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J Child Health Care published online 25 February 2013
DOI: 10.1177/1367493512473853

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Journal of Child Health Care

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DOI: 10.1177/1367493512473853

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Abstract

The objective of this article was to determine the impact of different bottles and teats for feeding babies with a cleft palate (with and without a cleft lip) on weight velocity, feeding behaviour, and maternal self-esteem. A mixed methods study incorporating the use of diaries to record feeding patterns of babies and levels of professional support received was used. Growth was assessed by converting weights into standard deviation scores and using the differences to express weight velocity over a six-week period. Visual analogue scales were used to assess mothers' perceptions of their children and themselves. The Edinburgh Postnatal Depression Score (EPDS) was used to identify maternal depression. The study demonstrated that the most significant effect on weight was determined by cleft type. Babies with isolated clefts of the hard and soft palate experienced greater feeding problems and suffered the biggest weight losses. This remained significant independently of the type of bottle/teat used. Poor weight gain was also associated with a mother's low perception of herself and her child, and her tendency towards depression. The study highlights the importance of the early assessment of babies' feeding skills and regular follow-up and support from trained and experienced nurse specialists.

Keywords

Cleft lip and palate, cleft palate, feeding behaviour, maternal self esteem, weight velocity

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Background

In England and Wales during 2010, 856 babies were born with a cleft lip (CL) and/or palate (CP) (CRANE, 2011). This represented an incidence of approximately 1 per 845 live births. For more than 55 years the literature has highlighted the difficulties of feeding babies with a CP (with and without a CL). In 1973, Spriestersbach reported that 85% of mothers with such children recalled feeding difficulties. Trenouth and Campbell (1996) wrote of mothers taking 45 to 90 min to feed their child a bottle of formula, whilst Tisza and Gumpertz (1962) described parents' experiences of their child choking and subsequently refusing feeds. Mothers have also recorded their own experiences of feeding their child, reporting the frustration of having a constantly crying, hungry baby (Grady, 1977) and the feeling of redundancy and failure (Haberman, 1988). Whilst the cause and subsequent management of feeding problems is still debated, the fact that children with a cleft have significant issues with feeding is well documented.

Feeding problems are closely linked with poor growth and development (Beaumont, 2008; Lee et al., 1997; Marques et al., 2009; Pandya and Boorman, 2001). There is also evidence that problems with feeding and poor infant growth can lower mothers' self-esteem and lead to maternal depression (Bachelor, 1999; O'Brien et al., 2004). The prolonged feeding time is responsible for increased effort and energy expenditure which further contributes to weight loss (Brine et al., 1994). Neiman and Savage (1997) and Motion et al. (2001) suggested that persistent feeding difficulties in early life led to significant impairment in children's motor, language and behavioural development. Martins et al. (2011) linked under-nutrition to poor mental development as well as behavioural abnormalities.

Failure to diagnose a CP at birth may exacerbate feeding problems. Habel et al.'s (2006) local assessment of the detection of CP at birth found that out of 344 cases, 28% had not been detected after 24 hours. A national audit by Clinical Nurse Specialists (CNSs) found in a study of 472 babies with an isolated CP (iCP), 105 (22%) were not detected on day 1 and seven were over a year before the diagnosis was made (Butcher, 2007). In a repeat of this audit in 2009, 130 (30%) of 435 babies born with a CP were not detected on day 1, showing a worsening detection rate (Williams, 2012).

In babies born with a CP, the altered anatomy of the soft palate, with abnormal velar muscular insertion, results in limited soft palate movement and an inability to create intra-oral negative pressure. This lack of sucking ability has prompted studies to compare the effectiveness of different bottles for feeding babies with a cleft. Two studies compared the efficiency of squeezable bottles with rigid bottles, using babies' growth as an outcome measure. Both the Brine et al. (1994) and Shaw et al. (1999) studies showed squeezable bottles to be more efficient. There was no evidence presented in these studies by which advice and support given to mothers could be assessed (Bessell et al., 2011).

In 1998, the Clinical Standards Advisory Group (CSAG) recommended that cleft care in the United Kingdom should be reorganised, and over a 5-year period the number of cleft centres in England and Wales was reduced from 52 to 9. A survey by Martin (2002) of the 52 centres before this study found that recommendations regarding feeding were highly inconsistent. It established that five different types of bottle and teat in different combinations were recommended to 148 parents by three different professional disciplines. Six centres had no specific professional to advise parents and many were left to choose their own bottles and feed their child by trial and error.

For this study, the first parent was recruited on 6 November 1997 and the last diary was completed on 28 September 2000. The final Regional Cleft Centre was agreed in 2003.

Table 1. Babies' recruitment characteristics according to cleft type and gender.

Cleft type	N	Male	Female
Isolated cleft palate (complete)	24	6	18
Isolated cleft palate (incomplete)	7	3	4
Incomplete unilateral cleft lip and palate	7	6	1
Complete unilateral cleft lip and palate	12	11	1

Aims of the study

The literature has highlighted that feeding difficulties and poor growth are major concerns relating to the early management of babies with a cleft.

The aim of this study was to determine whether the use of one particular feeding bottle could result in improved feeding behaviour and a lesser need for support from professionals, the starting hypothesis being that bottles that could be squeezed would be associated with greater weight velocity. The study used a combination of quantitative and qualitative assessments to measure indicators of effective feeding, patterns of feeding and behaviour using diaries to record answers to questions relating to method of feeding; number of daily feeds; time and average quantities taken; behaviour between feeds (from 'sleeps most of the time', 'awake and content', 'irritable', 'settles only when held', to 'cries all the time'); and ease of bringing up wind. The study also aimed to determine whether one particular feeding method afforded greater maternal self-esteem and a maternal perception of the child which was closer to the mother's ideal.

Methods

Participants

Babies born with a unilateral cleft of the lip and palate (UCLP) and with an iCP were recruited for this study before completion of the national reorganisation of UK cleft services. All participating hospitals were confident that their recommended bottle and teat was successful for feeding babies with a cleft. Each hospital used a different bottle, recommended only one bottle/teat type and received more than 20 new baby referrals per annum. Ethics approval was granted by the Multi-Centre Regional Ethics Committee. Fifty mothers were invited to participate as soon after referral to the cleft centres as appropriate, and informed consent was obtained from those that agreed.

CP types were divided into either isolated clefts of the soft palate (iCP incomplete) or isolated clefts of soft with one- to two-thirds of the hard palate (iCP complete). Unilateral clefts of the lip and palate were divided into two types: incomplete (IUCLP) and complete (CUCLP). Babies diagnosed with syndromes or respiratory problems (i.e. Robin Sequence) were excluded from the study. Table 1 shows babies' recruitment characteristics according to cleft type and gender. The median age of babies recruited was one week (range birth to nine weeks). The median gestational age was 40 weeks (range 30–40 weeks). The median birth weight was 3.3 kg (range 1.48–4.36 kg).

Procedures

Participating mothers were asked by the local specialist nurse or speech and language therapist to complete an enrolment questionnaire detailing the pregnancy and birth, family structure and the

Table 2. Method of feeding as recommended by the different hospitals.

Feeding method	Week 1 N = 50	Week 6 N = 50
Breast or breast + EBM	Breast 3 (6%)	Breast/EBM 1 (2%)
EBM	15 (30%)	7 (14%)
Formula	32 (64%)	42 (84%)
Squeezable bottle type		
Mead Johnson bottle (complete with teat)	19 (38%)	21 (42%)
Softplas bottle (with NUK orthodontic teat)	11 (22%)	13 (26%)
Haberma feeder (with squeezable teat)	12 (24%)	10 (20%)
Rosti bottle (and scoop)	5 (10%)	4 (8%)
Other bottle (breast see above)	3 (6%)	2 (4%)

EBM: Expressed breast milk.

mother's perception of her child using an adjective checklist. They were then asked to complete a diary of their baby's feeding for one typical day each week for six weeks.

The amounts of feed needed per 24 hours to sustain growth were calculated initially from birth weight and subsequently on predicted centiles. Time taken for each feed was compared with Arvedson's (1993) recommendation of no longer than 30 to 40 min for each bottle feed and Wilensky et al.'s (1996) recommendation of less than 39 min in breastfed infants, to prevent failure to thrive. Babies' weights were plotted on UK Growth Foundation Charts and the weight velocity calculated over a six-week period. Their predicted centile was calculated from their birth weight. Weights were converted to standard deviation (SD) scores using software supplied by the Child Growth Foundation and based upon 1996 UK standards, and the differences in the SD (dSD) were used to express weight velocity. The loss of one or two centile spaces represented one or two SDs. Health visitors recorded babies' weights weekly.

A final questionnaire was given at the end of the study to the mothers, by their feeding advisor. The final questionnaire comprised two pairs of Likert-type scales. The first pair was designed to elicit the mother's concept of her child and her concept of how she would wish her child to be. Both scales listed the same 11 bipolar adjectives on a seven-point visual analogue scale. On the first scale, mothers were asked to indicate where on the continuum they would place their own child, and the second where they would place their ideal child. The second pair of Likert-type scales was used for mothers to indicate first their own assessment of themselves, and second how they would wish to be.

Mothers were also asked to complete the Edinburgh Postnatal Depression Scale (EPDS), which lists 10 statements relating to symptoms of depression with four possible responses. Mothers were asked to indicate the response closest to how they felt. A free text area allowed parents to describe positive and negative aspects of their experiences to date and their perception of support or lack of it.

Results

A total of 50 questionnaires and diaries were received from five hospitals. Table 2 shows the method of feeding and the type of milk and bottle used by the different hospitals at the beginning and end of the study.

Feeding characteristics and behaviour

Numbers of daily feeds, time and average quantities taken, were compared with babies' behaviour. Of the 50 babies, seven were taking longer than 40 min to complete a feed, six were taking less than their predicted volumes, and 18 suffered with wind. No particular bottle was associated with this feeding behaviour. Using diary information, in week 1, 10 of the total 50 mothers stated that their babies were either 'irritable', 'settling only when held' or 'crying all the time' and 15 were stating this in week 6. The 15 babies in week 6 were cross tabulated according to cleft type. Six babies (two of each) were in the following cleft types: iCP (incomplete), CUCLP and IUCLP. The remaining nine babies had an iCP (complete), two suffering greatly with wind whilst a further four, who were slow to gain weight, were taking 60 min or longer to take a feed and taking less than their predicted volume requirements.

Professional support

Each cleft centre had a part-time feeding advisor. The support provided by advisors, together with midwives and health visitors, was collated. In the first week of the study, all but two families had contact with one of these professionals. The majority of visits (96%) were from a midwife or health visitor. By week 6, 66% of families were receiving a visit from a health visitor. In week 1, 76% of families were visited by a cleft team member, and by week 6, this had fallen to 40% of families. The amount of support given by professionals was cross tabulated with cleft type. In week 6, 74% of mothers of babies with a CLP were receiving support from a professional, as opposed to 68% of mothers of babies with an iCP.

Evaluation of babies' weights

At the end of the study, babies were grouped into three categories according to their weight. Adequate ($n = 27$) babies had normal growth between week 1 and week 6 ($dSD < -1.0$). Insufficient ($n = 16$) babies had lost one to two SDs (centile spaces) in weight between week 1 and week 6 ($dSD -1$ to -2). Deficient ($n = 7$) babies had lost two or more SDs (centile spaces) in weight between week 1 and week 6 ($dSD > -2$). The changes in weight (dSD) from week 1 for all the babies was analysed by the type of bottle and teat used, but the numbers using each of the different bottles and teats were too small to enable meaningful comparison.

To determine the relationship between type of cleft, type of bottle and type of teat to changes in weight, a multiple regression analysis was performed using dSD in weight (95% confidence interval (CI)) from week 1 to week 6 as the dependent variable. Figure 1 shows that the biggest effect on weight gain was determined by the type of cleft, and this remained significant independently of the type of bottle and teat used for feeding. Changes in weight (dSD) from birth were therefore cross tabulated with the type of abnormality. Figure 2 shows that iCP (complete) resulted in the lowest median value weight gain. The cleft type of all babies was further cross tabulated with the SD score to express the variables in weight velocity (Table 3). The mother of the baby with an iCP (incomplete) whose weight was in the $dSD > -2$ category indicated in her diary that the baby had a small chin, breathing problems and was originally tube fed, suggesting that this baby was an undiagnosed Robin Sequence. The results of cross tabulation of weight gain with type of abnormality showed that babies with an iCP (complete) had the most significant problems with weight gain, whilst those with a UCLP had the least significant problems, $\chi^2 = 7.94$; $df = 2$; $p = 0.019$.

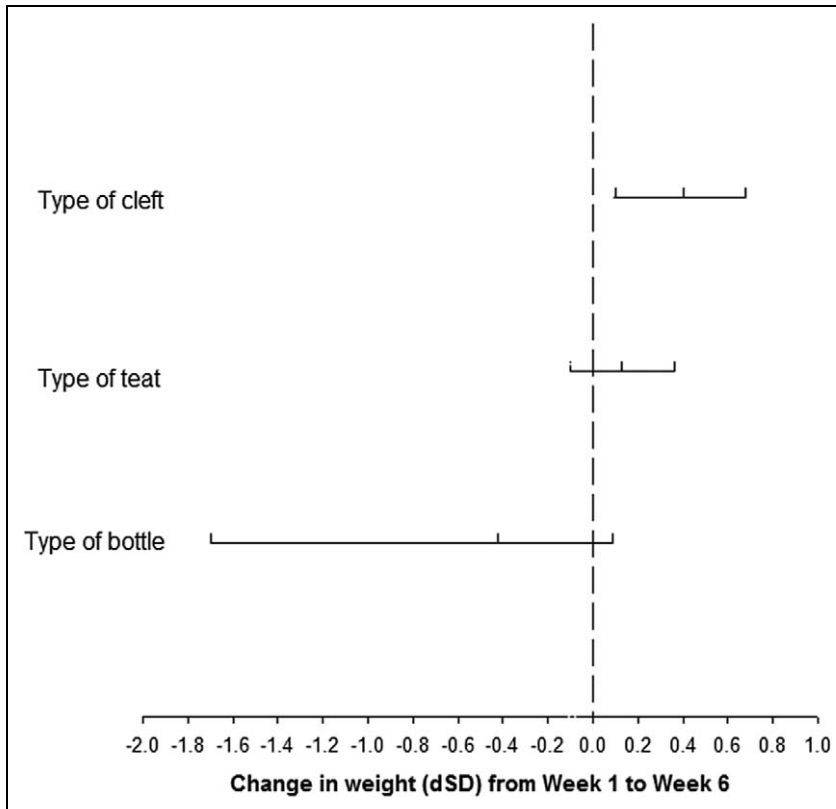


Figure 1. Change in weight (dSD) from week 1 to week 6 according to the type of cleft, teat and bottle.

Mothers' perception of their babies

The scores from the two Likert-type scales to elicit ideal child concept were subtracted from each other and cross tabulated with the child's cleft type. Twelve mothers of children who had an iCP had a low perception of their child. Six mothers of children who had a UCLP had a low perception of their child.

Mothers' perception of themselves

The scores from the two Likert-type scales to elicit ideal maternal concept were subtracted from each other and cross tabulated with babies' cleft type. Twenty-five mothers of children who had an iCP had a low perception of themselves. Eleven mothers of children who had a UCLP had a low perception of themselves.

The EPDS

The EPDS obtained for each of the mothers was compared with published results (Harris et al., 1989). The scores were cross tabulated with babies' cleft types (Table 4). Of all the mothers who

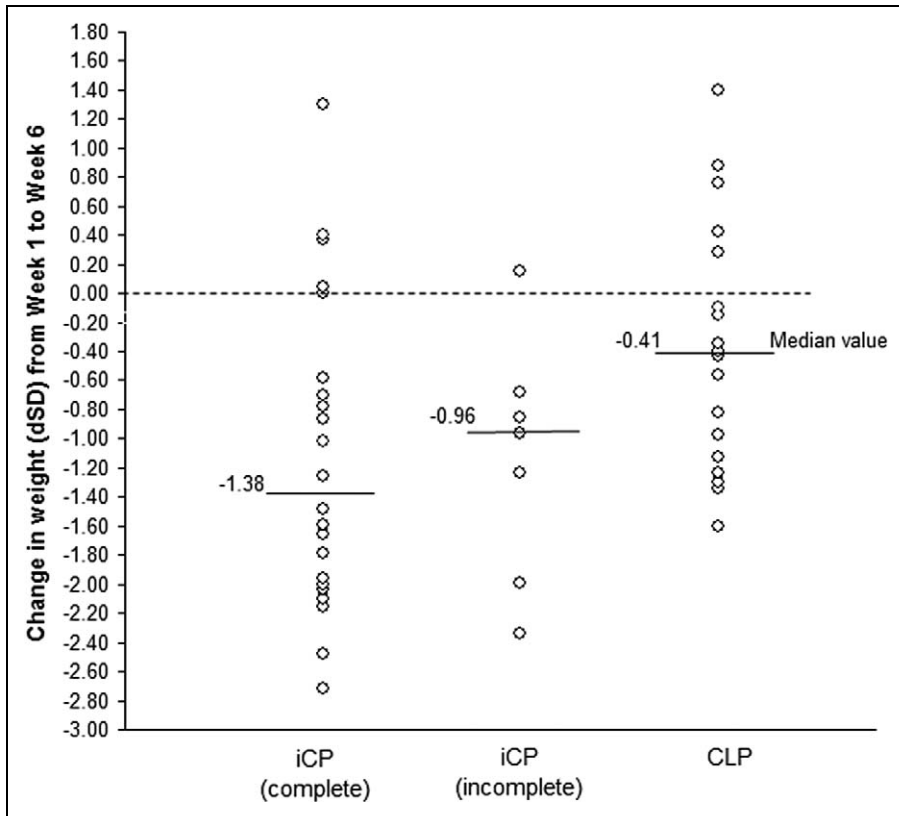


Figure 2. Change in weight (dSD) from week 1 to week 6 according to the type of cleft.

Table 3. Weight calculated in differences in standard deviation (dSD) (centile spaces) from birth centile.

Cleft type and total number of babies	dSD < -1.0 (adequate)	dSD -1 to -2 (insufficient)	dSD > -2 (deficient)
Isolated cleft palate complete (n = 24)	9 (37.5%)	9 (37.5%)	6 (25%)
Isolated cleft palate incomplete (n = 7)	4 (57.1%)	2 (28.6%)	1 (14.3%)
Cleft lip and palate (n = 19)	14 (73.7%)	5 (26.3%)	(0%)

had some form of depression, 18 had a poor perception of themselves and nine had a poor perception of their baby.

Maternal self-perception, depression and babies’ weight loss

Maternal self-perception and depression were cross tabulated with weight loss and cleft type to establish whether there were any links. Results from the questionnaire to evaluate mothers’ perception of their babies suggested an association between low maternal self-esteem, depression and

Table 4. Edinburgh Postnatal Depression Score according to cleft type.

Cleft type and total numbers	Edinburgh Postnatal Depression Score		
	1–6 (none)	7–11 (mild)	>12 (severe)
Complete cleft lip and palate ($n = 12$)	3 (25%)	9 (75%)	0 (0%)
Incomplete cleft lip and palate ($n = 7$)	0 (0%)	0 (0%)	0 (0%)
Isolated cleft palate (incomplete) ($n = 7$)	6 (86%)	1 (14%)	0 (0%)
Isolated cleft palate (complete) ($n = 24$)	11 (46%)	5 (21%)	8 (33%)

babies' weight loss. Of the mothers who had babies with an iCP, 25 had a low perception of themselves; five of these had babies in the 'insufficient' weight category ($dSD = -1$ to -2) and one had a baby in the 'deficient' category ($dSD > -2$). In this group, 20 babies had an iCP complete. In contrast, 11 mothers of babies with a UCLP had a low perception of themselves; only one baby was in the insufficient weight category and none were in the deficient category. Similarly, the likelihood of a mother having a lower perception of her child was slightly greater if the child had an iCP (12) than if the child had a UCLP (6). SD scores (SDS) for weight loss were cross tabulated with the mothers' perception of themselves and their babies and the EPDS. Of the mothers with $EPDS \geq 12$ (severe depression), seven had babies in the deficient weight category. Six of these had a baby with iCP complete. The mother of the baby with possible Robin Sequence had a good perception of both herself and her baby and scored between 1 and 6 on the EPDS. This mother recorded the most professional and family support.

Diaries

The use of diaries in this study suggests that keeping a diary can help mothers to constructively express their feelings and might even be of therapeutic value. More than half of the mothers used the free text area in the final questionnaire to write about their experiences of feeding their baby, many of them relating feeding difficulties to baby's illnesses or vaccinations. Thirteen mothers (26%) expressed their concern over difficulties feeding their baby and coping with their baby's wind. Five (10%) expressed their anxiety over milk coming down their baby's nose. Nine (18%) were anxious about their baby's failure to put on weight. Fifteen (30%) wrote that feeding their child was much easier than they had expected. Six mothers (12%) wrote about how hard it was for them to accept not being able to breastfeed or failing at breastfeeding.

Validity of the analysis

Because growth appears to be independent of the bottle and teat used for feeding, the validity of the relationship between cleft type and growth was checked and the possible confounding effects of family factors were examined using univariate analysis. Chi-square tests were used to compare the relationship between two variables and their likely significance in the general population (Reid and Boore, 1987). Probability was calculated as significant at the 5% level, that is $p = 0.05$ or less.

Babies scoring a dSD of < -1 were compared with those with a dSD of -1 to -2 and $dSD > -2$ over a range of parameters, including demographic factors (namely mother's qualifications, $p = 0.662$; father's qualifications, $p = 0.050$; family size, $p = 0.273$; family crowding, $p = 0.839$ and single mother status, $p = 0.053$), then compared against pregnancy satisfaction, $p = 0.751$, and

finally against cleft type, $p = 0.019$. Results of chi-square tests between weight gain and demographic information and pregnancy satisfaction were not significant. Chi-square tests showed a strong correlation between an iCP and weight gain ($p = 0.033$ at the 5% level). Chi-square testing also suggested a causal relationship between cleft type and weight velocity and a relationship between the mother's perception of herself and her child and weight velocity. These evaluations support the conclusions drawn from the questionnaire to evaluate mothers' perceptions of their babies and are suggestive of an association between maternal self-esteem and babies' weight loss. The Mann-Whitney U test showed a strong correlation between weight gain and a mother's low perception of herself ($p = 0.000$ at the 1% level), and a correlation between weight gain and her perception of her child ($p = 0.035$ at the 5% level).

Discussion

The primary aim of this study was to ascertain whether the use of one particular bottle was associated with greater weight velocity and resulted in improved feeding behaviour and a lesser need for support. All bottles chosen could be squeezed but proved not to affect weight gain. It was clear that cleft type did affect not only weight, but also feeding behaviour. The correlation between subtle oral-motor problems and risk factor of failure to thrive is well documented and is attributable to less efficient sucking patterns (Masarei et al., 2007; Reid et al., 2006; Reilly, 1999; Wolke, 1996). This study concurs with the findings of Reid et al. (2007), who suggest that babies with larger clefts generate even poorer levels of compression and suction. Four babies with large clefts fed for long periods, took less than their predicted volumes and were slow to gain weight. This endorses the Brine et al. (1994) findings that increased effort and energy expenditure contributes to weight loss.

Douglas (1991), Bachelor (1999) and O'Brien et al. (2004) all suggest that maternal depression is linked with failure to thrive. This study has confirmed that finding. Severe depression was demonstrated in 25% of mothers of babies who had an iCP (complete) and were in the deficient weight category. According to Magnusson et al. (2011), single mothers are more likely to have severe depression, but this was not evaluated. In contrast, no mothers of children with an iCP (incomplete) or a UCLP fell into this severe depression category. A correlation was also shown between weight gain and a mother's low perception of herself, with mothers of babies with iCPs having a lower perception of themselves and a slightly lower perception of their baby than mothers of babies with a CL.

Research by Sank et al. (2003) identified mothers of children with visible clefts as receiving a higher level of social support than those with clefts that were non-visible, and also linked greater support with lower levels of maternal depression. This study confirms these findings. Professionals were shown to be giving more support to families of a child with a CL than with a CP. The mother of a baby with possible Robin Sequence received the most support and scored the lowest in the EPDS.

The mothers were happy with the softplas, a bottle that most resembled a 'normal' bottle and was the easiest and most pleasurable to use. This was an imported Australian bottle and has now been replaced by a similar bottle made in this country by Mam. The Mead Johnson, a smaller and softer bottle, came a close second and is useful for mothers who are arthritic and have difficulty squeezing the Mam bottle. The Haberman feeder, parents claimed, was difficult to put together, had many parts and was the most expensive to buy. The Rosti bottle was the most difficult to attach the scoop to, and the volume of milk given to baby was not easy to control. The Haberman and

Rosti were the most likely to be criticised by other people. Specialist Centres now provide parents with their initial Mam bottles with the help of the CL and CP Association CLAPA.

There are currently nine regional cleft centres in England and Wales and two in Scotland, all of which have a team of CNSs who support parents of children born with a cleft. The care of these babies has improved beyond recognition. In the past, it was normal for the family to have a single visit from the surgeon or the orthodontist at birth. Now the CNS will come within 24 hours, make formal assessments of feeding and make regular follow-up visits. The centres work together to set standards that include diagnosis of the cleft at birth. Failure to do this may exacerbate feeding problems and faltering growth. Other standards include referral within 24 hours to the cleft team, a visit from the CNS within 24 hours of receiving the referral, an assessment of the child's feeding skills before introduction of a 'squeezy' bottle (Bannister, 2008) and continuing assessment of baby's feeding skills through home visits. CNSs recognise that babies with extensive palatal clefts are the most challenging to feed and that these families require ongoing support, regular visits and teaching to enable them to adjust to their child's health problems (Pelchat et al., 2007). Centres that do not have enough staff to fulfil these standards risk parents being unable to establish a regular feeding pattern for their child (Britton et al., 2011). Additionally, the National Special Interest Group of UK nurses has an audit and research group that continues to evaluate and set standards for best practice, taking account of the exceptional psychological situation affecting the family and recognising that close collaboration with maternity hospitals is essential (Kuttenberger et al., 2010).

Strengths and weaknesses

This study changed my own practice and that of my developing team. Our initial routine of telephoning mothers regularly was abandoned as it was now clear that they were unable to communicate about their problems effectively. We realised the importance of having an 'on call' system to enable us to visit newborn babies on day one and of supporting the family, regularly demonstrating and teaching the skills of feeding. This helped with the establishment of their routine. The regular assessment of weights, feeding patterns, volumes, and times taken to feed enabled us to prevent undue weight loss and to determine any babies who needed feed supplements. The fact that weight loss is associated with a mother's low esteem and can lead to severe depression is an important insight. We were not aware at the time of the study that in babies with an iCP, chromosomal abnormalities are common, often difficult to identify and can be associated with development delay and impact on growth. Some babies in this study may have had chromosomal abnormalities. Since service reorganisation, multicentre studies have become more feasible and will be useful in evaluating larger numbers of participants. A larger sample would have strengthened this study. Bessell et al. (2011) in the Cochrane Collaboration on feeding interventions suggest that future trials should present weight-for-height *z* scores.

These results suggest there would be benefit in conducting a randomised trial to evaluate the feeding and oral-motor function of infants with iCP (complete) compared with CUCLP and/or complete bilateral CLP, both of whom would have similar extensive hard palate involvement.

Conclusion

Although this was a small study, it provided some clear results to help practitioners caring for these families. A prompt diagnosis, especially of an iCP, and visit by the cleft team CNS immediately after the birth so that the family can be supported and taught the skills of feeding, is essential. It needs to be

recognised that parents of children with an iCP need as much, if not more, support as parents of children with a CL. The non-visible nature of an iCP can create the deceptive impression that the condition is a minor one. It is important that professionals give every child with a cleft the opportunity for normal physical and psychological development and every parent the opportunity to take pride in their child.

Acknowledgements

We wish to thank Neil Marlow DM, FRCP, FRCPCH, Professor of Neonatal Medicine, Department of Child Health, Nottingham University for his supervision of this thesis. We are also grateful for the contributions of Jane Sibley, Oxford Children's Hospital; Marie Pinkstone, previously of Mount Vernon Hospital, Northwood; Shirley Wallace and Ann Crawford, The Royal Hospital for Sick Children, Glasgow; and Morag Rush, previously of The Sick Children's Hospital, Edinburgh.

Funding

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

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