are shown in Figs 1.1 and 1.2 and the differences in the UK can be seen (EUROCRAN 2000-2004). Scotland has a greater number of cleft palate infants per 1000 births than England and a greater number of cleft lip and/or palate infants per 1000 births than both England and Wales

Fig 1.1 European Occurrence of CP per 1000 births

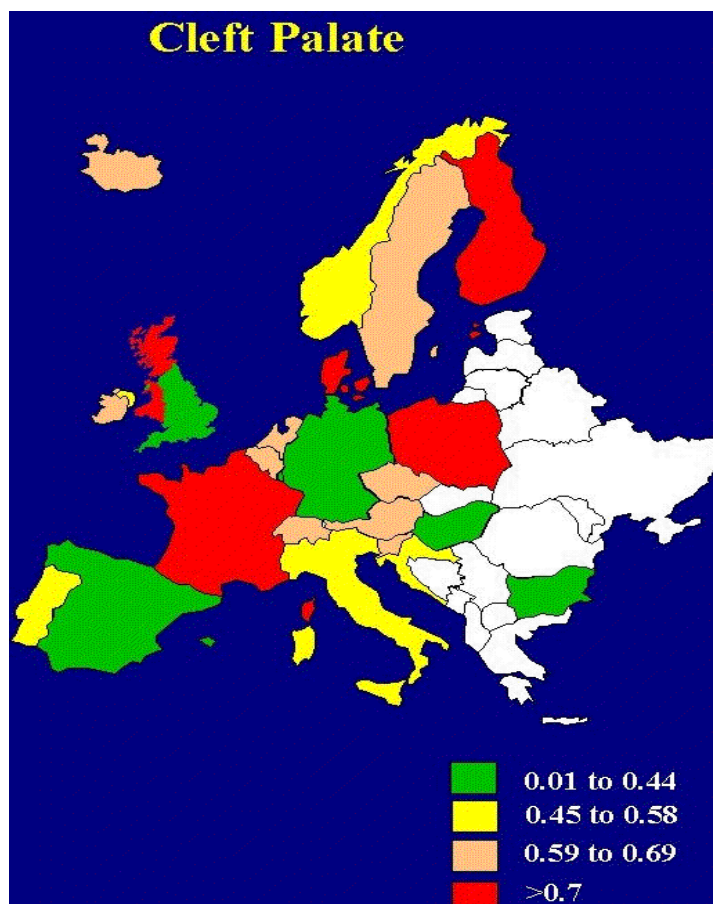
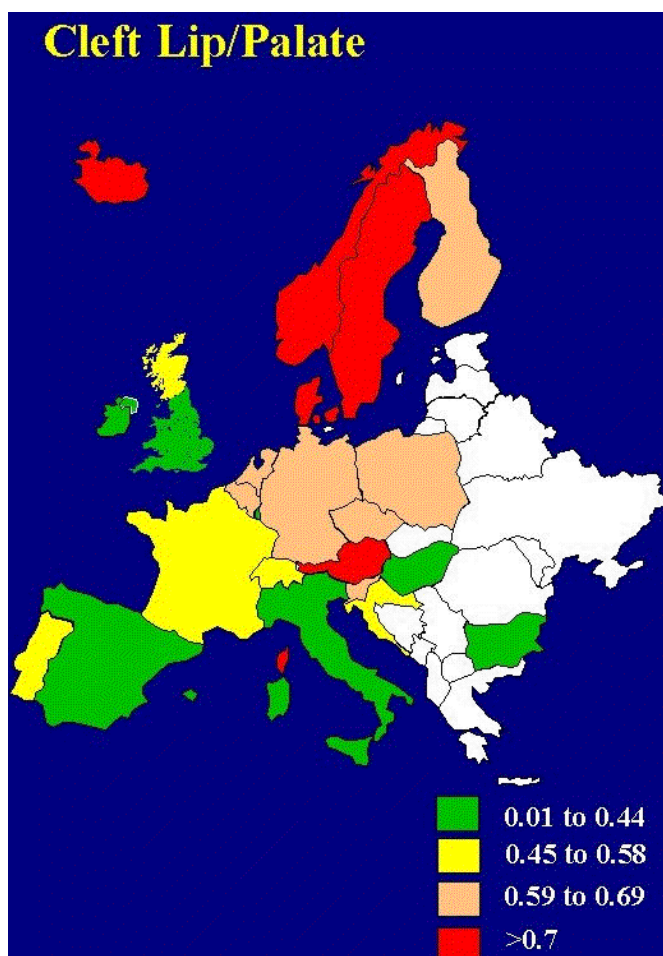


Fig 1.2 European Occurrence of CL+/- P per 1000 births

In Scotland there are between 70 and 90 cleft lip and palate infants born each year. Table 1.1 illustrates the rise in the incidence of cleft lip and palate in Scotland and the corresponding decline in England and Wales since 2001. In 2001, the incidence in Scotland was about a tenth that in England and Wales, now it is almost a quarter.

Table 1.1 Incidence of Cleft lip and palate in the UK (CRANE Report 2004-2005, CLEFTSiS)

Year	Scotland	England & Wales
2001	72	795
2002	75	651
2003	81	540
2004	91	377

The explanation for the decrease in the number of children born with a cleft in recent years in England and Wales is unclear but possible reasons could be the better nutrition and less deprivation, which may in turn be related to less maternal drinking and smoking during pregnancy (the aetiology of cleft lip and palate is discussed in more detail in Chapter 2).

In 1992, Shaw *et al.*, showed that treatment outcomes for children in the UK did not compare well for those in Europe. Good outcomes were achieved where there was standardisation, centralisation and the participation of high volume operators, and poor outcomes where there was non-standardisation and the participation of low volume operators.

As a result of this 1992 European study, the UK government asked a Clinical Standards Advisory Group (CSAG) to advise on standards of cleft care in the UK (Martin 2004). The publication of the CSAG report in 1998 coincided with the Scottish Needs Assessment Programme Report (SNAP), and they both recommended, "That care of cleft patients be concentrated in fewer centres ensuring greater experience for each team, opportunities for better record keeping, audit and involvement in clinical trials" (CSAG 1998; SNAP 1998). Martin also added that as a result of this re organisation the outcome for the patient, she hoped, would be better.

The SNAP report was commissioned by the SNAP Oral Health Group in 1997. This Health Group was made up from professionals providing cleft lip and palate services in Scotland who already met on a regular basis as The Scottish Cleft Lip and Palate Group – SCALP. The SCALP group were asked to suggest members for the SNAP working group (SNAP 1998).

The SNAP report suggested that although services in Scotland were already well integrated 'there should be a staged move toward no more than two cleft centres in Scotland whilst maintaining a network of high skill level locally'.

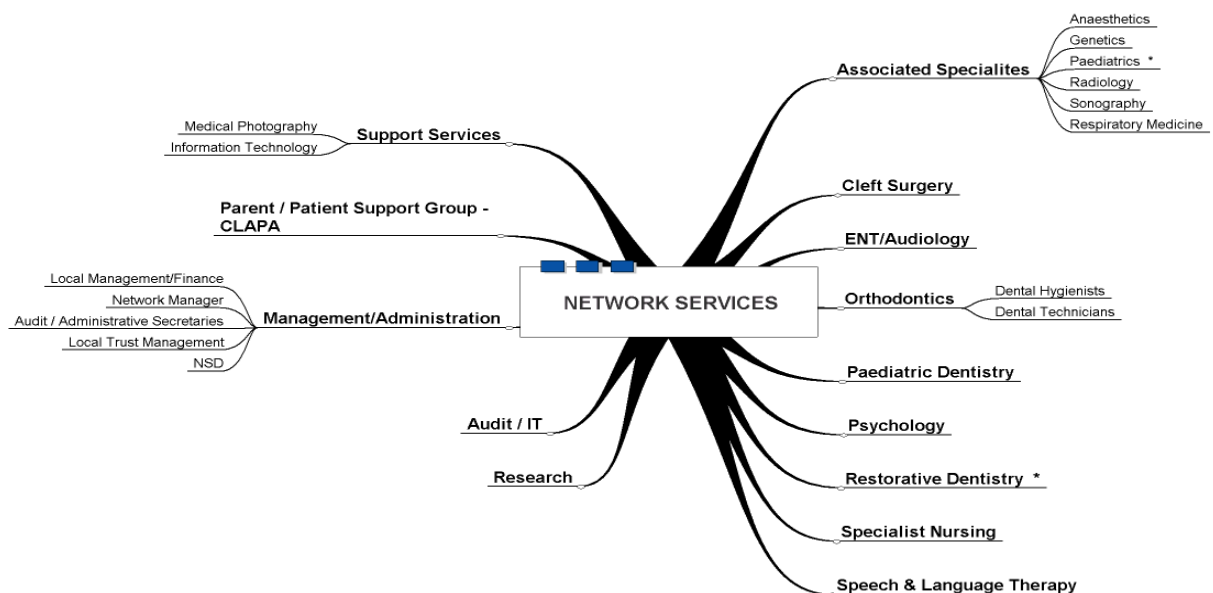
In 1989 SCALP, the Scottish Association for Cleft Lip and Palate had set up a registry and database, which started to record details of all babies born with a cleft lip and palate in Scotland. The Acute Services Review Report in Scotland (Scottish Exec Health Department 1998) recommended the development of managed clinical networks and the SNAP report had suggested that the cleft lip and palate services in Scotland would be a good pilot for this kind of clinical

network. As a result, an embryonic CLEFTSiS, a managed clinical network for cleft services in Scotland was established by interested clinicians in 2000 and they built upon the database initiated by SCALP in 1989. In 2002 the Scottish Executive Health Department supported the development of a managed clinical network for cleft lip and palate (NHS Circular: HDL 2002) and in April 2004 CLEFTSiS was commissioned by the National Services Division (NSD) to develop a national network of cleft lip and palate patients in Scotland (CLEFTSiS Service Specification 2005).

The aims of the network are to co-ordinate and optimise care and outcomes through standard setting and audit for all patients with cleft lip and palate (CLEFTSiS annual report 2006).

The CSAG report felt it was essential to provide a fully integrated multidisciplinary approach, centred on patients' needs from birth through infancy, childhood, adolescence and to the end of facial growth (Martin 2004). The specialities involved in the CLEFTSiS network are shown in the diagram below:

Figure 1.3 A diagram showing the organisation of Cleft services in Scotland (CLEFTSiS Annual Report 2006).



SCALP is now a registered charity, which supports research and education in orofacial clefts (CLEFTSiS Annual Report 2003). This study was initiated by members of SCALP (Professor P Mossey and Professor R. R Welbury) to

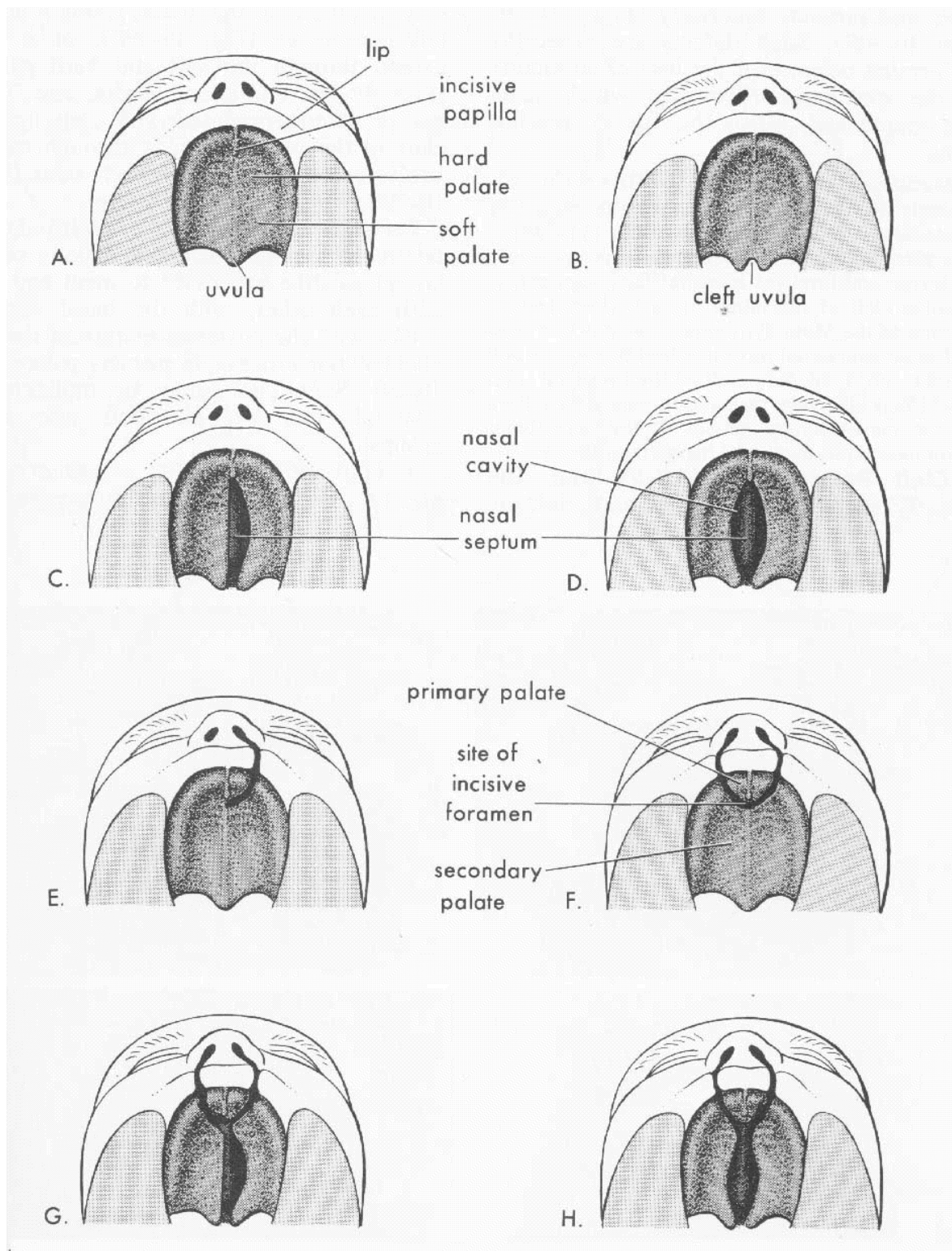
investigate the infant feeding practices in the West of Scotland with a view to further research into breastfeeding and maternal bonding in the cleft infant.

Chapter 2 Literature Review

2.1 Classification of clefts

There have been many attempts at classification of clefts from simple ones, which fail to distinguish between variations of severity to more complicated ones, which can be difficult to use (Watson 2001). SCALP, the Scottish Association for Cleft Lip and Palate and subsequently CLEFTSiS record all babies born with a cleft lip and palate including lip, alar, nostril floor, palate and uvula variations. They also record the shape of the cleft and any respiratory problems. This data is sent to the Craniofacial Anomalies Register whose aim is to record every cleft in Britain. For the purpose of this study the simple nomenclature cleft lip (CL), cleft palate (CP) and cleft lip and palate (CLP) with the prefix U and B for unilateral and bilateral respectively is used as it is the interventions for the cleft infant and the parents' experiences of these which are being investigated here. Figure 2.1 shows diagrammatic examples of the variation in the morphology of orofacial clefts.

Figure 2.1- Diagrammatic examples of the variation in morphology of orofacial clefts (www.goshen.edu/bio/dvert/cleft.jpg)



A-Normal view

C-Cleft palate

E-Unilateral cleft lip

G-Bilateral cleft lip and palate

B-Cleft of the uvula

D-Cleft palate

F-Bilateral cleft lip

H-Bilateral cleft lip and palate

2.2 Aetiology

In the majority of cases, a cleft will be the only defect but it may also be found associated with other congenital anomalies and may occur as part of a syndrome (Lees, 2001). A non – syndromic (NS) cleft is defined as a cleft that occurs in the absence of any other disabilities.

The aetiology of clefts is thought to be multi-factorial with possible genetic and environmental contributory factors.

2.2.1 Genetic Factors

Several genes may be involved in the aetiology of an NS cleft. Lees (2001) states that it does not follow a Mendelian inheritance, but evidence for a genetic predisposition of a NS cleft lip and palate comes from family and twin studies. Studies by the following authors have suggested this: Christensen, 1993; Mossey *et al.*, 1998; Palomino *et al.*, 2000; Wong and Hagg, 2004; Harville *et al.*, 2005; Turhani *et al.*, 2005; Zhu *et al.*, 2006. However, Kot (2005) found that “twin pregnancy does not change the risk of cleft anomaly”. While no specific disease-causing gene mutations have been identified in NS clefting, a number of candidate genes have been isolated through both linkage and association studies (Jugessur *et al.*, 2003; Cobourne, 2004; Ghassibe, *et al.*, 2006).

2.2.2 Environmental Factors

It has been recognised for some time that teratogens play a role in the aetiology of cleft lip and palate (Lees, 2001).

Socioeconomic Status

In Scotland a higher incidence of clefts were observed in areas with higher proportions of local authority housing involving young families, high unemployment and a preponderance of unskilled workers. The converse was found in the affluent areas with high proportions of professional and non-manual workers in large owner occupied housing (Womersley and Stone, 1987; Clark *et al.*, 2003). Clark *et al.*, carried out their study over a 10-year period looking at this relationship between deprivation and clefting and suggested that the results reflected an

association between deprivation and certain risk factors for clefts, especially tobacco smoking during pregnancy.

There were two reasons to include the demographics (age, postcode, and occupation) of the mothers taking part in our study. The first was to assess whether the incidence of clefting was linked to deprivation, and the second was to assess whether the incidence of breastfeeding was linked to deprivation, age and occupation of the mother. This is discussed further in section 2.1.2

Smoking

Maternal smoking during pregnancy has been suggested as risk factor for having a child with cleft lip and palate (Shaw *et al.*, 1996; Kallen 1997; Chung *et al.*, 2000; Lammer *et al.*, 2004; Bille *et al.*, 2007; Shi *et al.*, 2007).

Meyer *et al.*, (2004) found only an association between smoking and CP alone and Wyszynski *et al.*, (1997) found that smoking during pregnancy was only a minor risk factor for oral clefting. Honein *et al.*, (2007) also confirmed “the modest association between smoking and orofacial clefts” but also identified that “specific phenotypes were most strongly affected.” Little *et al.*, (2004) suggested it might be “useful to incorporate information on the effects of maternal smoking on oral clefts into public health campaigns on the consequences of maternal smoking”. A public health campaign in February 2007 by NHS Scotland on Scottish Television advertised a helpline for those women who wished to stop smoking if they were planning a family. Although no specific reasons for cessation of smoking were given, this must be regarded as a very positive move.

Alcohol consumption

The association between maternal alcohol consumption during pregnancy and oral clefts in offspring remains unclear (Meyer *et al.*, 2003). In this case-surveillance study, no correlation was found between low-level alcohol consumption and oral clefts. Mitchell *et al.*, (2001) also found no evidence of risk of cleft lip and palate with gene-environment interactions involving first trimester alcohol consumption. However Shaw and Lammer (1999) who also agreed with the previous authors regarding low-level alcohol consumption did find an increased risk of clefts with higher alcohol consumption. Munger *et al.*, (1996) found no significant association

between alcohol use and isolated cleft palate but found it may be a cause of isolated cleft lip with or without cleft palate. A European multicentre case control study by Lorente *et al.*, (2000) found the reverse, with an increased risk of cleft palate associated with alcohol consumption.

There is obviously conflicting evidence regarding the association between alcohol consumption and oral clefts although cleft palate has been described as an associated defect in 10% of severe cases of foetal alcohol syndrome (Lemoine, 1992; Kotch and Sulik, 1992).

Nutrition

There have been over 100 studies demonstrating the evidence of the protective effect of folic acid on neural tube defects (Czeizel and Dudas, 1992). However Weingaertner *et al.*, (2005) stated, “unless genetically caused, the occurrence of neural tube defects and clefts of the lip, alveolus and palate are not associated. These malformations do however, share some common causes, one of which is folic acid deficiency. Nevertheless, it is not known why a neural tube defect resulting from folic acid deficiency does not occur in combination with facial clefts.”

A number of authors have found that folic acid may reduce the incidence of some facial clefts (Tolavara, 1987; Shaw *et al.*, 1995; Lofredo *et al.*, 2001; Van Rooij *et al.*, 2004; Czeizel, 2004; Krapels *et al.*, 2006; Wilcox *et al.*, 2007). However Bower *et al.*, (2006), Shaw *et al.*, (2006), and Hayes *et al.*, (1996) all found no evidence of folate being an important factor in the prevention of facial clefts despite an earlier study by Shaw suggesting the reverse. The SNAP report (1998) states that “globally there has been no reduction in the birth prevalence of orofacial clefting despite considerable improvements in nutrition”. A recent study by Romitti *et al.*, (2007) suggested an association between specific types of alcohol consumption and folic acid intake and clefting.

Krapels *et al.*, (2004) also found that preconceptional intake of vitamin B seems to contribute to the prevention of orofacial clefts and Van Rooij *et al.*, (2003) found a low vitamin B (12) and a low vitamin B6 blood concentration in mothers increased the risk of orofacial clefts. Hosyak *et al.*, (2004), found a high intake of preformed vitamin A (retinol) might be a *cause* of orofacial clefts

At present, there are no guidelines on the recommended intake of folic acid required for the prevention of clefts (Lees, 2001). There are guidelines on the recommended intake of folic acid for the prevention of neural tube defects.

Drugs

Kallen (2003) found that maternal drug use seems to play only a small role in the origin of orofacial clefts. Park-Whyllie *et al.*, (2000) found an increased risk associated with maternal exposure to corticosteroids as did Carmichael and Shaw, (1999) with CL+/- P. Narbone and Di Perri, (1983) in a review of the literature found that the majority of oral facial clefts occurred in association with the anti epileptic drugs such as trimethasone and Phenobarbital rather than with phenytoin, carbamazepine, and valproate. However McElhatton (1994) suggested that the evidence for these earlier studies was flawed as many of the women were on multi- drug therapies and familial history of malformations was not available. Abrishamchian *et al.*, (1994) found that maternal epilepsy and its treatment accounted for a small proportion of the NS clefts in their study. Arpino *et al.*, (2000) found infants exposed to phenobarbital and methyl phenobarbital showed an increased risk of clefts.

Birth Order

The literature is conflicting regarding the association between orofacial clefts and higher birth order. Menegotto and Salzano (1991), Robert *et al.*, (1996), and Cooper *et al.*, (2000) found a positive correlation but Shaw *et al.*, (1991), Stoll *et al.*, (1991), and Rajabian and Sherkat (2000) did not find such an association. In 2002 Vieira and Orioli concluded in their meta- analysis that there was an increased correlation between higher birth order and oral clefts.

2.3 Breastfeeding

2.3.1 Infants with a cleft

It is universally accepted that breast-feeding is the preferred choice for infant feeding. The World Health Organisation recommends exclusive breast-feeding for

6 months. No other food for human babies can match breast milk for its nutritional, immunological and infection – protection advantages. Bannister (2001) states that one of the first experiences in an infant's life is to be fed. 78% of women in England and 70% in Scotland now choose to breastfeed (Infant Feeding Survey 2005). However, this reduces to 45% by six weeks. The main reason for terminating breastfeeding in normal children was that the mothers felt they had insufficient milk (Sacks, 1976; Martin and Monk, 1982; Wright, 1993). Wright went on to state how this belief can become 'common knowledge in the community ... and that beliefs are powerful determinants of behaviour'. Biancuzzo (1998) found that this was the same with mothers of cleft lip and palate infants and that these mothers were going to breastfeed until they found out that their baby had a cleft and then "leap to the conclusion that breastfeeding is unrealistic and even impossible". She advises that both bottle-feeding and breastfeeding are difficult when the infant has a cleft lip and palate but "perhaps the greatest difficulty is convincing the mother that, for many infants breastfeeding is not only possible but optimal".

Only a few studies however, suggest breast-feeding is possible in infants with a cleft (Clarren *et al.*, 1987; Lawrence, 1997). The advocates of breastfeeding seem to be the specialist nurses or doctors directly involved in cleft infant care and from mothers who are writing from personal experience. As well as Biancuzzo (1998) a number of other authors also support breastfeeding in cleft lip and palate infants: Hemmingway, 1972; Grady, 1977; Porterfield, 1988; Fisher, 1991; Danner, 1992; Crossman, 1998; Wilton, 1998. Danner (1992) said that 'successful breastfeeding helped normalise the infant to the family and that as well as encouraging normal physiological muscular involvement of the mouth and face, it benefits speech development, and provides protection against upper respiratory tract infections particularly Otitis Media'. This is discussed further in this section 2.6.

Grady (1977) describes her experiences of breastfeeding her own twins, one of whom had a cleft palate. She managed to breastfeed both twins successfully and describes how she feels it is 'the action of the jaws, tongue, cheeks, and gums that actually press the milk from the breast and that 'sucking only plays a small part in extracting milk from the breast.'

There are plenty of difficulties with breastfeeding a normal infant and balancing expectation with reality is a common problem for the health professionals involved.

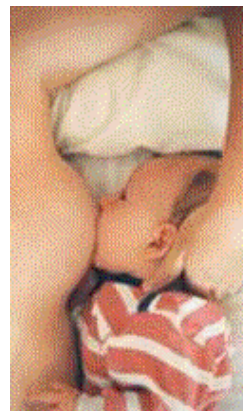
Feeding on demand does not fit in with modern life schedules. The feeding difficulties associated with cleft palate have been documented for many years (Reid, 2004) and the literature suggests that feeding an infant with a cleft lip alone is more easily achieved.

When breast feeding with a cleft lip, the cleft is initially covered in the mouth with a finger to maintain a vacuum during feeding. The mother supports her breast with her hand and when the baby has attached she gently pushes the breast upward to fill the cleft with breast tissue. The mother needs to keep the breast soft to enable it to go easily into the baby's mouth. An efficient 'let down' reflex is also helpful. Alternative positions to enable effective attachment are sometimes needed. The mother can try a version of the underarm position but with the baby sitting upright (Fig 2.2). Alternatively, the baby with a mature gag reflex can be fed lying down on its back with the mother letting the breast fall directly into its mouth as illustrated in Fig 2.3 (NHS Greater Glasgow Infant Feeding Guidelines 2003).

Figure 2.2 the underarm position



Figure 2.3 the lying down position



Courtesy of <http://images.babycenter.com/general/8784.html> (photographs by Jeb Wallace-Brodeur)

Biancuzzo (1998) states that the only time the infants' cleft is not apparent is when they are breastfeeding and "the infant appears quite normal". This may be an important consideration in increasing maternal child bonding.

However, one of the main reasons that mothers of cleft lip and palate infants find it difficult to breast feed can be explained by the action of sucking. Jain (1987) stated, "Sucking is achieved through the combined tasks of generating intraoral

negative pressure and making effective intraoral muscular movement". Choi *et al.*, (1991) found that breastfeeding infants with a cleft lip and palate or cleft palate were unable to create a vacuum and the appropriate negative intra oral pressure necessary to remove milk from the breast. Masarei *et al.*, (2007) found that the sucking patterns of infants with NS complete unilateral cleft lip and palate or a cleft of the soft and at least two thirds of the hard palate differ from those of their non-cleft peers.

Other problems encountered when breastfeeding cleft lip and palate infants include excessive air intake, nasal regurgitation, fatigue, coughing, choking and gagging, prolonged feeds and discomfort (Styer and Freeh, 1981; Jones *et al.*, 1982; Clarren *et al.*, 1987; Carlisle, 1998). These problems lead to increased feeding times and to increased anxiety and frustration for both mother and infant (Tisza and Gumpertz, 1962). Richard (1994) stated that feelings of inadequacy arise from the inability to provide satisfaction and nutrition for weight gain. Wright (1994) found that anxious mothers perceive their babies as fussy, hungry, and demanding and the challenge for the cleft team in trying to advocate more breast feeding is not to make the mother have an even greater sense of failure and frustration, which could have an adverse affect on the bond between her and her child.

For some babies expressed milk needs to be given until surgical closure is complete. However, it would take a very committed mother to express for 3 months until a cleft lip is repaired, and 9 months prior to a palate repair.

The Scottish joint breastfeeding initiative started in 1990 and this led to the creation of the Scottish Breastfeeding Group in 1995, which is a multidisciplinary group that contributes to policy development and the dissemination of good practice and information on breastfeeding. A national breastfeeding advisor was appointed between 1995 and 2005, and in 2006 a draft document on an infant feeding policy for Scotland was consulted upon. This was to form part of the Scottish Executive's Health delivery plan, (Health Scotland Delivery Plan 2006-2007). These positive initiatives have led to at least a 15% rise in breastfeeding in Scotland since 1995 (Table 2.1 in section 2.3.2).

In the West of Scotland, the aims and objectives of the Infant Feeding Policy and Guidelines for Health Professionals in NHS Greater Glasgow and Clyde (2003) are as follows:

Aims

- 1 To help every woman to make a fully informed choice about how she feeds her baby.
- 2 To provide every woman with skilled help with infant feeding.

Objectives

- 1 Ensure appropriate training of NHS staff.
- 2 Encourage breastfeeding for babies with special needs.

The document also highlights the importance of the “First Feed” and that if mothers are undecided in their feeding choice or lack the confidence to breastfeed, they should be encouraged by a good skin contact experience and positive support from their midwife, to offer a breastfeed.

These guidelines also state ‘that the success of long term breastfeeding is directly related to a positive breastfeeding experience within the first hour of birth’.

However infants with a cleft are not mentioned in the acceptable reasons for supplementation of breast milk and the document has contradictory notes about breastfeeding infants with a cleft. In the section on alternative feeding methods it states that “cup feeding provides a positive oral experience for babies who are unable to suck, i.e. babies with a cleft lip or palate” but then gives advice on how to breastfeed a baby with a cleft lip and palate in the section on ‘*Babies with Special Needs*’. These contradictory statements are confusing to the health professionals for whom the document is intended.

2.3.2 Incidence and duration

The Infant feeding survey of 2005 defines the incidence of breastfeeding as the proportion of babies who were breast fed initially even if this is only once. In Scotland the incidence of breast feeding in 2005 was 70% compared to 63% in 2000 and 55% in 1995. From table 2.1 below it can be seen that this increase over

the last 10 years has been greater in Scotland than both England and Wales, and Northern Ireland, yet levels are still less than in England.

Table 2.1 The Incidence of breastfeeding in the UK 1995, 2000, & 2005

Incidence of breastfeeding	Scotland	England & Wales	Northern Ireland
1995	55%	68%	45%
2000	63%	71%	54%
2005	70%	67%(W) 78%(E)	63%

A more realistic picture of breastfeeding in Scotland would be to look at the prevalence figures after one week and these reveal figures of only 35.6% nationally (Scotland) with levels as low as 7.6 % in some of the more deprived areas of Glasgow (Ferguson *et al.*, 1994).

The infant feeding survey of 1995 reported that mothers who had breast fed a previous child were most likely to continue to breast feed after the first few weeks, as were mothers educated beyond the age of 18, and women in non manual social class groups. The breastfeeding figures range from 39% for those who had left school at age 16 to 80% for mothers who remained in education beyond 18.

The mother's age also has a bearing on the incidence of breast-feeding with only 20% of mothers younger than 20 years of age breastfeeding their first baby. This rises to 52% when the mother is under 25 years and 76% for those mothers over 30.

There appear to be no significant epidemiological studies of breast feeding rates in the cleft population although one small study by Trenouth and Campbell (1996) found that a number of mothers who attempted to breastfeed (12/25) were not successful. This information together with the poorer breastfeeding rates for the general population in Scotland suggests that the rates for breastfeeding in the cleft population, especially in the West of Scotland, are likely to be low. This current study will investigate the incidence, prevalence, and duration of breast-feeding for cleft lip and palate infants in the West of Scotland and compare it with the government Health and Social Care figures for the general population.

2.4 Nutrition and growth

Cleft infants are faced with the challenge of anaesthesia and surgery early in life and good weight gain before these surgeries is essential (Richard, 1994). Failure to thrive (FTT) is a recognised problem associated with cleft infants and Balluff (1986) discussed the importance of serial nutritional monitoring to help achieve adequate nutrient intake.

In a three- centre study involving Glasgow, Birmingham and Liverpool, Jones (1988) found mean weight gain to be lower in the cleft population, with isolated clefts of the secondary palate being particular low. Gopinath and Muda (2005) found that cleft infants measured significantly lower on the height growth curve compared to infants without a cleft. In addition, Aviedan and Ruberg (1980) and Paradise *et al.*, (1984) found early weight loss in infants with a cleft. However Becker *et al.*, (1998) found that children born with an isolated cleft lip alone were no lighter than babies without a cleft. Lee *et al.*, (1997) and Jensen *et al.*, (1993) found that although weight gain was significantly low in early infancy, cleft infants attained their expected weight and height by the time they were between 2 and 3 years of age. These studies are valuable because they can show parents and carers that the low weight gain is only temporary (Aviedan and Ruberg, 1980). However the early months around the time of planned surgery are a critical time for the infant and optimal weight gain is very important.

Although cleft infants overall exhibit catch – up growth with the ‘normal’ population, significant developmental delays in some children with a cleft may be linked to their nutritional status. Jocelyn (1996) found that children with a cleft had lower scores on tests of cognition, comprehension, and expressive language abilities compared to the control children at 12 and 24 months. Nieman and Savage (1997) similarly found that cleft infants at 5 months showed decreased motor skill, reduced feeding skills, and lower cognitive scores. In addition, 3-year-old toddlers with a cleft showed noticeably less expressive language skills when compared with the ‘norm’.

2.5 Feeding Interventions

Reid (2004) found that studies of feeding infants with a cleft are full of all the potential difficulties of breastfeeding for both the mother and infant. Coughing, choking, gagging, nasal regurgitation, and prolonged feeding time are the most common problems (Styer and Freeh, 1981; Jones *et al.*, 1982; Clarren *et al.*, 1987; Carlisle, 1998). As a result, many feeding aids and interventions have been suggested in the last 30 years (CLAPA 2007a; CLAPA 2007b). These include modified teats and bottles, different feeding techniques, obturators or feeding plates, nutritional and feeding advice, and maternal support.

2.5.1 Modifications of bottles and teats

Shaw *et al.*, (1999) recommended that squeezable bottles should be routinely prescribed for infants with a cleft as parents in their study found them easier to use than a standard (rigid) bottle. Two examples of soft, squeezable bottles are shown in Figure 2.5. The Haberman Feeder (Campbell and Tremouth, 1987) shown in Figure 2.6 is a special teat which fits over a cylinder, which in turn consists of a non-returnable valve that allows milk into the teat. This fits over a normal bottle and allows the infant to suck on the teat without wasting any sucking on compressing the air inside the bottle. The cleft babies in this study fed faster and more easily without complications. However the initial study had only 6 infants, 3 of which were used as a control and a longer-term study was suggested by the authors. The Haberman feeder is a method that is currently used in the West of Scotland

Figure 2.4 Squeezable bottles. (www.clapa.com/feeding_equipment.php)



The Mead-Jonson bottle



The MAM soft bottle

Figure 2.5 the Haberman bottle. (www.cleft.ie/products.htm)

Another modified teat is the crosscut teat, which was first recommended by Pashayan and McNab in 1979. They took a standard teat and 'crosscut' the centre hole. The baby was then fed in the upright position to reduce nasal regurgitation and burped frequently to reduce aspiration. Their rationale was that parents of cleft infants do not want to use 'special equipment' and thus appear even more 'unusual' in front of family and friends. All the uncomplicated or NS cleft lip and palate babies in their study were fed using this method and they found weight gain (used as a measure of adequate nutrition) by these infants was normal. This method is rarely used in the West of Scotland.

A more frequently used teat in the West of Scotland is the regular Nuk (Mam) teat, which looks like a normal orthodontic teat but with a larger reservoir. Health professionals sometimes recommend a Nuk Cleft Palate teat (Figure 2.7). This is a much larger teat but Choi *et al.*, (1991) found this was worse at generating the negative intraoral pressure necessary to withdraw milk. He thought this might be because the regular Nuk teat allowed more movement of the lips and tongue. Choi *et al.*, reported that their findings applied only to those infants with a cleft lip only.

Figure 2.6 Photographs of different teats (www.clapa.com/cleftlip.html)

Orthodontic Shaped Teat



Regular Nuk (Mam) teat



NUK Cleft Palate Teat

2.5.2 Techniques

Cup Feeding

Cup feeding is used when a baby is going to be breast fed. Breast milk can be expressed and given to an infant through a bottle, naso-gastric tube, or cup and spoon. The latter method is sometimes advocated after cleft surgery. (UK Central Council for Nursing, Midwifery and Health Visiting 1991). Cup feeding provides a positive oral experience for cleft babies and helps avoid nipple/ teat confusion that bottle-feeding may cause. It also reduces the need for naso-gastric /oro-gastric tubes (Rapley 2002). Lang *et al.*, (1994) used this method with preterm infants and advocated it for infants with cleft lip and palate until after the repair. They also found it reduced the need for gastric tubes. Lingual lipase, which is present at the back of the tongue and assists with fat digestion, is stimulated with cup feeding. Psychologically the mother views herself as a future breast feeder even when this is a long way off (Rapley, 2002). The mother is giving her baby breast milk, which keeps her milk supply going until after surgery, when she can hopefully breastfeed in the normal way. A randomised controlled trial (RCT) by Darzi *et al.*, (1997) found that breastfeeding after cleft lip repair was safe and resulted in more weight gain than with spoon-feeding. Cohen *et al.*, (1992) also found no complications after lip or palate repair with unrestricted feeding using either bottle or breast.

Upright position

Lifton (1956) said that ‘sometimes all that is required to aid feeding in the infant with cleft lip and palate is to hold them in an upright or semi upright position’ (as described in section 2.3.1). This manoeuvre enables swallowed air to be expelled during feeding. Dunning (1986) also advocated this position “because it allows gravity to reduce the back flow (of milk) through the nose and prevent milk entering the middle ear which can contribute to ear infections.” Brine *et al.*, (1994) were also advocates of this technique.

The Enlargement, Stimulate, Swallow, Rest (ESSR) Technique

In 1991 Richard published a paper describing the ESSR technique (Table 2.2). In this description, the original word nipple used in Richard’s text has been replaced with teat to avoid confusion because Richard suggested it as a method for bottles

only. Richard suggested using the teat the infant is already comfortable with and adds that this should be done as early as possible before feeding problems are well established. At the time of publishing (1991) this method had been tried on over 200 infants and Richard stresses it is a very flexible method, which explains the need for occasional breaks in feeding not just widening the hole in the teat.

Table 2.2 Explanation of the ESSR technique

	Action	Effect
E	Enlarge pre-cut teat hole	Allows infant to receive formula to back of throat without having to rely on ineffective suction
S	Stimulate the suck reflex by rubbing teat against lower lip Insert and then invert bottle	Prepares infant for feeding due to enlarged teat. Inverting and inserting prevents spilling and waste
S	Swallow fluid normally	Receives an adequate amount of Formula without using excess energy and will meet nutritional requirements for proper weight gain.
R	Rest after signal. Infant will exhibit a facial expression indicating a short break is necessary. Repeat process until infant has eaten normal amounts of formula in normal amount of time	Allows infant to finish swallowing as formula already in back of throat and avoids gagging or nasal regurgitation

2.6 Pre-surgical appliances

The principle aim of pre surgical orthopaedic treatment for babies with cleft lip and palate is to realign the bony elements of the cleft to provide a more normal base for surgery, and reduce post surgical breakdown (Hathorn 2001).

Pre surgical orthopaedic appliances have been developed over the last 100 years. Burston (1958) advocated a method in which silver wire was passed through both

ends of the cleft alveolus before being progressively tightened to approximate the ends of the alveolus prior to lip repair. The realignment of the maxillary alveolar processes was thought to encourage more normal facial growth and dental arch development. Robertson (1983) wrote extensively on the subject and described various methods of pre surgical appliances using active and passive acrylic plates and external strapping. Similarly, other authors have advocated different presurgical appliances (DiBiase, 1983; McNeil, 1984; Brogan, 1986; Ball and DiBiase 1995; Hotz, 1990).

In the UK pre surgical appliances are made soon after birth and worn until primary lip surgery at about 3 months of age. Sullivan (1990) described the construction of the appliance during the first 24 hours after birth. An impression is taken of the baby's palate which is then used to make a working model for the construction of the appliance. In 2001 Hathorn described the different pre surgical appliances used for each cleft type and these are described below.

2.6.1 Clefts of the lip and alveolus

External strapping in the form of adhesive tape is used to redirect the distortions of the lip and alveolus as shown in Figure 2.8 (Sullivan 1990).



Figure 2.7 External strapping

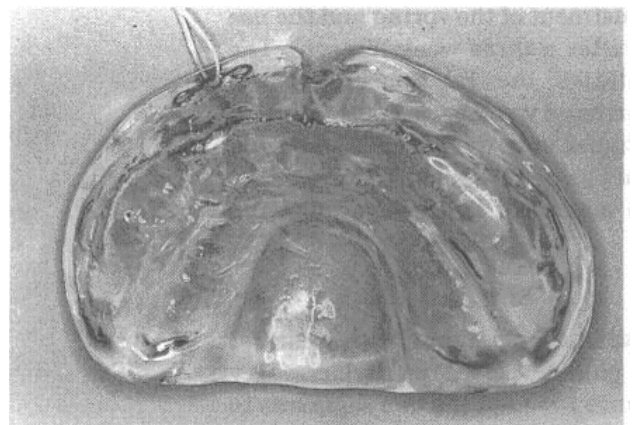


Figure 2.8 A passive appliance

2.6.2 Unilateral clefts of the lip and palate

There is considerable variation in the types of appliances that are used in this group. Where there is minimum distortion of the tissues a passive appliance can be used which acts to keep the tongue out of the cleft site and thus hopefully encouraging lateral shelf growth (Figure 2.8). At the other end of the spectrum when there is significant distortion a combination of both intra-oral appliances (Figure 2.9) and external strapping (Figure 2.8) may be used.

2.6.3 Bilateral clefts of lip and palate

The prominent pre maxilla is the main source of distortion in bilateral clefts and it occurs due to the vigorous growth of the nasal septum. Extra-oral strapping is necessary to restrain this growth and allow the posterior segments to advance. It is claimed that pre surgical appliances can stabilise the existing arch or allow expansion of the posterior segments in preparation for retraction of the premaxilla.

2.6.4 Clefts of hard and soft palate

A passive pre surgical appliance is again advocated to keep the tongue out of the cleft site and encourage lateral shelf growth.

In Pierre Robin Sequence a passive plate combined with positional nursing to keep the tongue forwards, encourages maxillary shelf growth and anterior mandibular growth.

Presurgical appliances were increasingly referred to in the literature as 'feeding plates' because it was thought that they would help with feeding (Hotz and Gnoinski, 1976; Hotz, 1983; Hotz *et al.*, 1986). Indeed Lifton (1956) described the use of 'obturators' which stimulated sucking and helped feeding. Glass and Wolf (1999) and Miller and Kummer (2001) described how 'feeding obturators' separate the nasal and oral cavities and provide a surface to oppose the nipple during sucking'. However Herzog- Isler (1994) found pre surgical appliances of limited use as a breastfeeding aid.

The effect of these appliances and the evidence for their use is conflicting. Mars *et al.*, (1992) found significantly better surgical results when pre surgical appliances were used. However Paradise and McWilliams (1974), Berkowitz (1978), and Ross and MacNemara (1994) found no significant benefits.

Other reported benefits of pre surgical appliances have included a reduction in maternal stress by preventing the tongue from entering the cleft site (Oliver, 1968). In addition Jones *et al.*, (1982) reported that an 'intraoral maxillary obturator' was useful in more severe cleft cases by reducing both nasal discharge and the time taken for feeding. These latter authors also reported a reduction in parental anxiety during feeding. Dunning (1986) suggested a 'feeding plate' if all other methods of feeding are not successful.

Abadi and Johnston (1982) reported that prosthetic therapy helped the development of normal speech, and thought that this could be instrumental in the psychologic and social acceptance of the cleft palate patient. Balluf and Udin (1986) found an improvement in daily weight gain when they used 'obturators' and early parental education before surgery. Although they recognised that this was not a significant result because of the small sample size and lack of a control group, they showed that the parents of these infants found that feeding was facilitated and feeding times were shorter. Turner *et al.*, (2001) found a reduction in feeding time and an increased volume intake when a passive palatal obturator and lactation education was introduced with both breast-feeding and bottle-feeding with a Haberman bottle. Osuji (1995) stated that a feeding appliance was indicated in complete unilateral and bilateral cleft lip and palate but contraindicated in isolated soft palate and submucous clefts. He found a feeding appliance "eliminated slow frustrating feedings" and reduced infections in the nasopharyngeal area as food stagnation in the clefts was minimised. Fleming *et al.*, (1985) described a modified feeding plate with a silicone soft lining. They found greater stability and improved retention with this appliance and also found it to be accepted more readily by the infants than the conventional acrylic feeding plate. A further advantage was that strapping to the infant's cheeks with tape was not required and this reduced nursing management problems as the strapping did not need to be changed after each feed. The lack of wire 'wings' and strapping tape was not only more cosmetically acceptable but because the soft lining was extended anteriorly, the facial appearance was improved.

Kogo *et al.*, (1997) describe using a Hotz-type plate for breast feeding mothers of cleft lip and palate infants. Four out of the 10 babies could successfully breast feed and although supplemental bottle-feeding was needed they describe this as “the first step to reaching an ideal breast feeding situation for these patients.”

However, an RCT by Prahl *et al.*, (2005) using passive maxillary plates in unilateral cleft lip and palate infants found no significant improvement in feeding and consequently nutritional status. A similar outcome was reported in a recent RCT by Masarei *et al.*, (2007) who also found that presurgical appliances did not improve feeding efficiency or general body growth. Prahl *et al.*, (2005) concluded, “The use of infant orthopaedics in unilateral cleft lip and palate can be abandoned”. Shaw *et al.*, (1999) actually abandoned an RCT with feeding plates because it was found they were not necessary to establish successful feeding.

Choi *et al.*, (1991) reported that a plate did not improve the negative intraoral pressure in cleft lip and palate infants, which would have facilitated withdrawal of milk from the breast or bottle.

The usage and acceptance of the feeding appliances in the West of Scotland will be investigated in this study.

2.7 The incidence of Otitis Media in cleft infants

Studies have shown that infants with a cleft are more at risk of contracting both secretory and acute otitis media. Dhillon (1998) and Paradise *et al.*, (1969) found middle ear effusions in 97% and 100% of their cleft patients respectively. The function of the eustachian tube is compromised when there is a cleft palate present. The contraction of the tensor muscle, which is supported by the levator veli muscle, normally opens and dilates the eustachian tube. However, in cleft patients, the medial insertion of these muscles is lost and their function is impaired. The resulting dysfunction of the eustachian tube is seen as one of the most important risk factors for otitis media (Doyle *et al.*, 1980). Aniansson *et al.* (2002) stated that there was little evidence to show that cleft repair and early treatment with grommets returned the eustachian tube to normal and prevented otitis media. They looked at the lack of breast-feeding as an influential factor in the

incidence of otitis media in cleft lip and palate children versus a control group. Their study showed a 'significant beneficial effect of feeding with breast milk on both secretory and acute otitis media.' Longer feeding times was particularly significant for the CP/CLP group. Their understanding is that breast milk contains immunoglobulins, antibodies, and antiviral agents, which protect against middle ear infections. Paradise *et al.*, (1994) found that expressed breast milk also had varying degrees of protection against Otitis media.

In this current study, we will investigate the reported incidence of Otitis media in cleft children in the West of Scotland and relate this to breast feeding and feeding with expressed breast milk.

2.8 Caries risk in cleft infants

Over the last 20 years, many studies have found a greater incidence of caries in cleft children (Johnsen and Dixon, 1984; Dahllof *et al.*, 1989; Ishida *et al.*, 1989; Bokhout *et al.*, 1997; Lin and Tsai, 1999; Chapple and Nunn, 2000; Bian *et al.*, 2001; Dalben *et al.*, 2002; Kirchberg *et al.*, 2004). However a recent systematic review of case control studies has drawn attention to the lack of standardisation of scientific method in the literature (Hasslof and Twetman 2007). From an early age good care is crucial to the success of later multidisciplinary treatment. Only if there is a high standard of oral hygiene and a healthy dentition can many of the advanced orthodontic and surgical procedures be offered (McGuinness, 1992).

The high energy formula milks that are sometimes recommended for an infant with a cleft, when there is a history of low weight gain, are more cariogenic than standard formula because of the type of sugars they contain (NHS GG Infant feeding policy 2003). Good dental hygiene is critical and it is essential that parents are advised about an appropriate fluoride regime for their child as well as dietary advice about hidden sugars. They should be advised to encourage a feeder cup as soon as possible after 6 months to limit the risk of dental caries.

Cleft children are faced with a multitude of anatomic and physiologic problems, which also places them at increased risk of caries (Kaufman, 1991). Adjacent to

the cleft site on the alveolar ridge there may be missing, hypoplastic, or supernumerary teeth. These anomalies together with crossbites and crowding which are also more common in cleft children, in addition to the presence of scars from surgery, all increase the caries risk (Ishida *et al.*, 1989).

Johnsen (1982) and Dalben *et al.*, (2003) investigated baby bottle caries and found that parents of children with specific health conditions find it difficult to say 'no' to their children and there was evidence of unhealthy dietary habits. The latter authors in Brazil also found that babies with a cleft experienced an early contact with sugar and that 'adding sugar or honey to the baby bottle was a common cultural habit'. There has also been a tradition of this practice in the West of Scotland and although there is only anecdotal evidence we will look at the possible prevalence of this in the current study.

2.9 Syndromes associated with clefting

There are over 400 syndromes with an associated cleft listed in the London Dysmorphology Database (Winter and Baraister, 1998; Lees, 2001). Syndromic clefts account for about 15% of all clefts. About 25-30% of syndromic clefts involve isolated cleft palate (SNAP, 1998). Some of the more common syndromes are:- Pierre Robin, Van der Woude, Stickler, EEC (Ectrodactyly-split hand/foot, Ectodermal-involving hair, teeth and nails, and Clefting), Kabuki, Treacher Collins, Oral-facial-digital and CHARGE (involving a cluster of malformations) syndrome (Watson, 2001).

In our study, we did not differentiate between the syndromic and non- syndromic clefts.

2.10 Specialist feeding advice for cleft infants

The one member of the multidisciplinary cleft team that is of critical importance with regard to establishing and maintaining an effective feeding regime is the specialist cleft nurse.

2.10.1 Specialist Cleft Nurses

Specialist cleft nurses provide pre and postoperative care for parents / carers. They also have an important role liaising with maternity units and paediatric ward staff. They will plan a feeding programme in conjunction with the family, midwives, health visitors, and the rest of the cleft team. When a mother does decide to breast feed specialist nurses look for signs that breastfeeding is not going well and use an observation chart (see accompanying material).

Specialist cleft nurses are of paramount importance because successful breastfeeding can be a means to establish bonding and this may be even more critical for “special needs babies”. The principles of establishing breast-feeding are the same for any baby: (NHS GG Infant Feeding Policies and Guidelines for Health Professionals 2003).

- 1 Prioritise the need for skin-to-skin contact leading to an early feed after birth.
- 2 Position and attach the baby well.
- 3 If the baby sucks poorly or is unable to attach, help the mother to express her milk and cup or tube feed the baby as appropriate.

Maintenance of optimal nutrition is particularly difficult in the post –operative period when feeding patterns become disrupted (Wellman and Couhlin, 1991). Poor nutrition can increase the surgical risk and jeopardize the postoperative recovery of these infants. The effectiveness of the nursing strategies to increase the intake of nutrients is therefore very important. Panya and Booreman (1994) looked at failure to thrive and as a result of their study, they instituted a feeding support nurse which considerably reduced the incidence of failure to thrive. De Chateau

(1980) found that “the success of long term breast feeding is directly related to a positive breastfeeding experience within the first hour of birth”. This illustrates the importance of specialised cleft nurses who can help families understand that breast feeding will not harm their child even when they choke and gag and that breast milk can be expressed and given via a bottle, syringe or naso-gastric tube, (NHS Greater Glasgow Infant Feeding Policies and Guidelines for Health Professionals 2003).

The health visitor is frequently the only health professional who is in regular contact with an infant with a cleft. However there are no specific guidelines for the health visitor to recognise an undiagnosed cleft although there are specific guidelines on managing a baby with poor weight gain. The information about the availability of the specialist cleft nurses at Yorkhill are inexplicably omitted from this NHS GG policy document

The Cleft Lip and Palate Association (CLAPA) is a voluntary organisation specifically helping those with, and affected by, cleft lip and palate (CLAPA, 2001 www.clapa.com/cleftlip.html). It was set up in 1979 as a partnership between parents and health professionals and its governing body are a board of trustees. CLAPA has completed many audits with the aim of increasing knowledge about cleft lip and palate among health visitors, midwives, nurses, and obstetricians who are normally the first point of contact for the parents of an infant with a cleft. The CSAG report (CSAG 1998) commented on the parental survey carried out by CLAPA which highlighted the confusion and distress caused by incorrect and conflicting advice given by those health professionals unconnected with the cleft team. CLAPA carried out a survey in 2006 (CLAPA, 2007a) of parents' experiences of their child's cleft care to follow-up their earlier study in 1996 and some of their findings will be compared with the experiences of the parents in the West of Scotland in this study:

- 1 The lack of knowledge of clefts on the maternity wards.
- 2 The delay in meeting a cleft team member within 48 hours of diagnosis.
- 3 Delay in the diagnosis of a cleft.
- 4 Encouragement to breastfeed infants with a cleft.

The current study will also investigate the support and advice given to mothers and families by all health professionals as well as those who are specific members of the cleft team.

2.11 Parental Experiences

2.11.1 Antenatal diagnosis

The CSAG report (1998) advocates that a suspected cleft revealed by ultrasound be confirmed by an experienced practitioner and reported to the clinician who requested the investigation. Immediate contact of the cleft team should then be arranged. However prenatal detection is low, especially in low risk patients (Suresh *et al.*, 2006).

Cash *et al.*, (2001) found a 93% detection rate for cleft lip and palate but only 22% for isolated cleft palates. Sohan *et al.*, (2001) also found similar results with 70% of cleft lip and palates detected but no detection of cleft palate alone. Although both these studies had low numbers of cases, two studies by Stoll *et al.*, (2000) between 1979 and 1998, and Clementi *et al.*, (2000) involving 20 European registries found comparable results. Stoll *et al.*, (2000) found that although detection increased over the 19 years it was still low at 26.5% for isolated cleft palates whereas detection of cleft lip and palate increased to 50% between 1989 and 1998.

Martin and Rose (2004) state that “although examination of the foetal face is a component part of the current guidelines for the second trimester ultrasound examination many units do not include this due to restrictions of staffing and funding”.

Nyberg *et al.*, (1993) found that “premaxillary protrusion is an important clue to the presence of cleft lip and palate and may be more conspicuous than the cleft itself”. In addition Babook and McGahan (1997) found that ultrasound evaluation of the axial view of the alveolar ridge of the maxilla allows identification of a cleft lip or cleft lip and palate. Campbell *et al.*, (2005) and Platt *et al.*, (2006) found a 3-dimensional ultrasound “reverse face” or “flipped face” technique assessed the

fetal palate with a high degree of accuracy. The use of this technique in the future should enhance antenatal detection of oral clefts, especially isolated cleft palates. This would then allow necessary antenatal counselling for prospective parents.

This study will investigate the antenatal detection of our cohort.

2.11.2 Ante and postnatal care.

In the CLAPA survey (2006) which studied parents' experiences of their child's cleft care, one of the recommendations was to 'aim for a 100% visit of nurses or other cleft team members within 48 hours of diagnosis - both ante and postnatal'. Their survey found that only 48% of parents had seen a cleft member within 48 hours after the diagnosis with 7% waiting up to 6 months.

This current study will investigate and compare findings in the West of Scotland.

Young *et al.*, 2001 found that 'parents of newborns with CL/P want basic information in the immediate newborn period, especially regarding feeding. They also found that even "educated parents may have incorrect ideas concerning the aetiology of CL/P ...and it was critical for parents to be told that it is not their fault". Johansson and Ringsberg (2004) found that although parents were satisfied with the craniofacial team there was a lack of knowledge in other healthcare professionals, which resulted in difficulty 'handling the situation and poor quality of advice on feeding'. This was also found by Oliver and Jones (1997) who conducted a postal survey of 100 parents' experiences in South East Wales. They also found that isolated cleft palates were associated with a high proportion of feeding via naso-gastric tubes both at discharge and at home.

Glenny *et al.*, (2004) in a review of the literature advocated, "Further studies of the most appropriate support and advice for mothers wishing to feed their baby with breast milk are required".

This current study will investigate the first and subsequent feeding methods of the cleft infants and the support and advice given by the cleft and non-cleft teams during the ante and postnatal periods.

Chapter 3 Aim and Objectives of Study

Aim

This study aims to look at feeding practices amongst infants who are born with a cleft in the West of Scotland and the feeding difficulties and challenges that the parents of these children experience especially in the first hours and months after birth.

Objectives

1. To determine the proportion of infants who are breastfed.
2. To determine the proportion of infants that are bottle-fed or use assisted feeding methods.
3. To ascertain whether demographics are a factor in the choice of feeding method used.
4. To assess the duration of feeding times.
5. To assess the incidence of ear infections.
6. To look at the use of feeding modifiers.
7. To assess feeding habits which would compromise dental health.
8. To look at the support and feeding advice given to their parents by both the Cleft Team and non-cleft Health Care Professionals.

Chapter 4 Method

There has been a rise in the number of infants born with a cleft in Scotland over the last 5 years. In the West of Scotland there has been an increase from 30 births a year in 2000 to 50 births during 2005. This accounts for almost 50% of the total number of children with clefts born in Scotland each year. To achieve the aims of the study it was planned to interview approximately 100 parents of children born with a cleft in the West of Scotland during the last 6 years. The maximum number of children available for the study was 120.

The Oral Orthopaedic Prevention Clinic

The Oral Orthopaedic Prevention Clinic (OOPC) is located at the Glasgow Dental Hospital and School and is a joint clinic incorporating orthodontic, paediatric and speech therapy for infants with a cleft in the West of Scotland. Potential access to the parents was possible during their child's routine dental appointment at the clinic. This approach would not include an extra appointment for the parents and would allow a "Face to Face" structured interview.

Criteria

All parents of infants visiting the OOPC were considered for the study. The only exclusion criterion was if the infant was older than six because at the time of this study CLEFTSiS had only been established for 6 years. Interpreter services could be accessed if necessary.

Recruitment

A Parents' Invitation letter (Appendix 9.4) was sent 2-3 weeks before their child's appointment. This letter invited them to take part in the study and to read the accompanying 'Parent Information Sheet' (Appendix 9.5). On arrival at the OOPC the investigator asked one parent to sign a Consent Form (Appendix 9.6) before taking part in the study. One copy of the Consent Form was given to the parent, one placed in their child's notes and the original was kept with the questionnaire.

Ethical Approval

Ethical approval was applied for and granted by the West of Scotland Ethics Committee (Appendix 9.1) as was approval from the local NHS Research and Development Office (Appendix 9.2).

4.1 Development of the questionnaire

The questionnaire (Appendix 9.3) was developed from two questionnaire sources: one designed by Dr Kay Hood and Dr M.T. Hosey for potential research purposes; one used by the Specialist Cleft Nurses at the Royal Hospital for Sick Children (Yorkhill) to annually audit their services (see accompanying material).

The final questionnaire consisted of 51 questions covering the following subject areas; Demographics; Parent's Experiences; Feeding Methods; Feeding Interventions; Pre-Surgical Appliances; Otitis Media; Feeding Habits; and Support and Advice given in the first year of the cleft infants' life.

4.1.1 Demographics

The first 13 questions gathered demographic information about the mother and child: Dental Hospital number (Q1); The hospital in which their child was born (Q2); Child's date of birth (Q3) (this was to ensure that no children over the age of 6 participated in the study); postcode (Q4). The postcode was then related to the Carstairs deprivation category, and given a Depcat Score (McLoone 2004). Depcat scores were then classified accordingly; Mothers age at birth of child (Q5); Cleft type (Q6); whether their child was a twin (Q7); if they had been a full term birth (Q8); the number of weeks premature if applicable (Q9); Parental occupations (Qs 10 & 11); whether they had any other siblings (Q12); and the birth order of their cleft infant (Q13).

4.1.2 Parents' Experiences

Parents were asked if they knew their child would be born with a cleft (Q14). Within the first 10 interviews it became apparent that some parents had found out at birth and some had undetected cleft palates which weren't discovered immediately at birth, so notes were taken about when the cleft was diagnosed and then when they subsequently saw the Cleft team. It was also determined if any siblings had been breast fed and if having a child with a cleft had changed the mother's choice of feeding, and if so why (Q15).

4.1.3 Feeding Methods

The parents were asked about the first feed their infant received (Q16), if they breast fed at all and for how long (Q17), the use of expressed breast milk (Q18), and whether they changed their method of feeding and what to (Q19). They were also asked if the feeding method changed after surgery (Q20).

4.1.4 Feeding Interventions

The parents were asked about the different bottles and teats they might have tried and the one which their infant adapted to most readily and preferred (Qs 21, 22 and 23).

4.1.5 Feeding Patterns

The parents were asked if they had problems with the length of time it took for their baby to feed, and how long it took their infant to settle into a regular pattern of feeding (Qs 24, 25 & 26). Question 27 inquired if they felt that the amount of food at each feed was adequate.

The next question (Q28) dealt with the difficulties their infant might have encountered during feeding:

- Coughing, choking or gagging.
- Food or fluid escaping into their infant's nose.

- Excessive air intake (wind).
- Excessive leakage of milk around the mouth.
- Exhaustion.
- Difficulty latching on (even with the specially designed bottles and teats).

Question 29 asked the length of time spent in hospital after birth and questions 30 and 31 enquired if the baby had ever been re-admitted to hospital for problems related to feeding and if so how many times. Parents were also asked for any additional comments relating to their babies feeding.

4.1.6 Ear Infections

Questions 32 to 35 asked about the number of times their baby had suffered from any infections and if it had ever interfered with feeding.

4.1.7 Feeding Modifiers

Parents were asked if their baby's cleft necessitated a pre-surgical appliance or feeding modifier and how helpful these were for feeding or how difficult they were to manage. Parents were also asked for how long their infant used a modifier and to comment on any reasons they may have had for stopping its use, with the exception of cleft surgery being completed. (Questions 36 to 40)

4.1.8 Feeding Habits

Questions 41 to 43 asked about adding sugar or other foods or juices to their baby's feed and if they took a bottle at night. Questions 44, 45 and 46 asked about their use of a dummy and if they dipped it into anything sweet, and if yes to specify.

4.1.9 Support and Advice on feeding

The last 5 questions were about the support and advice the parents received from members of the Cleft Team and other Health Care Professionals. They were

asked to rate the advice on a scale of 1-5 and to comment on anything they wished to add about their experiences. A score of 5 was deemed satisfactory with no unfavourable features and a score of 1 was deemed very unsatisfactory.

4.2 Statistical Analysis

Observational statistics were used for the majority of results and the SPSS® package for Windows® (version 14) was used to collate and analyse these results. Where comparisons and significant differences were explored chi square tests were carried out and P values were generated. The results were singly entered by the investigator. Significance was set at the 5% level. Content analysis was carried out on the qualitative data.

Chapter 5 Results

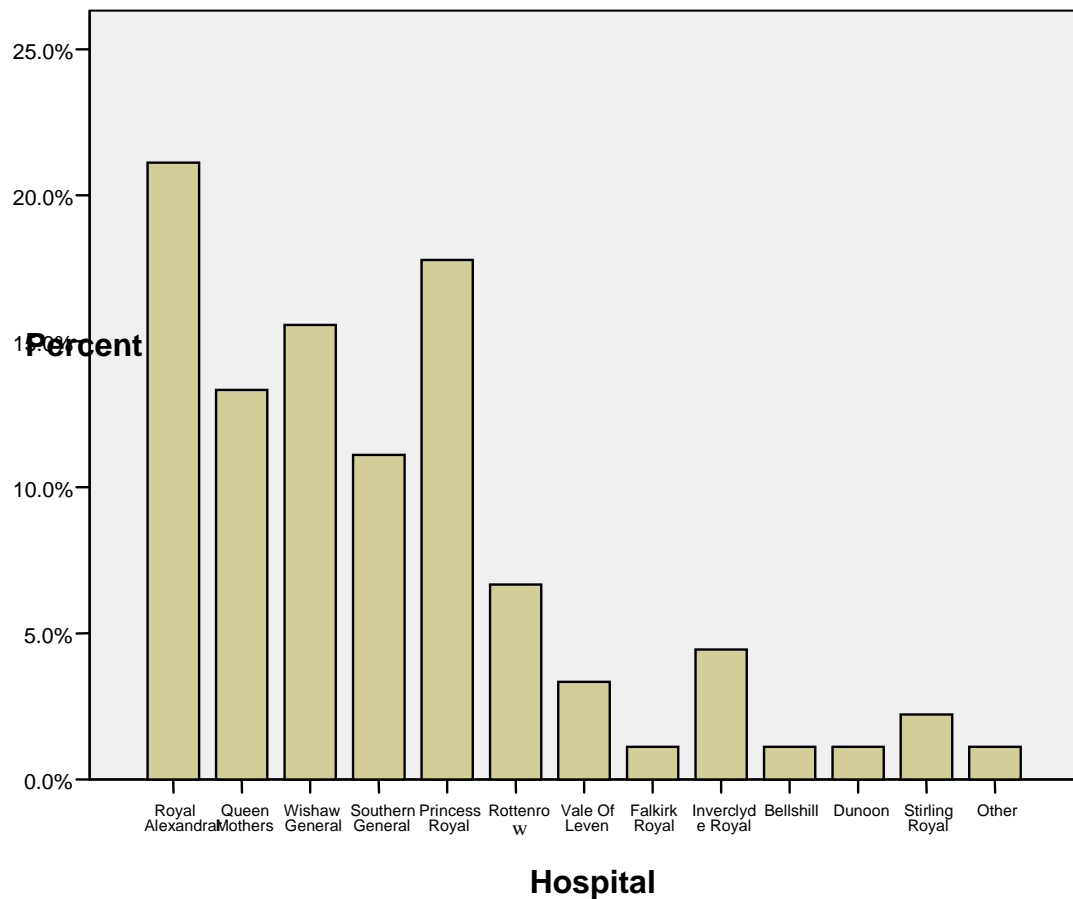
Ninety parents of children born with a cleft lip and palate in the West of Scotland were interviewed in the Oral Orthopaedic Clinic over a 13-month period (April 2006-May 2007). There was one refusal, from parents who did not have time to be interviewed.

Hospital of Birth

The hospitals in West and Central Scotland where the cleft infants in this study were born are shown in Table 5.1 and Figure 5.1. Births outside this region were recorded as 'other'. The most common hospitals were The Royal Alexandra Hospital in Paisley (22.5%) and The Princess Royal Hospital in Glasgow (18.0%).

Table 5.1 Hospital of birth

Hospitals	Frequency	Percent	Cumulative Percent
Royal Alexandra	19	21.1	21.1
Queen Mothers	12	13.3	34.4
Wishaw General	14	15.6	50.0
Southern General	10	11.1	61.1
Princess Royal	16	17.8	78.9
Rottenrow	6	6.7	85.6
Vale Of Leven	3	3.3	88.9
Falkirk Royal	1	1.1	90.0
Inverclyde Royal	4	4.4	94.4
Bellshill	1	1.1	95.6
Dunoon	1	1.1	96.7
Stirling Royal	2	2.2	98.9
Other	1	1.1	100.0
Total	90	100.0	

Fig 5.1 Hospitals of Birth

Gender

51.1% (46) of the infants were boys and 48.9 % (44) were girls.

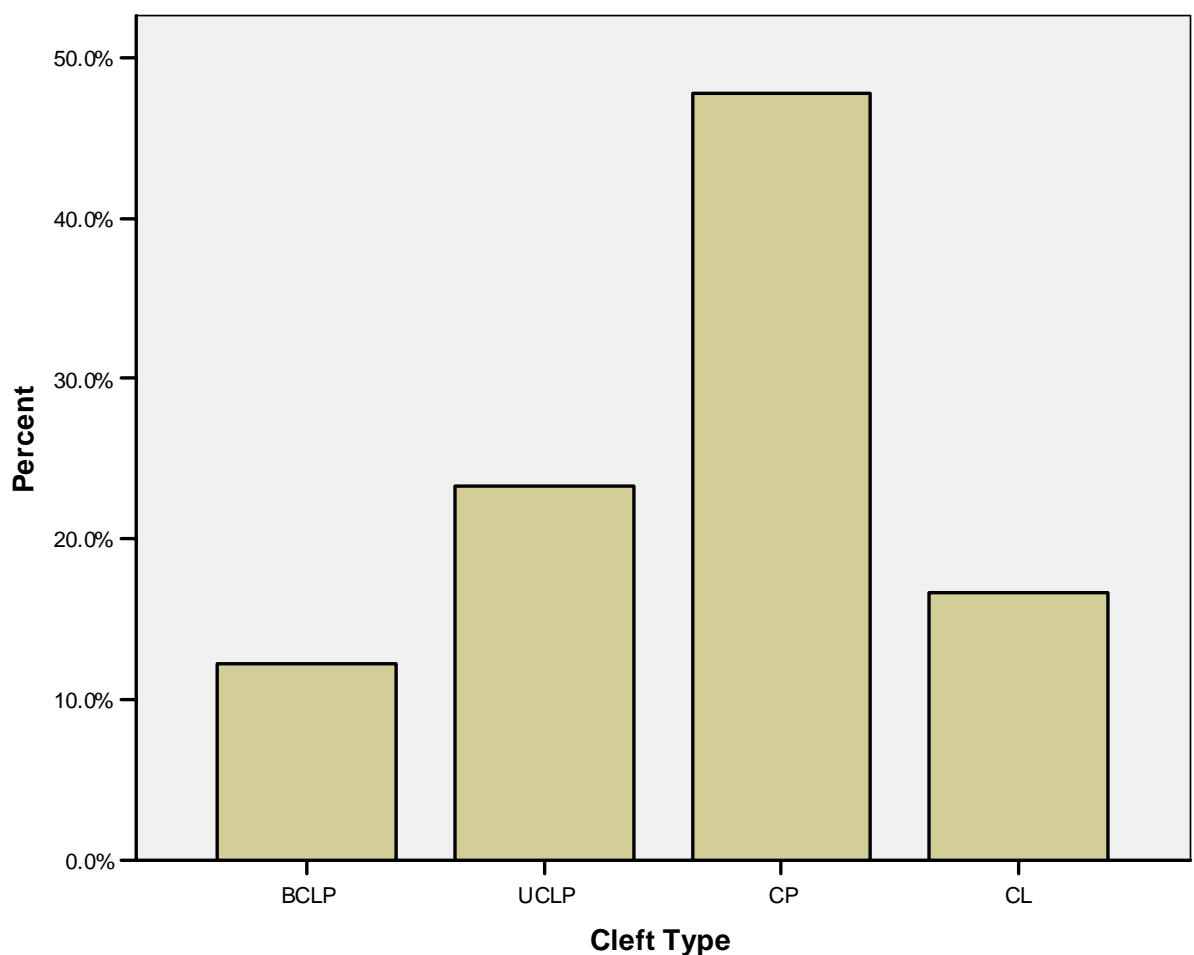
Cleft Type

The most common cleft type was a CP (47.8 %), with the next common being a UCLP at almost half that figure (23.3%). This is shown in Table 5.2a and Figure 5.2.

Table 5.2a Cleft Types

Cleft Type	Frequency	Valid Percent	Cumulative Percent
BCLP	11	12.2	12.2
UCLP	21	23.3	35.6
CP	43	47.8	83.3
CL	15	16.7	100.0
Total	90	100.0	

BCLP-Bilateral cleft lip and palate
 UCLP- Unilateral cleft lip and palate
 CP- Cleft palate
 CL- Cleft lip

Fig 5.2 Cleft types

When gender and cleft type were examined 76% (11/15) of the CL sample was male. Proportionally more males were affected in BCLP, UCLP and CL. More females were affected in CP. However there was no significant gender relationship to cleft type. The closest to significance was in CL (Table 5.2b).

Table 5.2b Cleft Type and Gender

	Gender		
	Male	Female	
BCLP	7	4	11
UCLP	11	10	21
CP	17	26	43
CL	11*	4	15
Total	46	44	90

* $P < 0.06$

Mothers age at child's birth

The most common age ranges of the mothers were between 26 and 30 years of age (31.1%) and between 31 and 35 years of age (28.9%). Only 1 mother was over 40 years old (Table 5.3).

Table 5.3 Mothers age at birth

Mothers age	Frequency	Valid Percent	Cumulative Percent
<25	22	24.4	24.4
26-30	28	31.1	55.6
31-35	26	28.9	84.4
36-40	13	14.4	98.9
40+	1	1.1	100.0
Total	90	100.0	

There was no significant relationship between cleft type and mother's age, $p < 0.99$

Socio-economic status (Depcat score)

The deprivation category (Depcat) was derived from the postcode of the parents taking part in the study using the Carstairs Depcat scale. Compared with the Scottish figures of population distribution (Carstairs and Morris Survey 2001;

McLoone, 2004) the sample of our cleft infants almost followed the Depcat distribution of the national figures, with the exception of Depcat 7. Actual figures were higher in Depcats 6 and 7 in our cleft study and lower in Depcats 1 and 2. The most common Depcat scores were from 3 (23%) and 4 (19.5%). This is shown in Table 5.4

The numbers in our sample were too small in Depcats 1 and 2 to look at the statistical comparison between cleft types and Depcat.

Table 5.4 Comparison of Cleft Depcat scores with National Figures

Depcat	Frequency	Cleft study %	Scotland (2001) %
1	5	5.7	9.0
2	6	6.9	16.8
3	20	23.0	24.3
4	17	19.5	22.3
5	14	16.1	12.3
6	12	13.8	9.4
7	13	14.9	5.8
Total	87	100.0	100
Missing*	3		
Total	90		

* Unknown postcodes

Twin

Only 2 of the cases (2.2%) were twins.

Full term birth

96.7% (87) of the infants were born at 38 weeks or above.

Birth Order

The percentage of first (38.9%) and second (40.0%) born children in our sample was almost the same. Only 4.4% resulted from 4th and 5th higher birth orders (Table 5.5).

Table 5.5 Birth order of cleft child

Birth order	Frequency	Percent	Cumulative Percent
1st	35	38.9	38.9
2nd	36	40.0	78.9
3rd	15	16.7	95.6
4th	2	2.2	97.8
5th	2	2.2	100.0
Total	90	100.0	

Mother's age at birth of cleft infants are shown in Table 5.6. Over 85% of mothers were under age 35. It was not possible to test for a significant relationship between birth order and maternal age because of the small numbers of mothers over 35 and the small number of 4th and 5th birth order children

Table 5.6 Mother's age at birth and birth order of cleft child

Birth Order	Mothers age at birth					
	>25	26-29	30-34	35-40	40+	
1st	12	17	6	1	0	36
2nd	6	8	15	7	0	36
3rd	4	1	4	4	1	14
4th	0	1	0	1	0	2
5th	0	1	1	0	0	2
Total	22	28	26	13	1	90

Time of diagnosis

Only 13.3% (12/90) of mothers had any prior knowledge of the cleft. 62.2% (56/90) found out at birth. 25.5% (34/90) were therefore undiagnosed at birth. However, by 24 hours after birth some 84.4% of infants had been diagnosed (Table 5.7).

Table 5.7 Timing of diagnosis

Timing	Frequency	Valid Percent	Cumulative Percent
Antenatal	12	13.3	13.3
At birth	56	62.2	75.6
0-2 hours	3	3.3	78.9
2-6 hours	1	1.1	80.0
6-12 hours	1	1.1	81.1
12-24 hours	3	3.3	84.4
2-4 days	4	4.4	88.9
5-7 days	4	4.4	93.3
2-3 weeks	4	4.4	97.8
4-6 weeks	1	1.1	98.9
6+ weeks	1	1.1	100.0
Total	90	100.0	

Feeding methods

52.2% (47/90) mothers said their initial method of breastfeeding had changed because of their child's cleft. One mother decided to breastfeed because of her child's' cleft.

At the initial feed 37.8% (34/90) of mothers' breastfed and 8.9% (8/90) gave expressed breast milk in a bottle or via a naso-gastric tube. 11 parents used other methods to give milk (7/11 used breast milk) which included using a syringe, cup or spoon. In summary 54.4% (49/90) of children received breast milk at birth (Table 5.8).

Table 5.8 Initial feed

Initial Feed	Frequency	Percent	Cumulative Percent
Breast	34	37.8	37.8
Exp/NGT	5	5.6	43.3
Exp/bottle	3	3.3	46.6
Exp/other	7		54.4
Form/bottle	20	22.2	87.8
Form/NGT	17	18.9	62.2
Form/other	4		100.0
Total	90	100.0	

Exp/NGT -Expressed milk via a naso-gastric tube.

Exp/Bottle- Expressed milk via a bottle.

Exp/ other - Expressed milk via syringe, cup or spoon.

Form/bottle – Formula milk via a bottle.

Form/NGT – Formula milk via a naso-gastric tube.

Form/other – Formula milk via other methods.

71.1% (64/90) changed their method of feeding after the initial feed or within days of the initial feed (Table 5.9). 81.1% (51/64) of these mothers changed to using formula milk and a bottle (Table 5.10).

Table 5.9 Did feeding method change?

	Frequency	Valid Percent	Cumulative Percent
No	26	28.9	28.9
After initial	24	26.7	55.6
Later	40	44.4	100.0
Total	90	100.0	

Table 5.10 What did feeding method change to?

	Frequency	Valid Percent	Cumulative Percent
Not applicable	26	29.2	29.2
Breast	1	1.1	30.3
Formula/NGT	3	3.4	33.7
Exp/bottle	7	7.9	41.6
Formula/bottle	51	57.3	98.9
Other	1	1.1	100.0
Total	89	100.0	
Missing System	1		
Total	90		

Breast feeding

The prevalence of breastfeeding for 1 day only was 64.4% (58/90). After 1 week this was 48.9% (44/90) and at 6 weeks, it was 30%, (27/90). Only 13.3% (12/90) breast-fed for 6 months or more (Table 5.11).

Table 5.11 Prevalence of breastfeeding

Prevalence	Frequency	Percent	Cumulative Percent
Not applicable	32	35.6	35.6
1 day	14	15.6	51.1
1 week	17	18.9	70.0
6 weeks	15	16.7	86.7
6 months	12	13.3	100.0
Total	90	100.0	

Cleft type

80% (12/15) of the mothers who had a child with a CL attempted breastfeeding at the first feed or switched to breastfeeding later. 66.7% (10/15) of these mothers continued for 6 months or more. This contrasts with those mothers who had a baby with a CP with or without a CL where 61.3% (46/75) tried to breast feed in the first few days but by 1 week only 45% (34/75) were still doing so. At 6 weeks, this had fallen to 22.7% (17/75) and only 2 continued for 6 months. Table 5.12 shows prevalence of breastfeeding with cleft type and Table 5.13 shows this prevalence by percentage.

Table 5.12 Cleft Type and prevalence of breastfeeding

Cleft Type	Prevalence of breastfeeding					
	None	1 day	1 week	6 weeks	6 months	
BCLP	1	2	3	4	1	11
UCLP	11	4	3	3	0	21
CP	17	6	11	8	1	43
CL	3	2	0	0	10	15
Total	32	14	17	15	12	90

Table 5.13 Cleft type and percentage of breastfeeding at different times.

Cleft Type	Did not breast feed %	% at 1 day	% at 1 week	% at 6 weeks	% at 6 months
BCLP	9.1	90.1	81.0	54.5	9.1
UCLP	52.4	47.6	28.6	14.0	0.0
CP	39.5	60.5	46.5	20.0	6.6
CL	20	80.0	66.6	66.6	66.6

All infants with a CL were breast-fed. Infants with a CP with or without a CL were all given expressed milk after 1 week except 3 infants with a CP alone who were breastfed for 2 weeks, 6 weeks and 6 months respectively and 1 infant with a BCLP who was breast-fed for at least 6 months.

When those infants with a CP +/- CL were compared with those with a CL only, the difference in prevalence at 6 weeks was significant, $P < 0.054$ (Table 5.14).

Table 5.14 Cleft type, incidence of breastfeeding and prevalence at 6 weeks.

Cleft Type	Breastfed at 6 weeks			Total
	None	incidence	6 weeks	
CP+/- CL	29	21	25	75
CL	3	2	10	15
Total	32	23	35	90

$P < 0.054$

Birth order

The birth order of the cleft infant was examined with relation to the prevalence of breastfeeding at different times. At 1 week, the prevalence was 40.0%, 52.8%, and 53.3% for 1st, 2nd, and 3rd babies respectively. At 6 weeks, prevalence was 20%, 38.9%, and 26.7% and at 6 months, it was 20.0%, 38.9%, and 26.7% (Table 5.15).

Table 5.15 Birth order of cleft child and breastfeeding prevalence (%)

Birth order	Breast feeding prevalence: Number (%)				
	Did not breast-feed	1 day	1 week	6 weeks	6 months
1st	13 /35	22 (62.9)	14 (40.0)	7 (20.0)	2 (5.7)
2nd	13 /36	23 (63.9)	19 (52.8)	14 (38.9)	8 (22.2)
3rd	5 /15	10 (66.7)	8 (53.3)	4 (26.7)	1 (6.7)
4th	1/2	0 (0)	0 (0)	0 (0)	1 (50.0)
5th	0/2	0 (0)	1 (50.0)	1 (50.0)	0 (0)
Total	32	14	17	15	12

When cleft type and birth order were compared, some 60% (9/15) of the CL infants in our study were 2nd born infants, $p < 0.003$ (Table 5.16).

Table 5.16 Birth order of cleft child and Cleft Types

Birth Order	Cleft Type				
	BCLP	UCLP	CP	CL	
1st	6	8	18	3	35
2nd	3	8	16	9*	36
3rd	2	3	8	2	15
4th	0	1	0	1	2
5th	0	1	1	0	2
Total	11	21	43	15	90

.* $p < 0.003$

The breast feeding prevalence at 1 week, 6 weeks and 6 months of the first and second born infants in our cleft sample (cleft) was compared with the UK percentage figures from 2000 (Infant Feeding Practices Survey 2000). This is shown in Table 5.17.

Table 5.17 Birth order prevalence compared to UK percentages (2000).

Birth Order	1 week		6 weeks		6 months	
	cleft	2000	cleft	2000	cleft	2000
1 st born	40%	58%	20%	42%	5.7%	19%
2 nd born	52.7%	54%	38.9%	42%	22.3%	23%

Maternal age

The incidence and prevalence of breastfeeding increased with maternal age. 56.5% (13/23) of all mothers under the age of 25 years were breastfeeding at birth but this had fallen to 30% (7/23) at 6 weeks. Whereas 76.9% (20/26) of 30-34 year olds breastfed at birth and 46% (12/26) were still breastfeeding at 6 weeks, (Table 5.18).

Table 5.18 Maternal age with incidence and prevalence of breastfeeding

Mothers age at birth	Incidence and Prevalence of breastfeeding				Total
	None	Birth	1 week	6 weeks	
< 25	10	2	4	7	23
26-29	11	5	2	9	27
30-34	6	4	4	12	26
35-40	5	1	1	6	13
40+	0	0	0	1	1
Total	32	12	11	35	90

Socioeconomic status

The sample of children born with a cleft in Depcats 1 or 2 was not large enough to allow comparison of socioeconomic status with the incidence and prevalence of breastfeeding in our study.

Other feeding methods

28.9% (26/90) cleft infants had to have a naso-gastric tube (NGT) to assist feeding either in hospital during the days following birth or later when there were concerns about the infant's weight (Table 5.19). NGT feeding in this study is not associated with supplementary feeding at the time of surgery.

Table 5.19 Other feeding methods

Feeding methods	Frequency	Valid Percent	Cumulative Percent
Not applicable	49	54.4	54.4
Experience of NGT	26	28.9	83.3
Syringe	8	8.9	92.2
Cup	7	7.8	100.0
Total	90	100.0	

Of the 26 who experienced naso-gastric tube feeding 25 had a CP, UCLP, or BCLP (Table 5.20). Only 1 child with a CL fed via a naso-gastric tube ($p < 0.001$).

Table 5.20 Cleft Type and other feeding methods

	Other feeding methods				
	none	experience of Ngt*	syringe	cup	
BCLP	4	5	1	1	11
UCLP	9	8	2	2	21
CP	22	12	5	4	43
CL	14	1	0	0	15
Total	49	26	8	7	90

* $P < 0.001$

Cleft repair

8.9% of mothers had to change their method of feeding after cleft lip repair and 10% had to change after cleft palate surgery.

Bottles and Teats

The most popular bottle (46.7%) was a soft squeeze type and the most popular teat (44.4%) was the 'cleft nuk' or 'mam' type (Tables 5.21 & 5.22). Both are modified types especially made for infants with a cleft.

Table 5.21 Type of bottle used

Type of bottle	Frequency	Percent	Cumulative Percent
Not applicable	8	8.9	8.9
Standard	14	15.6	24.4
Squeeze bottle	42	46.7	71.1
Haberman	25	27.8	98.9
Other	1	1.1	100.0
Total	90	100.0	

Table 5.22 Type of teat used

Type of teat	Frequency	Valid Percent	Cumulative Percent
Not applicable	8	8.9	8.9
Standard	13	14.4	23.3
Nuk(mam)	40	44.4	67.8
Modified Teat	3	3.3	71.1
Other	1	1.1	72.2
Haberman	25	27.8	100.0
Total	90	100.0	

None of the infants with a CL had used a squeeze soft bottle. 6 out of the 8 with a CL who had used a bottle preferred the standard type (Table 5.23).

Table 5.23 Cleft type and type of bottle used

Cleft Type	Type of bottle used					Total
	not applicable	Standard	Squeeze bottle/soft plastic	Haberman	Other	
BCLP	0	0	7	4	0	11
UCLP	0	0	14	7	0	21
CP	1	8	21	12	1	43
CL	7	6	0	2	0	15
Total	8	14	42	25	1	90

Feeding Patterns

67.8%(61/90) of parents had problems with the length of a feed with 45.6% (41/90) stating that feeds lasted longer than an hour (Table 5.24).

Table 5.24 Length of average feed

	Frequency	Valid Percent	Cumulative percent
<30 minutes	28	31.1	31.1
30-60 minutes	20	22.2	53.3
>60 minutes	41	45.6	98.9
No answer	1	1.1	100.0
Total	90	100.0	

46.7% (42/90) established feeding within a month but for 28.8% (26/90) it took longer than a month and 20% (18/90) never established a regular pattern to their feeding (Table 5.25).

Table 5.25 Regular pattern of feeding

Establishing a pattern of feeding	Frequency	Valid Percent	Cumulative Percent
Within 48 hours	3	3.3	3.3
Within 2-7 days	7	7.8	11.1
Within 2-4 weeks	32	35.6	46.7
>4 weeks	26	28.9	75.6
No regular pattern	18	20.0	95.6
NGT / peg fed*	1	1.1	96.6
No answer	1	1.1	97.8
Breast fed on demand	2	2.2	100
Total	90	100.0	

* 'Peg' is the term referring to direct tube feeding into the stomach via a gastrostomy.

Problems experienced by infant during feeding

42.2% (38/90) of parents felt their child's intake of milk to be inadequate.

90%(81/90) of infants experienced problems during feeding including fluid down the nose 70%, (63/90) and excessive air intake causing a lot of colic 52.2%, (47/90).

Of the 9 (10%) who had no problems, 5 were infants with a CL who were breast-fed and 3 were infants with a CP (1 breastfed and 2 bottle-fed).

2 (2.2%) infants were fed by a naso-gastric tube or peg fed alone and so were counted as not applicable (Table 5.26).

Table 5.26 Problems experienced by infant during feeding

Problems	Frequency	Percent
Coughing	38	42.2
Excessive air	47	52.2
Excessive leakage	37	41.1
Fluid down the nose	63	70.0
Exhaustion	39	43.3
Latching on	15	16.6
No problems	9	10.0
Not applicable	2	2.2

Time in hospital at birth

35.5% (32/90) of infants were in hospital more than 1 week and 22.2 % (20/90) for up to 4 weeks after birth (Table 5.27).

Table 5.27 Length of stay in hospital by days and weeks

	Frequency	Valid Percent	Cumulative Percent
Not applicable	1	1.1	1.1
1 day	3	3.3	4.4
2-4 days	25	27.8	32.2
5-7 days	29	32.2	64.4
8-10 days	9	10.0	74.4
11-14 days	3	3.3	77.8
2-4 weeks	9	10.0	87.8
4+ weeks	11	12.2	100.0
Total	90	100.0	

16.9 % (15/89) were readmitted for feeding problems and 26.6% (4/15) required more than one admission.

Chest/Ear infections

34.4% of parents said their child had suffered from ear or chest infections and 18.9% said they believed these had interfered with feeding. 50% (10/20) of infants with a UCLP had an early experience of these infections compared to 20% (3/15) of CL infants.

Pre-surgical appliances

25.5% (23/90) of parents said their infant had used a feeding plate or modifier. All of these children had a cleft of lip and palate (Table 5.28). One infant had just strapping without the plate. 69.9% (16/23) gave the plate a score of 4 or 5. On a scale of 1 to 5, a score of 1 was the 'worst' and 5 was the 'best', with regard to how they felt the plate had helped with feeding.

Table 5.28 Cleft Type and use of a plate

Cleft Type	Did your baby have a plate?		
	No	Yes	
BCLP	4	7	11
UCLP	5	16	21
CP	43	0	43
CL	15	0	15
Total	67	23	90

Surgery was the reason most parents stopped using the plate although 8 of the parents stated it was for other reasons (Table 5.29).

Table 5.29 Reasons for cessation of use of pre-surgical appliance

Reasons	Frequency	Valid Percent	Cumulative Percent
Not applicable	68	75.6	75.6
Surgery	14	15.6	91.1
Could not tolerate	3	3.3	94.4
Could not tolerate strapping	1	1.1	95.6
Could not tolerate plate	2	2.2	97.8
Other	2	2.2	100.0
Total	90	100.0	

Feeding habits

Only 1 parent said they put sugar in their baby's feed.

86.7% (78/90) of infants received a bottle before their night time sleep. The age at which the infants stopped receiving a bottle at night was not asked directly in the original questionnaire but it emerged that of the 66 parents who did volunteer the information some 65.2% (43/66) had a bottle at night until they were a year old and 22.7%(15/66) had one up to the age of 2. 15.2% (10/66) were breast or peg fed.

33.3% (30/90) of parents put other substances as well as milk in the bottle with 'juice' (16.7%) being the most popular choice (Table 5.30).

Table 5.30 Other substances in feeding bottle

Substances	Frequency	Valid Percent	Cumulative Percent
Not applicable	60	66.7	66.7
Juice	15	16.7	83.3
High calorie milk	7	7.8	91.1
Sweetened milk	4	4.4	95.6
Rice	1	1.1	96.7
Rusks	2	2.2	98.9
Other	1	1.1	100.0
Total	90	100.0	

When comparing the use of juice with Depcat score, none of the infants from Depcats 1, 2 or 3 had juice. 22.2% of those in Depcat 4 had juice, and 38.5% of infants in both Depcats 5 and 7 had juice. There was none from Depcat 6 (Table 5.31). Juice was not taken significantly more in any particular deprivation category ($P < 0.07$).

Table 5.31 Comparing other substances in feeding bottle with Depcat

	Other substances							
Depcat	None	Juice	High calorie milk	Sweet milk	rice	Rusks	Other	Total
1	3	0	1	0	0	1	0	5
2	5	0	0	0	0	0	1	6
3	17	0	2	1	0	0	0	20
4	11	4	1	0	1	1	0	18
5	6	5	2	0	0	0	0	13
6	11	0	0	1	0	0	0	12
7	7	5	1	0	0	0	0	13
Total	60	14	7	2	1	2	1	87

Use of a dummy

34.4% (31/90) of infants had a dummy but only 3 out of the 90 dipped it into anything sweet.

Support and Advice

Although the information regarding the arrival of the cleft nurses was not directly requested in the original questionnaire it was volunteered by most of the parents during the interview and enabled us to compare our results with the CLAPA (2007a) survey.

The arrival of the cleft team within 24 hours after a diagnosis occurred in 52.4% (32 /61 who answered). By 3 days after diagnosis, 90% (55/61) of cases had been seen. This is shown in Table 5.32. Table 5.33 shows the results from the CLAPA 2006 survey (CLAPA 2007a). It took a month for nearly 90% of cases to be seen in this survey.

Table 5.32 Time at which cleft team arrived after diagnosis

Timing	Frequency	Valid Percent	Cumulative Percent
Within 24 hrs	32	52.5	35.6
2 days	7	11.5	64.0
3 days	16	26.2	90.0
4 days	1	1.7	91.7
Other	5	8.2	100.0
Sub total	61	100.0	100.0
Antenatal diagnosis, no answers/ no answers	11		
Total	18		
	90		100.0

87.6% (78/89) of parents received advice in hospital with regards to feeding (1 infant was born at home so was counted as not applicable) and 91% (81/89) received advice at home. 94.3% (66/70) of respondents who were asked understood the advice (Table 5.33)

Table 5.33 Understanding of feeding advice

	Frequency	Valid Percent	Cumulative Percent
No answer	19	21.1	21.1
No	4	4.5	25.6
Yes	66	74.2	99.8
Not applicable	1	1.1	100.0
Total	89	100.0	
Total	90		

When asked to rate this advice 95.0% (70/74) of parents who answered and where feeding advice was applicable to their child gave a rating of 4 or 5 for the cleft teams advice in the hospital (Table 5.34) and 96%(72/75) at home (Table 5.35).

Table 5.34 Rating of the advice in hospital by Cleft Team

Rating	Frequency	Valid Percent	Cumulative Percent
No answer	7	7.8	7.8
Not applicable	9	10.0	17.8
1	2	2.2	20.0
3	2	2.2	22.2
4	9	10.0	32.2
5	61	67.8	100.0
Total	90	100.0	

Table 5.35 Rating of the advice at home by Cleft Team

Rating	Frequency	Valid Percent	Cumulative Percent
No answer	13	14.4	14.4
Not applicable	2	2.2	16.6
1	2	2.2	18.8
3	1	1.1	19.9
4	11	12.2	32.1
5	61	67.8	100.0
Total	90	100.0	

The advice by health care professionals who were not members of the cleft team was rated 4 or 5 in 54.6% (36/66) of cases in hospital and 68.2% (45/66) at home (Tables 5.36 and 5.37).

Table 5.36 Rating of the advice in hospital by Non Cleft Team

Rating	Frequency	Valid Percent	Cumulative Percent
No answer	13	14.4	14.4
Not applicable	11	12.2	26.7
1	13	14.4	41.1
2	7	7.8	48.9
3	10	11.1	60.0
4	4	4.4	64.4
5	32	35.6	100.0
Total	90	100.0	

Table 5.37 Rating of the advice at home by Non Cleft Team

Rating	Frequency	Valid Percent	Cumulative Percent
No answer	15	16.7	16.7
Not applicable	9	10.0	26.7
1	9	10.0	36.7
2	6	6.7	43.4
3	6	6.7	50.1
4	8	8.9	59.0
5	37	41.1	100.0
Total	90	100.0	

Comments from parents

The parents were asked for their comments about their personal experiences regarding the: diagnosis; birth; pre-surgical appliances; support from the Cleft Team; meeting the cleft Team at Yorkhill Hospital; and general comments about the support and care from non- cleft health care professionals. Favourable, unfavourable and mixed comments in each category are listed in themes below.

At Diagnosis

Positive

"Found out straight away"

"Cleft team there half an hour after born"

"Mum diabetic had read "baby could be born with problems"

"Picked up on scan at 24 wks. Husband born with Bilateral Cleft lip"

"Told at birth but felt ok, nothing major"

"Doctor at delivery didn't notice at first but nurse and husband did, but then doctor very relaxed about it. Special nurses there next morning (born Saturday night)"

"After initial shock, the way it was explained-really good, very positive."

"Scan at 20 weeks. Counselling, saw a palate repair and lots of information".

"Mum found out at birth as baby opened mouth to feed. "Midwife fabulous, Paediatrician came very quickly, finding out awful Were there syndromes? Cleft became insignificant; midwives said 'oh he's got a cleft lip'. Brought down photos of repaired clefts"

"Father has cleft lip and palate, no detailed scan given, still unprepared, still a shock... 'He's got a wee cleft lip' (midwife) very, very good, Palate fine. Born on Friday, Monday before cleft nurse came"

"Doctor put finger in his mouth to comfort him and found cleft, cleft team came day four"

"Had detailed scan at 40 weeks not picked up. Told at birth -not heard of before-told repairable by nurse from special care, cleft nurses came same day"

Unfavourable

"Found out at discharge -baby couldn't feed ,very sleepy-couldn't latch on - paediatrician found out 12 hours later... stayed in 2 more days"

"Found out immediately-special care team present because long labour, during suction of muconium, found cleft palate"

"Told baby was born with a hole in her face, not told until 3 days later that it could be repaired"

"Didn't find out had a cleft for 4 weeks"

"Knew would have small jaw from scan, taken to special care, nurse found cleft palate after baby couldn't breathe"

"Out of hospital, 5 days old, took her to hospital for routine test, nurse saw it then"

"Found out 12 hours later only because had jaundice and in special care unit"

"Placed in baby unit for 2 hours-never saw baby, midwife from IVF gave me leaflets but Easter holidays so no cleft team"

"Found out at delivery-knew something was wrong"

'Tried to breastfeed-couldn't do it. Paediatrician in hospital had commented but left it. GP sorted it. Went to Yorkhill at 2 weeks

'Had scan at 20 weeks, not picked up. 2 days after birth surgeon found cleft. Cleft nurse around, seen that day"

'Found out at birth, when heard breathing knew he would need special care. Not happy with paediatric ward, tried nasogastric tube, couldn't tolerate it"

"Had three scans at full term, not picked up. After a difficult birth baby taken to paediatrician, not told anything, very distressed and hysterical. Half an hour later paediatrician told me."

"1 week after birth couldn't feed. Midwife at home and diagnosed cleft. Had to wait a further 2 days for Cleft Nurses"

"Wasn't feeding properly, went to Paediatrician, told by nurse 2 hours after birth".

"Baby unable to suck, started to look blue- examined fully, found cleft palate then."

"Mum has cleft lip; never picked up on scan, nursing staff never said anything"

"Found out at birth, too shocked to take in especially as special nurses did not arrive until 72 hours later."

"Paediatrician missed it at birth, discovered it 1 week later when baby screaming, taking a while to feed, told Health Visitor, but not checked. After weekend Health Visitor said 'looks like a Cleft palate', went to Yorkhill, saw cleft nurse at 10 days"

"Doctor at birth, terrible birth (Ventouse) 'he has a hare lip' misshapen head, grunting, went to intensive care. 'Hare lip' in mum's family...that took a backseat...wasn't an issue at all".

"Scan at 34 weeks revealed cleft "never pre-counselled, born Thursday, cleft nurses Monday / Tuesday...Nurses in labour suite handed me a photo album and waited for more results, couldn't concentrate on anything"

"Wish it could have been discovered sooner, could that not be the first thing they thought of? ...took cleft nurse a few minutes... It was seven weeks after Nasogastric tube removed before picked up".

"Tried to breast feed for 12 hours, terrible, 24 hours later been sick through nose, paediatrician found out"

"Found out next day doctor took him away but didn't tell me he had a cleft. Special Care nurse told me, cleft nurses arrived 2-3 days."

"Breast feeding not going well, nurse came and put a finger in his mouth, brought back Paediatrician. A bit freaked out but explained could be repaired specialist nurses 2 days later"

"Baby had muconium in water... put to special care, cleft noted, nurse (in special care unit) explained everything as did Paediatrician"

"Told at birth, really good...told could be repaired. In Special Care Unit, 3rd day cleft nurses came, brilliant always been good "

"Found out at birth but not explained"

"Scan at 26 weeks (private) really prepared for cleft. Cleft nurses involved TOF and CHARGE Syndrome took over, -cleft not an issue".

"19 week scan-thought baby was Down or had a heart condition-hard to deal with when pregnant. Couldn't guarantee there wasn't something else-stayed with me until birth".

"Picked up at scan -having detailed scans as had lost other babies. Cleft nurses out to the house within 1 week, counselled. The day I got a scan, had a chat with paediatrician- everything fell into place quite quickly".

"Extreme shock -nurse told me it could be repaired, cleft nurse came third day"...

"Paediatrician told us right away cleft nurses came straight away".

"Midwife told us 'hole in palate', didn't understand- paediatrician explained it all - cleft nurses came that day, brought bottles, and explained about feeding".

"Private scan at 30 weeks, didn't see it", husband told wife at birth. Paediatrician said, "Fine, nothing to worry about" cleft nurse didn't get to hospital, came at 4-6 weeks later".

"Midwife said had a cleft palate and that was that".

"Had baby in the bath (in hospital) so noticed right away. Biological dad & family all have one so kind of expected it but never told anyone. Specialist nurses (cleft nurses) explained everything next day".

Pre-surgical appliances

Favourable

“Stopped after lip surgery ... made templates of plaster to have as baby changed and grew, helped to be organised”

“Stopped after first surgery, helped cosmetically as well”

Unfavourable

“Had to change strapping tape sometimes 13 times a day because wet from milk coming down the nose”

“Crying constantly, had plate for 3 hours.”

“Plate rubbed on gum, adjusted, but also allergic to tape, tried different types”

“Stopped after first surgery but (plate) irritated mouth and tape annoyed face”

“Advised to stop, couldn't feed using Haberman... kept putting on wrong way round, tape caused blotches.”

“Used to pull off plasters after a couple of months”

“Baby played about with it, like a toy, was too old”

Advice and Support

Cleft Nurses

Favourable

"Very positive –could always phone special nurse or dietician if didn't understand".

"Special Nurse spoke for about one hour in hospital, very helpful".

"Very encouraging about breastfeeding, can be difficult but not to be put off".

"Cleft nurses fantastic ...stressed up till then, and then when they left, still quit (breastfeeding) but no pressure...phoned, came out very quickly".

"Counselled by cleft nurse within 1 week of scan (day of scan chat with paediatrician)".

"Really nice, a lot of help"

"Could phone cleft nurses about other problems".

"Cleft nurses -absolutely brilliant- couldn't explain enough-good home contact-on phone"

"Came to house when needed".

"Brilliant"

"Very nice, really helpful after operation"

"Fine but so busy, end of phone for advice they make the effort and individually very helpful but not enough time".

"Had great experience after I met the cleft nurses ".

"Absolutely fantastic-wouldn't have coped or survived without them"

"Hospital nurses, wrong advice, didn't know had cleft special nurses, at end of phone, very helpful".

"Really good, very supportive, lots of information, things happened quickly".

"Cleft nurse phoned. Never felt disappointed in their attitude"(Dad)

"Cleft nurse realistic... Likelihood of not being able to breastfeed, gutted after first visit".

"Baby on normal bottle then nasogastric tube, then soft bottle once cleft nurse came".

"Cleft nurses -holiday weekend, came four days later -nurse in hospital started".

"Cleft team great, phoned when found pregnant with second child...been involved with first".

"Would have felt lost without cleft nurses ...on phone...had other problems heart & kidney, ordinary nurses didn't really help....hospital needs to be proactive".

"Really supportive cleft nurses"

"Cleft nurses good advice given really, .could have used special nurses more, glad third child not my first".

"Can phone any time or pop down to see you when in hospital. The team is really good".

"Really good , very supportive, lots of information, things happened quickly"

"Very clear"

"Always on phone right away ".

"Very encouraging about breastfeeding, can be difficult but not to be put off"

"Cleft nurses always on the phone also happy with what I read".

"Really good, came out to house, reassuring. They were great".

"Everyone was trying desperately to help us Special care nurses absolutely fantastic".

Unfavourable

. "Too much information (from cleft nurses) too emotional to take it in".

"Too much information too emotional to take it in".

"The support nurses were rushed that day. Didn't get the help maybe would have done with the teats, etc".

"It was nine weeks when I saw cleft nurses for first time. Hospitals fault, never told Yorkhill"

"At start a blur, too much information at once, said should have seen at scan".

"Left it to his mum ran out of ideas really, felt let down by (cleft)nurses, they didn't do what I thought they would do".(Father)

Midwives

Favourable

"Midwife gave advice on general feeding"

"Helped with nasal tube".

"Very good. Different ones would have a go (at feeding) and work at it to help me".

"Really good as had a midwife who had had a cleft lip, midwife came out reassured".

"One not helpful one helpful- and she continued to see my child at home even though we stayed outside area, very good actually".

"Midwife and Paediatrician encouraged expressing".

"Great".

Unfavourable

" Midwife walked right past me".

"Baby weighed over Christmas -negative comments" mother had post natal depression (twin boys had died at 24 weeks) "psychiatric nurse bossy"

"They could be given some training -even an hour a week"

"Didn't know much"

"Sound coming from mouth after birth, unable to breastfeed. Cleft picked up by midwife". Doctors and nurses no advice, no reassurance"

"Dad lost temper with hospital nurses as none of them could feed our daughter; nobody knew how to use a normal bottle and nobody could use soft bottle when we did get it. When we were feeding it was fine but when nurses fed she was sick...blamed it on shift workers ...attitude in hospital - would like to change"

"Not familiar with cleft palate situation- felt a bit of pressure to feed properly, - baby's sugar low because diabetic. I felt didn't have problems or concerns just the time".

Maternity ward nurses

Favourable

"General staff very helpful".

Fed by Nasogastric tube -taught about that nothing to do with the cleft palate. There was a lot of babies but very attentive and always came back to us". (Mother)

"No complaints about any of staff...appreciative of all help" (Father)

"One of the nurses had a niece with a cleft lip, brought in pictures, which helped understand repair"

"Been good from start, always been able to pick up phone".

"Very good ".

"Quite nice".

Unfavourable

"Nurses made me keep breast feeding but that's why I was readmitted, as I had tried to express and give a bottle but it didn't work, once specialist nurses, came, great."

"Very poor".

"Not so much help with feeding had nasogastric tube -they were not keen to sit and take bottle – it was one of his needs and a bit frustrating that they didn't try-too easy and quick to take food down tube. Cleft nurses sit with me when feeding"

"So busy, not there to help you, very stressful being in hospital and operations, not good at all, child nurses but not a caring attitude".

"CP had been identified at 6.00 in the morning, got up to breastfeed –one nurse said 'for goodness sake if you didn't want to breastfeed you only had to say'. I was upset because of diagnosis, when told (about cleft) left alone, no help with electric pump, no support with hand pumps...lovely people but too busy, if you don't breastfeed they want nothing to do with you".

"Nurses in hospital were adamant I could breast feed but couldn't-they did not have enough knowledge, but supportive"

"Nurses in hospital conflicting advice, very difficult, had to use different methods".

"Couldn't help with feeding".

"Didn't know that much, in ICU, nurse not that helpful, ignored"

"Put in a room away from other mums, felt couldn't give support Special care nurse- "fantastic gave photos"

."Paisley nurses -don't think they understood our situation-they see so many children-pressure put on nurses -the system let them down which let us down-tried to force mum to use breast- we were treated as if we were lepers". (Father)

"Helpful first night not with cleft-didn't have a clue".

"Pack to read by nurses on ward. Couldn't concentrate, very clinical". Didn't know much themselves and didn't know how to use Haberman"

"Didn't really know much about it".

"I don't think they knew what to do one nurse had never seen a cleft before".

Mixed

"Good with baby but no advice"

""Nurses in hospital ok".

"Not hospital policy(lap feeding) so had to make a choice, Haberman given but not allowed to take it home so got a prescription for Boots but not allowed to leave until had a replacement, nursing staff avoided me to be honest... they brought in nurses to watch me double express....very poor, no understanding their way or no way".

"No nurses could help in hospital until Special Nurse came; found a Haberman bottle but no valve. I wanted to come home but had no bottles. Had to feed (baby) with a spoon I was upset at being unable to breast feed but Midwife helped."

"Nurses on ward could be explaining to students about development/psychological issues in front of me but one nurse was very good".

"One particular nurse was good 'don't be scared'...gave first feed. For other nurses' attitude & cleft knowledge 1&2 (rating)...too short staffed"

"Helped with expressing, there could be input for professionals on using the bottles available they had never come across certain types"

"Advice very poor except for one older nurse who was great".

"Ok not brilliant let cleft nurses to get on with it"

"Didn't listen but ok"

"All whispering and conferring when born, let me get on with it -not in a bad way, I felt I didn't need help"

"Never really bothered with me, baby care unit told me to hit glass bottle against gum, before had squeeze bottles".

"Said to me 'if you need extra help come back -just cosmetic, she'll be fine as long as feeding well'.

"Some horrendous, some great ". "

Health Visitors

Favourable

"Kept giving information that baby should have been taking more milk"

"Very supportive"

"Got teats, one of the Health Visitor daughter's had a cleft palate so the team was clued up, looked at teats, watched the flow, gave helpful tips"

"Had son with a Cleft lip".

"Didn't know enough".

"Left it to cleft team".

"Left me to it, because I'm a nurse, 'if you need us call us', follow up care not great"

"Been excellent had another cleft child" (under care).

"Absolutely fantastic (a man) helped me through a lot".

"Had a patient who had a cleft but second hand information".

"Wasn't great to be honest, never got anyone to help me"

"Rubbish"

"Good but tried to encourage breast feeding".

"Nice person, daughter had a cleft –felt ok, reassured".

"Hopeless -stopped her coming out wouldn't look at him more interested if I had depression"

"Fantastic, gave heavier milk, really helped with colic by 13 weeks anyway"

"Met other mums with cleft infant, for the Health Visitor showed me photos and that helped -it's only cosmetic"

"Fine"

"Good"

"Health Visitor and nurses in Dunoon –brilliant, fantastic –Health Visitor pushed for a speech therapist"

."Willing to find things out, would read up before hand"

"Pretty good".

"Excellent, wouldn't leave me alone, came to the house".

"Brilliant, no experience, panicked a bit but referred us to Yorkhill ...did too much".

"Very good worked in Yorkhill, knew a lot about it"

"Really good got extra bottles found out information, quite supportive"

"Really good 'Starting Well' out every week".

"Great -tried to explain as much as she could- referred from another Health Visitor within practice"

"Very supportive".

"Came out of district, ordered teats and bottles made a difference good support".

"She was really good ".

"Helpful".

"Very good ".

"Had a cleft son, she really understood, got bottles for me. After that ok".

Unfavourable

"Didn't know anything about clefts at all. It wouldn't have crossed my mind to phone anyone at Health Centre".

"No help at all, never seen -I went to Yorkhill to see cleft nurses".

"Put me in touch with breast feeding groups, reassured with weight gain but didn't mention bottles"

"Pretty useless, didn't check as often as should, all she said was persevere"

"Did not know much about it"

"Told me to feed baby this amount at certain times cleft nurse told me differently. I got upset, which is right? ...My baby's weight bothered me but Health Visitor not very reassuring, don't get a set one, they're asking me, what's going on?, they don't tell me anything I don't know".

"Not really that helpful-she really stressed me out; she'd never had a baby with a cleft before"

"Didn't really know a lot"

"No experience of it kept weighing her and telling me not feeding enough".

"Didn't understand".

"Harassed hardly came near me first night".

"Not good ".

Mixed

"Definitely know they were getting information off me, not her fault"

"Alright, not great",

"First awful second lovely" worried about depression but I said I was ok just stressed and so stopped breastfeeding"

Health Visitor /Dietician -"Didn't know a lot about it...at Wishaw started to get to know people better, good at what they did ,didn't know much about cleft and underlying condition" -" "Not really any help general weighing and checking weight but not specific for cleft palate not her department"-Father

"Didn't know much about it but good for weight, she sent baby in to hospital ... but she had to go on the internet, never come across Pierre Robin Syndrome before."

"She was ok, but not really to do with the cleft palate"

"Lovely person but lack of help with feeding and putting in tube, but has since found out things".

"Didn't know much about the cleft -learning from us, had other clefts in area so learnt about them as well".

Meeting whole Cleft Team

Favourable

"Daunting but reassuring to know people involved".

"Team great, very proactive. It was different for twin in cardiology-had to seek advice, never had the file, never felt they had a team and missed things"

"Cleft team, very well organised, no pressure, cleft nurses would pop in and see you in the hospital, good to see a familiar face. Dentist on preventive clinic very in depth (from 6 months) would have picked up on anything that wasn't right"

"Fine, good to meet people with experience...orthodontist nice, surgeon helpful...cleft nurses popping in and out of Yorkhill when there (at 5 weeks)".

"Fine -better seeing all at one time"

"Cleft team good"

"Brilliant, fantastic"

"Very supportive answered anything you needed to know-reassured; 'don't worry leave it to us'"

"Not scary, very helpful, answered any questions we had ...I worried about (patient name) but was fine, not intimidated...didn't get a chance to be."

"Introduced to everyone, but realise not enough time"

"Cleft team really nice"

"Didn't meet cleft team till 5 yr check"

"Lovely, really nice, very teary at that meeting-husband spoke to them more"

"Cleft team (nurses) very supportive...prepared you for the whole team".

"I would rather have specialists in one room...never felt rushed, had a lot of questions always someone to answer...sitting around a desk would be better".

"I wasn't really stressed...more worried about the general anaesthetic but kept informed".

"Really happy once I came out...had a laugh, felt comfortable, good to meet everyone altogether rather than apart".

"Quite liked it...realised a big team their to help and work together, every specialist".

"Great, very positive you could ask any questions...if you wanted to have more kids then geneticist there, very supportive for surgery".

"They were brilliant ...compared to ENT team".

"Listened to what we had to say, gave us assistance and help"

"Quite reassuring nurses (cleft) very calm".

"Fabulous - very reassuring".

"Felt terrified but mind put at rest meeting cleft team...all numbers in 1 place...well looked after...we were really well informed".

"Apprehensive about surgery but cleft nurses there, very reassuring and consistent"

"Scary thinking about what's going to happen...Frightened of unknown, how different he would look but the newspapers had before and after pictures and so did 'Scotland Today' article...it was a positive experience".

Negative

"Very vague, talking about syndromes, like an interview panel, not expecting that".

"Not very reassuring, I felt so flat after first visit, almost scaremongering (Father).

"Not very supportive about breastfeeding" (Mother).

"Overawing for child...normally placid but screams every time she sees them" (Father). "All looked in mouth, intimidating ...is it necessary for all 12 people to be there. Can information be passed on?"(Mother).

"Walking in for an interview-you could have it a bit more informal. Whole introduction could be changed, someone could take you in and meet one at a time, smooth you in instead of being the only one facing them. I can appreciate time factors and it can be good to see everyone at once, but I worry, 'what's wrong with my child'?"

"Scary-all a bit daunting...going into the room and everyone there...felt this is serious".

"On my own -scary-but part of growing up-quite happy to do it-easiest and quickest way- if have a question -all there. Shock to the system, number of people, 8 or 9 people on panel, quite intimidating, not quite as focused".

"A row of 12 people looking at you, not easily intimidated but like a job interview...some people no role?, always running late ,want to hurry you along".

"Slightly intimidating but how else are they going to do it...a panel interview...had daft questions to ask but hard in front of them...could ask the cleft nurses ...1 week in hospital (surgery) tremendous experience... never looked back".

"Overwhelmed, didn't really talk to me only to my mum, and asked me questions the second time and I knew more". (Mother) "Them and us -intimidating at first. A circle would be better than a line of people' (Grandmother).

" Quite nice, quite frightening, lots in one room about eight of them...some just sit there and don't say anything...but all have to be there".

"A bit imposing but generally ok...but couldn't tell you who all of them were or what they did" (Mother). "Didn't have a problem with students but would like to know before hand" (Father).

"Nervous, like a big panel of judges, all just sit and look at you, 6-8 of them...its alright, better one on one but maybe we need to see all -just don't need to sit in a line like judges".

"Perfect diversity...little bit intimidating, not sure who everyone is, speech therapist introduced us ...these are the people you know and these are the others".

Genetic advice -"Didn't want to talk about personal things in front of whole team-would have liked that separate".

"There's about 14, hundreds of them, extra people, you're just sitting there, maybe just a couple of people at a time would be better".

"Quite intimidating one line across from you , not introduced speak to you as if you were expected to know what they wren talking about, felt quite alienated but because of reputation you trusted them, obviously knew what they were doing, could have been more parent friendly".

"Full team put in place is a contradiction to what we were told at birth "small tear", needs to be put in context and toned down"

Mixed

"Cleft nurse told us who was in the room and it was normal-but I would have panicked if she hadn't told me ...answered questions/queries".

"A bit like going for a job interview but they were friendly and all our questions were answered"

."Surgeon - encouraging and reassuring, great -too much to see whole team, need to lessen impact, balance."

"Cleft team was good but like a panel of people a bit intimidating. Only 3 the other day -joking about seems really relaxed, everyone introduced themselves, getting all information at one time -really good".

"Surprised how many folk there...not expecting such a big set up.. dark room...you and wife and child sat in front, felt self conscious ...not sure who everyone is...know main players, but in one sense reassuring, notes in one place so helpful".

"They just sit there; just say nothing...new surgeon great, more relaxed I really liked him."

"Nurse very helpful, told us everything we needed to know...a bit daunting at first...like a job interview...better that they are all there".

General comments

Favourable

"Felt although special nurses were great, it's not the same as having to deal with it. Much better talking to other mums. I felt nobody could feed better than me I would support a network of mums to be at end of phone to be given phone numbers... don't like to ask for help. I had a guilt trip because I couldn't breast

feed. If had been second baby, maybe not so difficult or guilty. Special nurses always at end of phone but CLAPA helpful, speaking to other mums".

"In total shock but took a view and just got on with it".

"Special breastfeeding nurse very encouraging, went to breastfeeding group once a week, community midwife did not come to house as baby in hospital for 5 days",

"Everyone excellent, pulmonary hypertension with twin, concentrated on that...cleft twin brought on Downs syndrome twin, cleft not linked to a syndrome...could have been worse, shocked at first but when found out ,it could be repaired-ok".

"Surgery went well, could still breast feed afterwards".

"Doctor gave good advice. Used a childminder, but not happy with this, preferred a one on one".

"Used CLAPA leaflets and a US website".

"Wasn't that bad cleft nurses on phone, I was coping quite well, it wasn't that bad a pretty positive experience".

"Having all the information before hand meant I could explain to other people and two other boys-showed photographs"

"GP had a cleft son –very 'helpful".

"I would volunteer to visit, speak to other mums, definitely.(my child) starting school, still many questions to ask".

"Went on to breastfeed third child".

"Much better cleft team than Audiology"

"Overall delighted with care".

"CLAPA information very helpful"

"CLAPA -leaflets, books and parties."

"A bit hazy at first -left leaflets/literature, family could look at pictures. Special care unit had before and after pictures, a great idea".

"CLAPA- good website for families if have any questions. Good speaking to people who have a cleft kid".

"Once had right teat, baby fine, surgery success. Could call special nurses at any time, and gave great advice".

"From very beginning everyone has been great, support been fantastic Doctors great"

Unfavourable

"Wasn't offered a scan could have been more prepared for it, no communication, 2nd child given folic acid and two detailed scans"

"CLAPA - too much information on cleft lip, not a lot on cleft palate Cleft nurse said you have got to get used to feeding times".

"Was offered other mums to speak to, in other circumstances I would have used this service"

"Paediatrician said –'have you been on drugs'-I was worried I had done something"

"Too much air with Haberman bottle and needed more after a few weeks"

GP-"Not a lot of support".

"Maternity hospital not great. I didn't know anything between birth and Cleft team coming. When will operation happen? Especially Cleft lip, 24 hours not knowing."

"Stirling Royal out of date leaflets but this was 5 yrs ago. Went on Internet to CLAPA site after scan."

"The price of bottles is a disgrace, £14 every 2 weeks"

"I feel my daughter has been neglected she only put on oz's in 6 weeks but it was still not picked up by nurses, GP's, Health Visitors or Midwives"

"Nurses and Doctors didn't have a clue. Did not go down route of CLAPA, felt unhelpful, if need CLAPA would be for child"

"At home didn't know who to phone cleft nurses not always there and had to wait, knew they would get in touch but left for a day or two.."

"Too much information. A shock 1st child" (Father)

"Paediatrician came whilst I wasn't there-a bit too much, he couldn't explain what operation was needed. Because it's our first kid -might have been calmer if wasn't". (Mother)

"Pelvic floor broken during delivery, v poor support, no Doctor seen".

"No advice even after it (the cleft) picked up".

"Difficult to get answers out of doctors-left too long without explanation-want to be reassured it can be fixed immediately".

Mixed

"Local doctors hardly know much -needed to go on internet. There were good nursery nurses. Cleft nurse -very good -good to know not the only one -if it wasn't for her it would have been really bad-hospital staff horrible- she (Cleft nurse)gave leaflets/bottles, and photos before and after"

"Don't want detailed scan if have another baby, nice surprise if doesn't have a cleft"(Father).

"GP- complained of having to prescribe Infrateeny out of budget. Surgeon more approachable listened to us". (* Infrateeny is a brand of high calorie milk).*

Dietician-"Good tips but met after surgery"

"Didn't know about CLAPA till came to OOPC at one year old".

"Wouldn't feed in hospital one of the nurses at Yorkhill in ward suggested I go home. After discharge was ok at home because sister in law is a breast feeding nurse"

"I had no difficulties. I didn't need advice on feeding in hospital".

"Didn't really need advice".

"Leaflets in hospital - a lot to take in".

"Once sat and read leaflets, understood".

"Could call special nurse at any time, and gave advice, teats, and bottles." Would have felt lost without cleft nurses ...on phone...had other problems heart and kidney, ordinary nurses didn't really help....hospital needs to be proactive"

Parent Recommendations

"To meet with other mums would be nice; I would speak to new mums. Albums of children as they grow up with different pictures of different types of clefts would be a good idea"

"Too emotional to take advice but (child's) dad understood. Would have helped to see other mums to let you see their baby after surgery, would be willing to speak to others".

"CLAPA Website ok, used more with first child" Dietician-"Not seeing the bigger picture, it would have been helpful to have a case conference between cleft team and dietician and other members. It's a complicated case (child) was at Yorkhill for stomach surgery. After strapping and naso-gastric tube removed, needed to desensitise nasal area still has problems should have had peg earlier"

"Orthodontist most reassuring, felt could take baby about (with feeding plate)"
Doctor, did not want to confront us. Cleft nurses good (visits even at home) but
couldn't really be there all the time...leaflets too much-it would be better to have a
bank of folk, a volunteer mother or parent of a cleft child to visit a new mother to
see photos of their cleft child or even to meet a cleft child".

Chapter 6 Discussion

Since 2004, CleftSiS has been responsible for the care of cleft infants in Scotland. This study provides the first external audit of one part of CLEFTSiS activity in the West of Scotland. It particularly focuses on the feeding methods, patterns, and habits of infants with a cleft, paying particular attention to the incidence, prevalence, and duration of breastfeeding amongst the cleft population. The results are discussed where appropriate, with reference to national (Scottish) statistics and a recent survey published by (CLAPA 2007a www.clapa.com/cleftlip.html).

Demographics

Ninety parents took part in this investigation. This constituted 90% of the intended sample. Even though the West of Scotland covers a large geographical area, more than 85% of cases were from Greater Glasgow and Lanarkshire alone. A large percentage of the infants had been born in the Royal Alexandra Hospital in Paisley (21%) and the Princess Royal in Glasgow (17.8%), the latter having replaced the now closed Rottenrow Maternity Hospital. Together with the Southern General and the Queen Mothers Hospital, the hospitals in Greater Glasgow made up 70% of the sample. A further 15.6% of cases were from Wishaw General in Lanarkshire. Only one child was born outside the West of Scotland. There was an even distribution of male and female infants in the sample, but a significant number of the cleft lip sample were male (76%). The maternal age was evenly distributed between those mothers under 25, 25 to 30, and 31 to 35 years of age. The proportion fell after 35 and there was only one mother older than 40. There was no significance in the birth order of the cleft infant. The suggestion that a higher birth order relates to a higher incidence of clefting could not be demonstrated in this sample, as there was an equal distribution of first and second born babies and together first and second born babies accounted for 79% of the sample. All but two of the infants were full term and there were only two sets of twins in this sample.

The measure of social deprivation used in our study was Carstairs deprivation category (Depcat) scale (McLoone 2004) using the postcodes of the families taking part. The Depcat scale is from 1 to 7, the higher the score the higher the level of deprivation. The occupations of the mothers had been obtained in our study but not in sufficient detail to use the new National Statistics Socio-Economic Classification (NS SEC) thus the educational level of the mothers taking part could not be factored into the comparison of breastfeeding figures. However, McLoone (2004) aggregated NS SEC scores against the Carstairs Depcat scores, and while parental occupations have not been addressed at an individual level the postcode and consequent Depcat score does take account of this factor. As demonstrated in the results the Depcat scores in our study followed the national distribution figures for Scotland except for Depcat 7, which was more evident in our cleft study. There were also fewer infants born with a cleft in Depcats 1 and 2 and higher numbers of cleft infants born in Depcats 5, 6 and 7 compared to the national population distribution. The figure of 14.9 % for the proportion of cleft infants born in Depcat 7 compared to the national population Scottish figure of 5.8% may reflect the higher percentage of the population in Depcat 7 in Glasgow compared to the rest of Scotland. 30% of the population of Glasgow live in a Depcat 7 area (McLoone 2004). There was far less incidence of clefts in Depcat 1 and 2 in our sample, reflecting the literature that reports that there is a higher incidence of clefts where there is greater social deprivation. (Womersley and Stone, 1987; Clark *et al.*, 2003) Our results show that the greatest proportion of cleft type was a CP (47.8 %). This reflects the national Scottish figures from 2003-2005 but differs from the CLAPA survey 2006 (CLAPA 2007a). This is shown in Table 6.1 below.

Table 6.1 Comparison of cleft type between national (Scottish) figures, our Cleft Study, and the CLAPA survey 2006.

	CL	CP	CLP
* Scot 2003	27.2%	44.4%	28.4%
Scot 2004	20.9%	56.0%	23.1%
Scot 2005	21.5%	49.5%	29.0%
Cleft Study	16.7%	47.8%	35.6%
CLAPA survey 2006	13.7%	38.1%	48.7%

* Scot –Scottish Figures

From our results, there was also a greater percentage of the cleft population residing in Depcats 3 and 4 and this was reflected in the demographic results where the most frequent numbers of the general population live.

Diagnosis

The 2006 CLAPA (CLAPA 2007a) survey reported a significant increase in the number of cases diagnosed antenatally since a previous CLAPA survey carried out in 1996, rising from 15% in 1996 to 45% in 2006. In our study in the West of Scotland, only 13.3% were diagnosed antenatally. The reasons for this could be threefold. Firstly, as previously mentioned our study had a higher percentage of infants with a CP only and as found in the literature (Clementi et al., 2000; Stoll et al., 2000; Cash et al., 2001; Sohan et al., 2001) this is harder to detect antenatally. Secondly, the majority of the parents who took part in the CLAPA survey had children born in 2003 to 2005 (over 80%) whereas our sample contained just over 50% from the same period. Since 3D scanning is a recent phenomenon in antenatal screening it is possible that the availability may be higher across England and Wales than in the West of Scotland, and this may have contributed to the lower figure found in our study. Thirdly, antenatal scans may be carried out later in pregnancy in England and Wales when detection of a cleft is easier. In the West of Scotland, antenatal scans are routinely carried out between 12 and 14 weeks. To detect anomalies such as cleft lip and palate later scans between 18 and 24 weeks are advocated.

CLAPA were concerned that 14% of their cases were not diagnosed at birth, yet 25.5% of our cases were undiagnosed at birth. This again may be due to the greater proportion of CP infants in our study compared to the CLAPA Survey (Table 6.1). Habel *et al.*, (2005) found that the delayed detection of CP was not uncommon. They recommended that "trainee doctors and midwives be instructed to inspect visually using a light and tongue depressor, then digitally if submucous CP is suspected."

Feeding

In order to compare the breastfeeding rates of our cleft study group with national figures we used data from 2000 (Infant Feeding Practices 2000) and 2005 (Infant

Feeding Survey 2005). This is a more useful comparison than one single set of data as the infants in our study were born between 1999 and 2006. The incidence of breastfeeding in our study at birth was 54.4% (49/90). In Scotland, by comparison the incidence of breastfeeding in 2000 was 63%, and 70% in 2005, thus indicating a relatively lower rate for our cleft population. However, the breastfeeding rate did rise in the first few days following birth amongst the cleft infants to 64% (58/90) which is more consistent with the national figure. This increase can be attributed to 6 mothers whose infants had initially been given a naso-gastric tube to assist feeding then went on to express after their first feed, and 3 mothers whose infants were given formula and a bottle and who used a combination of expressed milk first and formula later. A more realistic picture would be to look at the prevalence of breastfeeding after 1 week, 6 weeks and 6 months (Table 6.2), because some of the clefts were undiagnosed at birth and it took time for mothers to find the right feeding method for their infant. At 1 week, 93% of the clefts had been diagnosed, and at 6 weeks, all but 1 case had been diagnosed. At 1 week, 49% of the infants were still receiving breast milk, which is again comparable to the national levels of 50% and 57% in Scotland in 2000 and 2005 respectively. At 6 weeks for cleft infants, it was 30% compared to 40% (2000), and 44% (2005) in Scotland. At 6 months for cleft infants, it was 13.3% compared to 24% (2000 and 2005) nationally. Although the prevalence at 1 week for the cleft population is very encouraging, this level falls more dramatically at 6 weeks and again at 6 months to almost half the national level.

Table 6.2 Comparison of the prevalence of breastfeeding between our cleft study and the national figures for 2000 and 2005.

Prevalence	Cleft study	Scottish 2000	Scottish 2005
1 week	49%	50%	57%
6 weeks	30%	40%	44%
6 months	13%	24%	24%

An explanation for this could be that only 13.3 % were actually being breast-fed after 1 week, while the rest were being given expressed breast milk. The practicalities of expressing then feeding are often very difficult to maintain. However, in terms of nutrition, it shows that at 1-week infants with a cleft are no worse off than their non-cleft counterparts and the commitment of these mothers

to continue to express and give their children breast milk has to be commended. However, in terms of maternal bonding where actual breastfeeding is said to be more favourable these figures represent a different picture.

The relationship between incidence, prevalence, and duration of breastfeeding with birth order and the socio-demographic characteristics of the mother has been discussed in the literature review. The incidence of breastfeeding is higher among mothers of first babies but the prevalence and duration is higher with second babies as it is usually mothers with a positive experience of breastfeeding who breastfeed their second child and do so for longer. In our study, there was an equal distribution of first and second born babies. However, changes in birth order appeared to have no significant impact on the incidence of infants being given breast milk in our sample, with figures of 62.9% and 63.9% for first and second infants respectively. This differs from the national figures for Scotland, which were 67% and 59% for first and second babies in 2000 and 73% and 66% in 2005 (the national figures for second born babies are for mothers who breastfed first babies).

Breastfeeding prevalence at 1 week was 40% for first and 52.7% for second born infants in our study. This decreased more dramatically at 6 weeks and 6 months in the first-born sample but followed national trends with second born babies being breastfed longer. However, from all the results it can be seen that levels of breastfeeding are much lower amongst the cleft infants (Table 6.3). There are no corresponding 2005 national figures for 1 week and 6 weeks.

Table 6.3 Birth order and prevalence of breastfeeding compared to UK percentages, 2000 and 2005.

Birth Order	Birth			1 week			6 weeks		
	cft	2000	2005	cft	2000	2005	cft	2000	2005
1 st born	63%	67%	73%	40%	58%	-	20%	42%	-
2 nd born	64%	59%	66%	53%	54%	-	39%	42%	-

cft –our cleft study

This lower rate of breast-feeding amongst the cleft population was to be expected, given that the literature identified that those infants with a CL only, were more likely to breastfeed. Indeed the results comparing cleft type and prevalence of breastfeeding showed that 80% of the CL infants breastfed initially and 67% went

on to breastfeed for at least 6 months, ($P < 0.054$). This contrasted with the infants with a CP (with or without CL) where 61% had tried to breast feed initially but by 1 week only 45% were still doing so, and by 6 weeks this had fallen to 23%. Only 2 continued for 6 months.

All the CP infants (with or without CL) were given expressed milk via a bottle or naso-gastric tube except where two mothers actually breastfeed their infants for 6 months. 60% of the infants with a CL accounted for 25% of second born babies and only 8.6% of the first-born. This suggests that in our study cleft type had a greater influence over choice of feeding method rather than the birth order and any previous experience of breastfeeding amongst this cleft population.

Breastfeeding has been shown to increase with the age of the mother (Infant feeding practices 1995). When comparing the prevalence of breastfeeding after 1 week with maternal age there was a significant rise in breastfeeding over 30 years of age in our study. Only 41% of mothers' breastfed in the 25-29 year age group at 1 week compared to 62% in the 30-34 year age group. After 6 weeks, this decreased to 30% and 46% but was still higher in the older age group. This is comparable with national trends even though the figures are much lower. The national figure in 2005 at 1 week for 25- 29 year olds was 63% and 73% for 30 and 34 year olds. At 6 weeks, it was 47% and 58% (Infant feeding practices UK 2005). This is shown in Table 6.4.

Table 6.4 Comparison of the prevalence of breastfeeding between 25 – 29 year olds group and 30- 34 year olds in our cleft study and the UK, 2005.

Maternal age	At 1 week		6 weeks	
	cleft	UK 2005	cleft	UK 2005
25-29 years	41%	63%	30%	47%
30-34 years	62%	73%	46%	58%

There was no significant relationship of cleft type with maternal age ($P < 0.99$) in our study because the different cleft types were evenly distributed over the maternal age groups without a predominance of one cleft type in a particular maternal age group. The breastfeeding figures in our study are still much lower

than the national ones and reflect the difficulty of breastfeeding an infant with a cleft.

As the sample of clefts from Depcats 1 and 2 were small, we could not find a significant correlation between breastfeeding and level of deprivation.

Our study found that 47 of the 90 mothers (52.2%) decided to change their method of feeding from breastfeeding to another method because of their child's cleft and only one mother decided to breastfeed as a result of her child's cleft. 71.1% (64/90) changed their method after the initial feed or within days of the first feed and 81.1% of these mothers most frequently changed to using formula milk and a bottle.

From the results and comments, feeding a child with a CP with or without CL was found to be especially difficult in the maternity wards as parents were unable to access specialised bottles and teats as one mother quoted:

"No nurses could help in the hospital until the Special Nurse came; they (hospital nurses) found a Haberman bottle but it had no valve. I wanted to come home but I had no bottles so had to feed my baby with a spoon."

In most cases, the cleft nurses would usually bring the specialised bottles and teats to the hospital. This emphasises the need for them to be more readily available in maternity wards. There is only one full time equivalent cleft nurse for the whole of the West of Scotland and although most of the hospitals are supplied with bottles, lack of funding and rotation of nursing staff in the maternity units usually means they run out of supplies without informing the cleft nurses. Many of the maternity and ward nurses were unaware of any "special bottles" and felt that since the cleft team had been notified they themselves were no longer responsible for the mother with regard to cleft issues. The parents felt that the maternity units were understaffed, and most agreed that it was the roles and actions of individuals that contributed either to a good or bad experience. Unfortunately, most of the parents felt that unless they were breast-feeding they were generally ignored. This can be seen from the quotes below.

"One particular nurse was good and said 'don't be scared' when I gave the first feed. The attitude and knowledge of cleft issues in other nurses was poor. They were too short staffed".

"The CP had been identified at 6 o'clock in the morning. I got up to breastfeed and one nurse said 'for goodness sake if you didn't want to breastfeed you only had to say'. I was upset because of the diagnosis, there was no help with electric pump, no support with hand pumps...lovely people, but too busy, if you don't breastfeed they want nothing to do with you".

"The ward nurses were not so much help with feeding .The baby had a nasogastric tube and they were not keen to sit and try to give him a bottle. They were so busy".

28.9% of cleft infants had to have a naso-gastric tube to assist feeding. Either this was in hospital during the days following birth or later when there were concerns about the infants' weight. Only 1 of these had a cleft lip only. 33.3% (25/ 75) of infants with a CP with or without a CL experienced the use of a naso-gastric tube.

The most popular bottle (46.7%) was a soft squeeze type and the most popular teat (44.4%) was the 'cleft nuk' or 'mam' type. Both are modified teats especially made for infants with a cleft. Some of the parents expressed concerns over the expense of these bottles and others noticed the Haberman bottle did not come with a lid. Nearly all parents who used these bottles and teats commented on the difficulty in getting a supply and were very grateful to the Cleft Nurses and Health Visitors who helped with this. 61.1% of parents had problems with the length of the feed and in 45.6% feeding lasted longer than an hour. In the CLAPA survey (2007a), it was reported that 70% of mothers had established successful patterns within 24 hours after birth yet only 3.4% had established a regular pattern after 48 hours in our study. In our study, 48.3% had established feeding patterns after 1 month, 28.9% took longer than a month, and 20% never established a regular feeding. This represents a large and significant discrepancy between our study and the CLAPA survey. The lack of supplies of bottles and teats in the hospitals appears to be similar in both surveys and lack of knowledge of the nursing staff on the wards and Health Visitors appears to be a common complaint.

The CLAPA survey (2007a) had looked at how soon a cleft team member visited the mother after diagnosis because of the lack of general support and knowledge in maternity hospital (Table 6.5).

Table 6.5 Time at which cleft team arrived after diagnosis (CLAPA 2007a).

Timing	Percent	Cumulative Percent
Within 24 hrs	27.15	27.15
Within 48 hrs	21.27	48.42
Within 1 week	17.19	65.61
Within 1 month	21.27	86.88
Within 6 months	7.24	94.12
Other	0.45	94.57
Within 2 months antenatally	5.43	100.0
Total	100.0	100.0

Although this question was not posed directly in our study, such information emerged voluntarily during some parental interviews. The Cleft Nurses in the West of Scotland arrived within 24 hours after diagnosis in 52.5% (32/61) of cases, a further 7.8 % within 48 hours and by 3 days 90% of cases had been seen. In the CLAPA survey only 27.2 % were seen within 24 hours, a further 21.2% within 48 hours and it took 1 month before 87% of cases were seen. Therefore, it cannot be suggested that it was the delayed arrival of the cleft nurses that hindered feeding patterns in the West of Scotland. Another factor could be that in 45% of mothers in the CLAPA survey there was an antenatal diagnosis compared to 13% in our study. This would have given the CLAPA mothers longer to assimilate all the information about having a baby with a cleft including the potential feeding difficulties that lay ahead and the bottles or other feeding methods that would have to be addressed. The late diagnosis of 25% of the infants in the West of Scotland compared to 14% in the CLAPA survey could also have contributed to the lack of feeding patterns. In addition the frustration and worry of our mothers over their babies' inability to feed and possible subsequent weight loss may have been a contributory factor in the late establishment of feeding patterns in this West of Scotland sample of parents.

Alternatively, the results could be reflective of the two different methods used in the studies. The CLAPA survey was a postal questionnaire whereas our study

involved a personal interview. The mothers spoke at length during our interview and could express themselves more perhaps than on paper.

42.2% of parents felt their child's intake of milk to be inadequate, and all but 10% experienced problems during feeding: fluid down the nose (70%); excessive air causing colic (52.2%); coughing during feeding (42.2%); excessive leakage of milk (41.1%). Many of the parents said that feeding became less challenging once they had the correct bottles and teats, but only became easier after surgery. 16.9 % (15/89) were readmitted for feeding problems and 4 of these infants required more than one admission.

Chest/ Ear infections

34.4% of parents reported that their child had early ear or chest infections. Infants with a UCLP seemed to be more at risk with 50% (10/20) of the sample in this group experiencing infections compared to approximately a third of CP and BCLP infants and 20% of CL infants. This is consistent with the literature as the UCLP group also had the least amount of breastfeeding. Aniansson *et al.*, (2002) and Danner (1992) both found a link between lack of breastfeeding and both upper respiratory tract infections and otitis media, and Paradise *et al.*, (1994) found expressed breast milk also conferred varying degrees of protection. In our study, the mothers of infants with a CP and BCLP were the highest expressers of milk, and the mothers of infants with a CL were the highest actual breast feeders. Three parents reported that although their infants had not had infections they still required insertion of grommets.

When researching national figures for chest or ear infections to compare our results, no Scottish figures were found. Indeed, in the SIGN Guidelines (SIGN 66 www.sign.ac.uk) on 'Diagnosis and Management of Childhood Otitis Media in Primary Care', there is only one reference to UK literature (Hart and Bain 1989). This states that one in four children will have an episode of Acute Otitis Media during the first 10 years of life with a peak incidence occurring between the ages of three and six years. Other references in the Guidelines are sourced from American and Dutch studies. We can therefore only roughly gauge that the figure of 34% for our sample with chest or ear infections is high compared to the general population of the same age.

Pre-surgical appliances

25.6% (23/90) of infants had used a pre-surgical appliance. This represented 71.9% (23/32) of the BCLP and UCLP cases in this sample. Nearly 70% of the parents rated the appliances with a high score of 4 or 5 and were happy with the 'improved feeding and cosmetic results'. However, 50% did have difficulties with the appliances especially the tape used for the strapping as witnessed from some of their comments:

"Had to change strapping tape sometimes 13 times a day because wet from milk coming down the nose"

"Crying constantly, had plate for 3 hours."

"Plate rubbed on gum, adjusted, but also allergic to tape, tried different types"

"Stopped after first surgery but (plate) irritated mouth and tape annoyed face"

"Advised to stop, couldn't feed using Haberman... kept putting on wrong way round, tape caused blotches."

Feeding Habits

Early childhood caries (ECC) is a term used to describe dental caries presenting in the primary dentition of young children (Fayle 2005). The main contributors to this pattern of decay are fruit juice drinks given frequently in a bottle. Our study looked at the feeding habits within the sample and found that 15 infants were given juice in a bottle, 11 had high calorie milk, or sweetened milk and a further 2 were given Rusks in their bottles. Although the study did not look at the actual caries rate of the infants in the sample, 31.1% (28/90) of infants had habits that would promote development of early childhood caries. (None of the infants had sugar in their bottle as was highlighted in the literature review). The National Dental Inspection Programme (NDIP) for 2006 in Scotland (NDIP 2006) found that only 54% of the 5-year-old population was caries free and that 100% of the established decay was found in 38% of the population. Decay is also more likely in the higher Deprcat, where there is more social deprivation. If the number of infants given high calorie milk is excluded (as this had been recommended by health professionals), juice,

sweet milk and rusks were more likely to be given in the higher Depcats (4, 5, and 7). There was only 1 infant in Depcat 6 who had sweet milk. Fayle (2005) also suggests that although studies in animals have shown that cows' milk does not cause caries there is some evidence of it doing so when given at night. 85.6% of infants were given milk at night in a bottle. As previously reported in the results section the age at which the infants stopped receiving a bottle at night was not asked directly in the original questionnaire but of the 66 parents who did volunteer the information 65.2% (43/66) had a bottle at night until they were a year old and 22.8% (16/66) had one up to the age of 2. The NHS GG Infant Feeding Policies and Guidelines for Health professionals does stress that "many specialised formulas are more cariogenic ... and good dental hygiene is essential" There is therefore a need within CLEFTSiS to try to ensure that preventive advice regarding potentially cariogenic fluids and foods is translated into good practice.

Support and advice

87.6% of parents received feeding advice in hospital and 91% received advice at home. 93% of responders understood the advice. When asked to rate this advice 93.3% of parents who answered and where applicable (70 out of 75) gave a high score of 4 or 5 for the advice given by the cleft teams in hospital and 96% at home. The advice by health care professionals who were not members of the cleft team was rated 4 or 5 in only 54.55% of cases in hospital and 68.1% at home. As witnessed by the comments, the cleft nurses provided very valued and encouraging advice. Some examples are given below.

"Cleft nurses....-absolutely brilliant... couldn't explain things enough....good home contact on phone"

"Really good, very supportive, lots of information, things happened quickly"

"Cleft team great.. phoned when found I was pregnant with second child...previously they been involved with first child"

"Would have felt lost without cleft nurses"

There are currently only two Specialist Cleft nurses job working 32 hours between them for the whole of the West of Scotland yet nearly all the parents commented that the cleft nurses "were always at the end of the phone". Many parents called

them the 'CLAPA Nurses' which endorsed the high profile of CLAPA amongst the parents of cleft children in the West of Scotland.

There were many negative comments about the nurses in the maternity wards. Parents felt there was a general lack of knowledge regarding clefts and unless the mothers were breastfeeding, they tended to be left to their own devices. Some examples of the comments can be seen below:

"Nurses in hospital were adamant I could breast feed but I couldn't.....-they did not have enough knowledge... but they were supportive"

"Nurses in hospital gave conflicting advice. It was very difficult; I had to use different methods"

"Nurses not familiar with cleft palate situation- felt a bit of pressure to feed properly"

Many of the mothers felt unsupported until the cleft nurses arrived. Individual nurses did take an interest but most could not provide further information about the cleft or provide advice to parents about the management of the cleft. Even though the cleft nurses arrived within 24 hours in most cases, the first few hours after birth is a stressful and worrying time for most parents especially when a cleft diagnosis has been made and their baby is having difficulty feeding. When the infant was taken into special care, it was seen as a positive move as the special care nurses tended to be much more proactive and more understanding and some infants were given a naso-gastric tube to assist feeding. Some 29% of the infants had a naso-gastric tube, however if specialised feeding bottles were more readily available it is conceivable that fewer infants would need this form of feeding. For those mothers with a baby with an undiagnosed cleft it was even more frustrating as they could not understand why there was a feeding problem. The nurses and midwives sometimes commented that the mother could not breastfeed because of the cleft and did not always explain how expressing milk and feeding with expressed milk might be achieved:

"I don't think they understood our situation...they see so many children and were under-pressure. The system let them down which in turn let us down. They tried to

force mum to use breast and we were treated as if we were lepers". (Comment by a father)

"General Nurses made me keep breast feeding but that's why I was readmitted, as I had tried to express and give bottle which didn't work. Once specialist nurses came it was great."

"Nurses in hospital gave conflicting advice. Very difficult, had to use different methods"

The mothers' comments also reflected the way they were treated once the cleft of their infant had been diagnosed. One mother reported students coming in without her consent to watch her double express and another said that a nurse discussed 'psychological issues' in front of her:

"Nurses on ward could be explaining to students about development/psychological issues in front of me".

The literature review drew attention to a recent major public information initiative in Scotland to promote breastfeeding. This is to be welcomed because the evidence from this research shows that a cleft was often seen as an 'inconvenience' for staff who had neither the knowledge nor the information necessary to support the mothers of cleft infants prior to the arrival of the cleft nurses. Some further comments are listed below:

"Doctors and nurses no advice, no reassurance"

"Maternity hospital not great. I (mother) didn't know anything between birth and cleft team coming, e.g. when will operation happen? I was 24 hours not knowing."

"Not hospital policy (lap feeding) so I had to make a choice. Haberman was given but I was not allowed to take it home, so I got a prescription for Boots. I wasn't allowed to leave until the ward had a replacement"

There was a mixed reaction to the advice and support given by the Health Visitors. There was very little knowledge of clefts unless the Health Visitor had been involved in a previous case or had a child or relative with a cleft. This was

surprising, because they were concerned with the weight gain of the cleft infant. Occasionally they would discover a cleft because of poor weight gain. Some Health Visitors also recommend high calorie milk if the cleft had been diagnosed and the infant was not gaining weight. Some individuals were considered unhelpful but most Health Visitors would assist with acquiring bottles and were willing to learn and read up about cleft management and care. However, the support and assistance should not be left to chance. Cleft care should be addressed in the training of Health Visitors, as it is they who are usually the first point of contact for mothers once they leave hospital after the birth of their child.

Meeting the Cleft Team at Yorkhill Hospital was generally a positive experience. Parents were impressed that a team was in place so that any questions could be addressed, however nearly all expressed the view that “it felt like an interview” and it could have been less structured and more informal. This was also the view of parents who took part in the CLAPA survey. Some of the parents in our study suggested that smaller groups arranged in a circle rather than a long table would have been preferable but the general comments on individuals in the cleft team were favourable and parents felt supported by the cleft nurses who they already knew. Some parents did say that on the one hand they had been told “it (the cleft) was nothing and easy to repair” but this seemed to be contradicted by meeting the cleft team which as one parent put it “had hundreds of people in it”! Some comments about the Cleft Team are shown below:

“I would rather have specialists in one room...never felt rushed, had a lot of questions always someone to answer...sitting around a desk would be better”

“Scary-all a bit daunting...going into the room and everyone there...felt this is serious”

“A row of 12 people looking at you, I’m not easily intimidated but like a job interview...some people no role? Always running late, want to hurry you along”

“There’s about 14, hundreds of them, extra people, you’re just sitting there, maybe just a couple of people at a time would be better”

“A bit like going for a job interview but they were friendly and all our questions were answered”

Some parents requested greater consistency between the initial message and the follow up care. In addition there was a perceived need for improved communication between the cleft team and other health care professionals, particularly if a child's cleft was part of a wider syndrome or if there had been other medical complications requiring management by other medical and surgical teams in the hospital.

Critique of the study

We were unprepared for the amount and nature of parental comments when initially constructing the questionnaire. In hindsight we would have allowed the space for this in the questionnaire and in addition would probably have included the facility for recording parental comments. This may have resulted in a more in-depth content analysis of the comments. However for the purposes of this study we delineated parental comments into themes and within the themes whether comments were favourable, unfavourable, or mixed.

Questions about the timing of the diagnosis and meeting the Cleft team were added to the questionnaire, as they were issues that were raised by the first parents questioned. All parents were subsequently asked these questions.

Reflection

This questionnaire was a cathartic experience for some families as bad memories were recalled when parents relived their individual experiences. However there were many positive experiences as well. Without question, the parents welcomed the opportunity to voice their thoughts and experiences in the hope that the service can be improved for future families. We are very grateful to the parents for their time and honesty.

Chapter 7 Principal findings

1. The incidence of breastfeeding at birth was 54.4%. At 1 week, the prevalence was 49%, at 6 weeks 30%, and at 6 months 13.3% of infants were still receiving breast milk.

Cleft type had a significant impact on whether the infant was breastfed.

80% of CL infants breastfed initially and 60% went on to breastfeed for at least 6 months, whereas 61.3% of infants with a CP with or without a CL breast-fed initially and 22.7% continued for 6 weeks. Only two continued for 6 months. These two infants and the infants with a cleft lip only were actually breastfed, while all the rest received expressed milk.

2. 81.1% of mothers changed to using formula milk and a bottle after the initial feed 86% of infants with a CP were fed using formula milk and a bottle as the method of choice. 96% of those infants who used a nasogastric tube to assist feeding had a CP with or without a CL.
3. The Deprivation category (Depcat) scores of the sample of the cleft population in this study followed the trend of the national population figures for Scotland except for Depcat 7 where our study had a larger proportion of cleft infants. This may have been due to the highest proportion (85%) of the births of cleft lip and palate infants in our sample being from Greater Glasgow and Lanarkshire, which have larger areas of deprivation than the rest of Scotland. The sample of infants with a cleft lip and palate from the more affluent areas in the West of Scotland (Depcats 1 and 2) was too small to allow comparison of feeding methods between the different Depcat populations.

Birth order appeared to have a correlation with breastfeeding but this may have been due to the greater proportion of infants with a cleft lip in the second born group

The age of the mother had a significant effect on whether the infant was breastfed (cleft types were similar in each age group).

Prevalence of breastfeeding at 1 week and 6 weeks did increase with the age of the mother. After 1 week, 60% of mothers between 30 and 35 years of age were breast-feeding whereas the figure was only 44% for mothers between 25 and 30. After 6 weeks, these figures had decreased to 45% for mothers over 30 and 32% for mothers less than 30 years of age. This is comparable with national trends even though the actual figures are much lower.

4. 61.1% of parents had problems with the length of the feed with 45.6% lasting longer than an hour. 48.3% established feeding within a month but for 28.8% it took longer than a month and 20% never established a regular pattern to their feeding
5. 34.4% of parents said their child had had ear or chest infections. 50% of infants with a unilateral cleft lip and palate had an early experience of these infections compared to 20% of infants with a cleft lip only.
6. 25.5% of parents said their infant had used a pre-surgical appliance and 69.6% rated the appliance highly in terms of feeding. The majority of parents (65%) stopped using the appliance after their infants cleft lip surgery.
7. 31.1% of infants had habits that would predispose to early childhood caries.
8. 87.6% of parents received feeding advice in hospital and 91% received advice at home. 93% of responses understood the advice. When asked to rate this advice 93.3% of parents who answered gave a rating of 4 or 5 for the cleft teams' advice in the hospital and 96% at home. By comparison, the advice given by health care professionals who were not members of the cleft team was rated 4 or 5 in only 54.6% of cases in hospital and 68.1% at home.
9. Only 13.3% had any prior knowledge of the cleft. 62.2% found out at birth. 24.5% were undiagnosed at birth but by 24 hours postnatal some 84.4% of cases had been diagnosed.
10. The arrival of the cleft team within 24 hours after a diagnosis was 52.5%, by

3 days, 90% of cases had been seen.

.

Chapter 8 Recommendations

1. To dedicate more time to the training of the health care professionals who are not members of the cleft team but who can have a significant impact on cleft families. Specific areas that need to be addressed are:
 - General knowledge of cleft conditions, their treatment, and their outcomes.
 - Recognition that feeding difficulties may be due to an undiagnosed cleft.
 - Knowledge of the availability and use of specialised feeding bottles for cleft infants.
2. To increase the availability of specialised feeding bottles on maternity wards.
3. To increase the sessional availability of cleft nurses. Increased availability will have an impact in the following areas:
 - Increase the percentage initial contact with cleft families within 24 hours of diagnosis.
 - Increase the quality in hospital with cleft mothers aiming to establish appropriate feeding regimes as soon as possible.
 - Training of non-cleft professionals.
4. Reduce the habits that predispose to ECC by increasing the availability and frequency of preventive advice.
5. Explore the logistics of reconfiguring the format of appointments with the Cleft Team so that these are less intimidating

These recommendations will be disseminated to the UK Cleft Teams via the Annual Scientific Meetings of the Craniofacial Society Of Great Britain and Ireland. They may be used by the cleft teams in the UK in their discussions with local providers and policy makers. Implementation of these recommendations will lead to improvement of local services and more favourable outcomes for cleft children and their parents.

Chapter 9 Appendices

9.1 Ethic Committee correspondence

North Glasgow University Hospitals
Division

NHS
Greater Glasgow
West Glasgow Ethics Committee 2
Western Infirmary
Dumbarton Road
Glasgow
G11 6NT

Telephone: 0141 211 6238
Facsimile: 0141 211 1920

21 February 2006

Professor R.R. Welbury
Professor of Paediatric Dentistry
Glasgow University Dental School
378 Sauchiehall Street
Glasgow G2 3JZ

Dear Professor Welbury

Full title of study: A retrospective investigation into infant feeding practices in cleft children within the West of Scotland
REC reference number: 06/S0709/13

The Research Ethics Committee reviewed the above application at the meeting held on 21 February 2006. The Committee wished to thank you for attending the meeting to discuss this study.

Ethical opinion

The Committee had no ethical issues in relation to this study.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to complete Part C of the application form or to inform Local Research Ethics Committees (LRECs) about the research. The favourable opinion for the study applies to all sites involved in the research.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Application	5.0	03 February 2006

Investigator CV		01 January 2006
Protocol		01 February 2006
Covering Letter		01 February 2006
Questionnaire Non-validated		01 February 2006
Letter of invitation to participant		01 February 2006
Participant Information Sheet		01 February 2006
Participant Consent Form		01 February 2006

Research governance approval

You should arrange for the R&D Department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research at a NHS site must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/S0709/13

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



Andrea H Torrie
Ethics Manager – West Ethics Committees

Email: andrea.torrie@northglasgow.scot.nhs.uk

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
Standard approval conditions [SL-AC2](#)*

Copy to: R & D Greater Glasgow Primary Care Division
Research and Development Directorate
Great Western Road
Glasgow
R & D WIG

West Glasgow Ethics Committee 2

Attendance at Committee meeting on 21 February 2006

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present?</i>	<i>Notes</i>
<i>Dr N Pace - Chairman</i>	<i>Consultant Anaesthetist</i>		
<i>Dr R Soutar</i>	<i>Consultant Haematologist</i>		
<i>Mrs H Millar</i>	<i>Lay Member</i>		
<i>Rev R Currie</i>	<i>Lay Member</i>		
<i>Dr S Langridge</i>	<i>GP Member</i>		
<i>Dr E Douglas</i>	<i>Pharmacist</i>		
<i>Sister C Donald</i>	<i>Nurse Member</i>		
<i>Dr S Humphries</i>	<i>Expert Member</i>		
<i>Mr K Wallace</i>	<i>Lay Member</i>		
<i>Dr M T Hosey</i>	<i>Expert Member</i>		

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
<i>Ms Sharon Jenner</i>	<i>Admin Assistant</i>
<i>Dr Lorna McLintock</i>	<i>Observer</i>

Comments received from:

Prof Chris Robertson *Statistician*

9.2 Research and Development Office correspondence



Yorkhill Division

Research & Development Office
Dalnair Street
Glasgow
G3 8SJ

Tel: (0141) 201 0005
E-mail: alison.wood@yorkhill.scot.nhs.uk

8th March 2006

Professor RR Welbury
Glasgow University Dental School
378 Sauchiehall St
Glasgow
G2 3JZ

Yorkhill R&D Management Approval

Dear Professor Welbury,

Re: Infant feeding practices in cleft children
R&D Project Number: 06/DE/01, Ethics Ref: 06/S0709/13

Thank you for submitting a protocol and a copy of your ethics submission for the above project to the R&D Office. I am pleased to inform you that your project has been approved by the Yorkhill Division R&D department. This letter ensures that you and the researchers working with you, who hold substantive or honorary contracts, are indemnified by the NHS under the CNORIS scheme. This means you can now proceed with your project at Yorkhill once you have written confirmation of ethics approval for the study.

Amendments – The R&D office needs to be kept informed of any changes to the project for example regarding patient recruitment, funding, personnel changes or your project status. If changes are made to the protocol they will need to be considered by the ethics committee.

Should you have any queries please contact the R&D office quoting the Project ID number. Please let me know if the R&D office help in any way with the study. May I wish you every success with your research.

With very best wishes,
Yours sincerely,

Alison Wood

3. May 2006

Dr. Alison Wood
Research & Development Manager



Yorkhill Division
Research & Development Office
Dalnair Street
Glasgow
G3 8SJ

Tel: (0141) 201 0005
E-mail: alison.wood@yorkhill.scot.nhs.uk

8th March 2006

Professor RR Welbury
Glasgow University Dental School
378 Sauchiehall St
Glasgow
G2 3JZ

Letter of Sponsorship

Dear Professor Welbury,

Project: Infant feeding practices in cleft children

R&D Ref: 06/DE/01

I am pleased to confirm that NHS Greater Glasgow, Yorkhill Division has agreed to act as Research Sponsor for the above project, under the terms of the Scottish Executive's "Research Governance Framework for Health and Community Care".

With very best wishes,
Yours sincerely,

A handwritten signature in dark ink that reads 'Alison Wood'.

Dr. Alison Wood
Research & Development Manager

9.3 Feeding questionnaire

Feeding Questionnaire-*Infant Feeding in the Cleft population in the West Of Scotland*

Study no.

1 **Dental Hospital number**

2 **Hospital of birth**

3 **Child's D.O.B**

4 **Postcode**

5 **Mothers age at child's birth (years)**

6 **Cleft Type**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
BCLP	UCLP	CP	CL	

7 **Twin?**

<input type="checkbox"/>	<input type="checkbox"/>
yes	no

8 **Full Term Birth?**

<input type="checkbox"/>	<input type="checkbox"/>
yes	no

9 **Number of weeks
Premature**

10 **What is your occupation**

11 **What is your partners
occupation**

12 **How many children do
you have?**

13 **Please indicate the birth
order of your child**

1st

2nd

3rd

4th +

14 **Did you know your child would be born with a cleft?**

yes

no

15 **Did your baby's cleft change your choice of feeding?**

yes

no

If yes why?

16 **How did your baby get the first feeds?**

Breast

Expressed milk
/bottle

Expressed milk/nasogastric

Formula milk
/bottle

Formula/Nasogastric

Other

17 If you breast fed, how long did you do it for?

Days(number)

Weeks

Months

18 Did the way you feed your baby change after the initial feed or later?

Yes

No

If yes why?

19 What method(s) did you change to?

Breast

Expressed milk
/bottle

Expressed milk/nasogastric

Formula milk
/bottle

Formula/nasogastric

Other

Comments

20 After surgery, did your method of feeding change?

Yes

No

If yes, please specify

21 If you used a bottle, what type did you use?

Squeeze bottle (soft plas)

Habermann -
long teat

Standard bottle

Other

Comments

22 **Type of teat**

Standard teat

Modified teat -
enlarged holeNuk teat –(or mam)
normal/orthodonticCleft nuk teat
(very large teat)

Other

23 **Which feeding method worked best for you and your baby?****Feeding Patterns**24 **Did you have problems with the length of time taken for your baby to feed?**

Yes

No

25 **How long did the average feed last?**

Less than 30 minutes

30-60 minutes

More than an hour

26 **How long was it before your baby settled into a regular feeding pattern?**

Within 48 hours

2-7 days

1-4 weeks

More than one
month

Comment

27 **Did you ever feel that the amount of food taken at each feed was...**

Adequate

☐

Inadequate

☐

28 **Did your baby experience any of the following difficulties during feeding**

Coughing/Choking/Gagging

☐

Food/Fluids
escaping into
nose

☐

Excessive air intake

☐

Exhaustion

☐

Excessive leakage of milk
around the mouth

☐

Latching on

☐

29 **How long did your baby stay in hospital after birth?**

Days

☐

Weeks

☐

30 **Was your baby ever re-admitted to hospital for problems related to feeding?**

Yes

☐

No

☐

31 **How many times was your baby re-admitted to hospital for problems related to feeding?**

☐

Comments

Ear Infections

32 **Did your baby get any ear infections?**

Yes

☐

No

☐

33 **When was their first ear infection?**

Less than a month

☐

1-3 months

☐

4-6 months

7-12 months

34 **Did it ever interfere with feeding?**

Yes

No

35 **If yes, how long after infection was normal feeding resumed?**

1-3 days

4-7 days

1-2 weeks

Longer than 2
weeks**Feeding Modifiers**36 **Did your baby ever wear a dental feeding plate in their mouth?**

Yes

No

37 **Did you feel that this helped your baby's feeding?**

Yes

No

38 **Indicate how helpful this was by circling a number**

Not helpful

1 2 3 4 5

Very
helpful39 **Did you or your baby have any difficulties with the plate?**

Yes

No

40 **How long did your baby wear the plate?**

Weeks

Months

Reasons for stopping

Feeding Habits

41 **Did you ever add sugar to the baby's feed?**

Yes

No

42 **Just before your child stopped using a bottle, how often did he/she have one in bed or during the night?**

Every night?

4-6 nights a week

1-3 nights a week

Less than once a week

Never

43 **Apart from milk, did you ever put any other drink in the bottle?**

Yes

No

Please specify

44 **Did you ever give your child a dummy to suck?**

Yes

No

45 **To make the dummy taste nice, did you ever dip it in anything sweet?**

Yes

No

46 **What was it dipped into?**

Honey

Jam

Other

Please specify

Support and Advice on Feeding

47 **Did you receive advice on feeding?**

In Hospital?

☐

yes

☐

no

At home?

☐

yes

☐

no

☐☐

48 **Did you understand this advice?**

Yes

☐

No

☐

Comments

49 **Who gave you this advice?**

Midwife

☐☐

Specialist Cleft Nurse

☐☐

Nursing Staff on ward

☐☐

Doctor

☐☐

Speech Therapist

☐☐

CLAPA

☐☐

Other

☐☐

50 **Please rate the advice/ feeding support given by team**

In Hospital:

Totally Unsatisfactory	1	2	3	4	5	Satisfactory
------------------------	---	---	---	---	---	--------------

: At Home:

Totally Unsatisfactory	1	2	3	4	5	Satisfactory
------------------------	---	---	---	---	---	--------------

Additional Comments

51 **Please comment on your
experience of meeting the
Cleft team**

9.4 Parent invitation letter



UNIVERSITY
of
GLASGOW



19th April 2006.

Dear

Re: Infant feeding practices in children born with a cleft in the West of Scotland

We are writing to invite you to take part in a research study that we will be undertaking at the Dental Hospital during the normal Prevention Clinic hours on Wednesday mornings. Please could you take the time to read the enclosed information sheet that explains the purpose and the details of the study.

We will follow up this letter with a phone call to answer any questions or concerns you may have and will be available on the Wednesday mornings in the clinic if you wish to see us before your child's scheduled prevention clinic appointment.

Kind regards

Yours sincerely,

Professor Richard Welbury

Principle Investigator

Sarah McDonald

Researcher

9.5 Parent information leaflet

PATIENT INFORMATION LEAFLET

Infant Feeding Practices in children born with a cleft in the West of Scotland

To Parent/Guardian

You are being invited to take part in a research study. Before you decide it is important for you to understand, why this research is being done and what it will involve. Please take time to read the following information carefully.

The title of this study is, **To Investigate Infant Feeding in Children born with a Cleft in the West of Scotland**

Part 1 tells you the purpose of this study

Part 2 gives you more detailed information about the conduct of the study

Please ask us if anything is not clear or if you would like more information.

Take time to decide whether or not you wish to take part.

Part 1

The aim of this study is to look at current feeding practices for children with clefts in the West of Scotland. There are no statistics for the cleft population on how many children breast-feed; bottle feed or use assisted feeding methods. The information from this study will help further research into highlighting the importance of early establishment of feeding methods for these children.

The project is also one of the agreed areas of research of CLEFTSiS, the managed clinical network for cleft children in Scotland. Your participation will help to improve the CLEFTSiS service for future parents and infants

You have been identified as a parent of a child born with a cleft within the last 5 years and who attends the 'Oral Orthopaedic Prevention Clinic' at Glasgow Dental Hospital.

We are asking you to participate in the study while attending your child's routine Prevention Clinic appointment on Wednesday mornings at the Dental Hospital.

All the information we gather will be confidential.

Part 2

You will be asked to complete a questionnaire with the help of a researcher, Sarah McDonald. This will take about 10 minutes.

The questionnaire will ask about;

1. Your Feeding methods and patterns
2. Any difficulties
3. The use of Feeding plates
4. The Support and advice you were given at the time

You will only be asked to do this once and it will not involve any extra visits to the Dental Hospital for you or your child.

The questionnaires will be stored in electronic databases and will be anonymous. The information will be kept for 10 years.

No details will be taken about who you are and where you live, however we will ask your permission on a consent form to quote directly from any comments you make.

The results of the study will be published in scientific journals and presented to appropriate groups. You will have a chance to hear about the results of the study yourself through a future CLAPA meeting.

If you decide to participate you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care your child receives.

If you have any concerns please ask to speak to Professor Richard Welbury who is the Principle Supervisor. If you remain unhappy and wish to complain formally you can do this through the NHS Complaints Procedure. Details will be supplied by the Dental hospital.

Thank you for taking time to read this and ***for considering taking part.*** Your help with this study will be greatly appreciated.

(This study was given a favourable ethical opinion for conduct in the NHS by the Central Office for Research Ethical Committees)

9.6 Consent form

(Form to be on headed paper)

Centre Number:

Study Number:

Patient Identification Number for this trial:

CONSENT FORM

Title of Project: Infant feeding in children born with a cleft in the West of Scotland

Name of Supervisor: Professor R. Welbury

Name of Researcher: Sarah McDonald

Please initial box

1. I confirm that I have read and understand the information sheet dated 14/12/05 for the above study. I have had the opportunity to consider the Information, ask

questions and have had these answered satisfactorily. ☐ (Version 14/12/05)

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my or my child's medical care or legal

rights being affected. ☐

3. I understand that the anonymous data collected during the study, may be looked at by responsible individuals from CLEFTSiS and from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this

research. I give permission for these individuals to have this data ☐

4. I agree to have my comments quoted directly. I understand they will be

anonymous. ☐

5. I agree to take part in the above study.

☐

Name of Participant

Signature

Date

_____	_____	_____
Name of person taking consent (If different from researcher)	Signature	Date
_____	_____	_____
Researcher	Signature	Date

(When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes.)

Glossary

BCLP	Bilateral cleft lip and palate
CL	Cleft lip
CLAPA	Cleft Lip and Palate Association
CLEFTSiS	The National Managed Clinical Network for Cleft Services in Scotland.
CSAG	Clinical Standards Advisory Group, an independent source of expert advice to the UK Health Ministers on standards of clinical care, access and availability of services to NHS patients
CP	Cleft palate
Gene-environment	The effect of environmental factors on genes.
HDL	Health Department Letter, formal communications from the Scottish Executive Health Department to NHS Scotland.
NHS GG	NHS Greater Glasgow
NS Cleft	Non-Syndromic cleft
SEHD	Scottish Executive Health Department. It is responsible for health policy and the administration of NHS Scotland.
SIGN	Scottish Intercollegiate Guidelines Network. It was established in 1993 by the Academy of Royal Colleges and Faculties in Scotland, to sponsor and support the development of evidence-based clinical guidelines for NHS Scotland.

List of References

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